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# Risking Reproduction: Reproductive Health Among Women With Sickle Cell Disease

Paula Thompson Ross  
*Wayne State University,*

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**RISKING REPRODUCTION  
REPRODUCTIVE HEALTH AMONG WOMEN WITH SICKLE CELL DISEASE**

by

**PAULA THOMPSON ROSS**

**DISSERTATION**

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of

**DOCTOR OF PHILOSOPHY**

2013

MAJOR: SOCIOLOGY

Approved by:

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Advisor

Date

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## **DEDICATION**

This dissertation is dedicated in memory of  
Tiffany Jordan (1986-2010)

## ACKNOWLEDGEMENTS

First I would like to thank my family for their support through this long process. I wasn't always there when I should have been, or could have been, and I thank you for understanding.

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have protected and honored the stories shared with me. May your stories serve as a testament to both your struggles as well as your successes living with sickle cell disease.

## TABLE OF CONTENTS

Dedication.....	ii
Acknowledgements.....	iii
List of Tables .....	vii
List of Figures.....	viii
CHAPTER 1 – Introduction.....	1
CHAPTER 2 – Literature Review .....	7
CHAPTER 3 – Theoretical Framework.....	54
CHAPTER 4 – Methodology.....	64
CHAPTER 5 – Results-Responses to Discouraging Reproductive Messages.....	100
CHAPTER 6 – Results-Reproductive Decisions and Behavior .....	136
CHAPTER 7 –Results-Experiences with Reproductive Health Care.....	167
CHAPTER 8 –Conclusion .....	201
Appendix A – Potential Participants Screening Questions.....	217
Appendix B – Interview Guide .....	218
Appendix C – Demographic Questionnaire .....	221
Appendix D – Recruitment Flyer.....	225
Appendix E – Participant Information Sheet .....	226
Appendix F – Participant Resource Sheet .....	228
Appendix G – HIC Notice of Approval .....	229
Appendix H – HIC Amendment Approval .....	230
Appendix I – HIC Notice of Continuation.....	231
Bibliography .....	232

Abstract.....	274
Autobiographical Statement.....	276



## LIST OF TABLES

Table 1 – Genetic Transmission of Sickle Cell Disease .....	33
Table 2 – Genetic Transmission of Sickle Cell Trait.....	35
Table 3 – Participants’ Sociodemographic Characteristics .....	88
Table 4 – Participants’ Medical History Characteristics .....	91
Table 5 – Participants’ Reproductive Health and Behavior Characteristics.....	96
Table 6 – Participants’ Responses to Discouraging Reproductive Messages.....	135
Table 7 – Participants’ and Partners Uptake of Genetic Testing .....	166

## LIST OF FIGURES

Figure 1 – Flow of Normal and Abnormal (Sickled) Red Blood Cells .....	32
Figure 2 – Participant Recruitment Diagram .....	74

## CHAPTER 1

### INTRODUCTION

#### STATEMENT OF THE PROBLEM

Reproductive health encompasses the full range of the reproductive cycle (e.g., contraception, conception, pregnancy, childbirth, abortion) and includes various reproductive challenges (e.g., egg donation, surrogacy, reproductive technologies, etc.) (Ross 2006a). It is a reflection of the lifelong health of the reproductive system and processes, setting the stage for health beyond the reproductive years and affects the health of the next generation (Roberts 1990, Rutherford 1992). Throughout history African American<sup>1</sup> women have had pejorative experiences with reproductive health through forced breeding during chattel slavery, medical experimentation, forced sterilization, unavailability of safe, legal abortions, forced use of birth control pills and other contraception methods, and coercive birthing process and hysterectomies (Nsiah-Jefferson 1989, Roberts 1997, Ross 1992, Ross et al. 2007). Much of the work on reproductive health among African American women has been brought to light through recounting historical accounts of legal violations of reproductive rights with the intent to achieve retribution and legal footing. Reproductive rights have been situated within the human rights and social justice paradigm as put forth by the Universal Declaration of Human Rights (1948) and subsequently, the United Nations International Covenants on Economic, Social and Cultural Rights (UNICESCR) and the United Nations International Covenants Civil and Political Rights (UNICCPR) to advance reproductive interests (Cook 1995, Okin 1998). Additionally, reproductive health is most often discussed either (1) under the guise of the binary pro-choice or pro-life discourse, leaving other areas such as pregnancy prevention, family planning, birth

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<sup>1</sup> The terms African American and Black are used interchangeably throughout this dissertation.

spacing, and health promotion neglected or (2) in reference to women in underdeveloped countries (Price 2011, Ross et al. 2007, Smith 2005). Regrettably, women with sickle cell disease experience more gynecological complications than do those unaffected by the disease, including delayed menarche, dysmenorrhea, ovarian cysts, fibrocystic disease of the breast, as well as a high prevalence of vaso-occlusive pain associated with menstrual cycles (Creary, Williamson and Kulkarni 2007).

Sickle cell disease (SCD) is a condition with a complicated clinical sequelae, accompanied by a myriad of health complications, unremitting, extreme pain, and frequent hospitalizations. Consequently, much of the existing literature has focused on the experience of symptoms and clinical management rather than how those with this condition maintain their health (Abrams, Phillips and Whitworth 1994, Anie, Steptoe and Bevan 2002, Fuggle et al. 1996, Hurtig and Park 1989, McClish et al. 2005). Indeed, the knowledge of symptoms and subsequent treatment are important components of ensuring optimal health care provision, however, this narrow focus precludes gaining a broader understanding of the multifaceted experiences and identities women with sickle cell disease have regarding their reproductive health.

Women with sickle cell disease also bring to fore a unique nexus of reproductive health, race, gender, and genetic illness. As a sub-group of African American women, women with sickle cell disease may experience suboptimal reproductive health care or limited independent decision-making regarding reproductive issues due to race, class, or illness. Seemingly, restrictions of reproductive choice and limited reproductive care are likely for this population through denied reproductive health information, coerced sterilizations and abortions, and discouraged pregnancies due to concerns of genetic transmission and pregnancy complications

(Fort et al. 1971, Fort and Morrison 1972, Horger 1971). Although there has been continued anecdotal speculation to this end, recent, empirical evidence either supporting or refuting whether such violations continue is lacking. Furthermore, studies exploring how women with sickle cell disease experience reproductive health care and choice embedded within multiple social, and often marginalized, identities are limited.

### **STATEMENT OF PURPOSE**

Contemporary research concerning reproductive health care among African American women in general and women with sickle cell disease in particular is scarce (Daniels 1996, Gallo et al. 2010). To date, much of the sociological literature on how women with sickle cell disease have been limited to (1) health beliefs of women with sickle cell trait (Anie, Berger and Asgharian 2003b, Gustafson et al. 2007), (2) care-giving experiences of families with a child with sickle cell disease (Brown et al. 1993, Hill 1994a, Moskowitz et al. 2007, Thompson et al. 1993a, Thompson et al. 1993b), (3) financial burden of disease management (Barbarin et al. 1999, Bediako 2010), (4) concerns regarding genetic and prenatal screening (Dyson 1997, Petrou et al. 1992), and (5) attitudes and experiences regarding the transition from pediatric to adult care (Baskin et al. 1998, Jordan, Swerdlow and Coates 2013, Telfair et al. 2004).

To understand women's health experiences it is important to understand women's reproductive lives more broadly, with a broader focus than addressing only their bodily functions (Doyal 1995). The specific aims for this study were to (1) explore and describe the reproductive health experience of women with sickle cell disease, (2) describe social, environmental, and cultural factors that influence their reproductive health experience, and (3) investigate the ways in which individuals who occupy these positions manage their reproductive health. This study

will use qualitative in-person interviews with adult women with sickle cell disease with varied socioeconomic, parity, and marital status to capture a broad perspective of experiences. The questions this research explored are:

**How do women with sickle cell disease think about and experience reproductive health?** That is, how do they perceive the type and quality of care they receive concerning their reproductive health? What importance do they give to their reproductive health? What priority does their reproductive health have in their lives? What behaviors do women with sickle cell disease engage in that they believe help maintain their reproductive health? What impact does having sickle cell have on their reproductive lives including desires for motherhood and intimate relationships?

**How do race, gender, and genetic illness affect the reproductive lives of women with sickle cell disease?**

**What social, environmental, and cultural factors influence the ability of women with sickle cell disease to either seek or receive reproductive health care?** That is, what sources of information, advice and guidance do women with sickle cell use to learn about reproductive health?

### **SIGNIFICANCE OF THE STUDY**

Nearly four decades ago the life expectancy of individuals with sickle cell disease was a staggering 14 years old; yet today the average life span reaches 42 years for men and 48 years for women (Lanzkron, Carroll and Haywood 2013, Platt et al. 1994). This dramatic increase in life expectancy is related, in part, to early detection, use of penicillin prophylaxis in young children, improved education regarding disease complications, and improved clinical management (Driscoll 2007). Perhaps because of the limited number of individuals with sickle cell disease and the fact that it is only in recent generations that women with sickle cell disease live longer lives, it remains somewhat of an unknown illness. Consequently, the short life expectancy caused much of the scholarship surrounding this condition to be limited to child and adolescent populations who were frequently considered asexual. Their sexual and reproductive health was

discounted. However, this population is now transitioning into adulthood, with increasing survival estimates well into middle-age; therefore knowledge concerning their attitudes and behavior toward reproductive health is becoming increasingly important to both social and health audiences.

Reproductive health among women with sickle cell disease remains a critical gap in the literatures on sickle cell disease, reproductive health, and women's health. Most often, the reproductive health of this population has been relegated to biomedical examinations of pregnancy complications, risks and outcomes, primarily maternal and infant mortality rates, pregnancy complications, and appropriate methods of contraception and acceptance of prenatal genetic testing (Creary, Williamson and Kulkarni 2007, Dauphin-McKenzie et al. 2006, Hassell 2005). Yet to date, limited research exists exploring the experiences of women with sickle cell disease, and even less focusing on understanding how women with sickle cell experience reproductive health care and choice and the ways in they prioritize and exercise agency in this area of their lives.

This study has been designed to explore the ways in which women with sickle cell disease think about and experience reproductive health and the factors that influence their identities and experiences. The findings of this study have both clinical and sociological implications. From a sociological perspective, this study may extend existing ideas concerning the availability of, and barriers to, information and appropriate reproductive health care, improve the understanding regarding the significance of reproductive health in general and within the context of illness, and assess the ways in which women with sickle cell disease perceive their ability to exercise agency in making informed and independent decisions about their reproductive lives. A better understanding of these concepts will help health care providers

understand how factors such as economic status, race, gender, and genetic illness may intersect to influence the reproductive health experience of women with sickle cell disease and inspire improved care for this population.

## **ORGANIZATION OF THE DISSERTATION**

The first chapter has provided an introduction to the research topic, significance of the research and the purpose of the study. Chapter Two includes an outline of sociology of the body, which illustrates how individuals with sickle cell experience the condition. Following this section of the literature is a review of the socio-historical research of reproduction health of African American women, disabled women, and women with genetic conditions. This chapter also provides an introduction to sickle cell disease, which includes an overview of the clinical manifestations and disease management. Chapter Three provides an outline of the theoretical and methodological approaches using Sociology of the Body as the conceptual framework for the study. Chapter Four explains the use of Colaizzi's phenomenology method for data collection and analysis and outlines the participants' characteristics. Chapters Five through Seven describe the findings of the dissertation. Chapter Five focuses on the participants' responses to various discouraging reproductive messages. Chapter Six focuses on the motivations and perceptions regarding genetic-related reproductive decision-making. Chapter Seven focuses on participants' reproductive health care experiences. Chapter Eight concludes this study and presents the limitations of this study.



## **CHAPTER 2**

### **LITERATURE REVIEW**

### **REPRODUCTIVE HEALTH**

The most comprehensive conceptualization of reproductive health was developed during the International Conference on Population and development (ICPD) held in Cairo in 1994 and the International Conference on Women sponsored by the United Nations in Beijing in 1995. The World Health Organization, Chapter VII of the Programme of Action of ICPD, adopted this definition of reproductive health:

Reproductive health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are the right of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant (Germain and Ordway 1989).

Additionally, reproductive health includes decisions rooted in mothering in the broadest context. Regardless of whether a woman decides to have a child, not have a child, adopt a child, or submit her child for adoption, women are socially defined as mothers or potential mothers and ultimately make decisions about mothering (Hanigsberg 1995). Therefore, reproductive health involves access to information, the ability to interpret this information, and the freedom to make complex decisions that involve their ability and desire to become a mother.

## **Reproductive Health and African American Women**

Compared to women from other racial groups in the United States, African American women have experienced more incidents of coercive sexual encounters, unwanted pregnancies and abortions, and less social support for raising their children (Barbee and Little 1993, Hill 2009). Moreover, this experience extends beyond the biomedical domain into the unique socio-historical context under which African American women have endured forced motherhood (e.g., slavery (re)production, lack of access to safe abortions), denied motherhood (e.g., legal regulation of conception, coerced or forced sterilization, subjection to contraceptive testing or use of long-term contraceptive methods), and disciplining of mothers-to-be (e.g., legal regulation of behavior during pregnancy) (Ehrenreich 2008, Ross 2006b).

### *Forced Motherhood*

Forcing women to become mothers forces them into a servant caste, which subjects them to a special duty to serve others and not themselves (Koppelan 1990). Dating back to slavery, African American women have experienced a long history of racist and discriminatory behavior with respect to systemic efforts to control their sexuality and reproduction (Roberts 1997). The slavery experience epitomizes the patriarchal use of a woman's body for reproduction and the most brutal example of the denial of autonomy over reproduction. Limited access to health care resources serves to perpetuate restrictions of their reproductive health and emerges as a contemporary method of forced motherhood (Hooton 2005, Ross 2006c, Silliman et al. 2004).

## Reproduction During Slavery

Within the institution of slavery, Africans were kidnapped and sold, and women were forced to reproduce in order to provide a laboring population that fueled the slave-based mode of production (Davis 1983, Jones 1985). During slavery, Black women experienced the most atrocious denial of reproductive autonomy. Female bondage was severe because these women were often forced to bear children—to which slave mothers had no legal claim—and cope with sexual abuse in addition to doing the work assigned to them (Jennings 1990, Jones 1985). This history is important because it suggests that controlling the reproductive rights of women of color extends beyond issues of fertility and also serves to reduce the importance of issues of chastity and virginity. Once the female slave accepted that she did not have control over her body, the importance of her virginity was considerably reduced (Gubrium 2007). Thus, not only did the concept of Black female sexuality develop out of the experience of slavery, but slavery also influenced later perceptions of Black female sexual morality (Roberts 1997). Angela Davis (1983) claims the subjugation of the female slave was the slave master's symbolic attempt to break her ability to resist. Davis states:

In confronting the Black woman as adversary in a sexual contest, the master would be subjecting her to the most elemental form of terrorism distinctively suited for the female: rape. Given the already terroristic texture of plantation life, it would be as potential victim of rape that the slave woman would be most unguarded. Further, she might be most conveniently manipulable if the master contrived a random system of sorts, forcing her to pay with her body for food, diminished severity in treatment, the safety of her children, etc. (1983:213).

One way in which African American women have been made to feel dehumanized is through sexual denigration. The system of slavery forced female slaves to serve as human subjects in scientific experiments resulting in significant contributions to scientific progress, usually without consent (Savitt 1982). For example, painful experimentation on slave women

resulted in a cure for vesicovaginal fistula, a condition that allows urine to escape into the vagina—a procedure that came to be known as the ovariectomy (Washington 2006). Slave women also played an important role in the perfection and development of the cesarean section (Byrd and Clayton 2000, Dula 1994, Washington 2006). Openly deliberate and undisguised medical abuse of African Americans was possible because of the existence of ideals of White superiority and the inferiority of the Black body. Black bodies were also thought to be owned by Whites, thus furthering abuse. The historical legacy of medical experimentation continues to influence the delivery of optimal medical care to African Americans (Byrd 1990, Chandler 2010, Washington 2006).

#### Limited Access to Reproductive Health Services

African American women experience some of the worst reproductive health outcomes when compared to women from other racial groups, particularly in the areas of low birth weight, infant mortality, maternal mortality and prenatal care (Anachebe and Sutton 2003, Parham and Hicks 2005). African American women also have the highest risk of pregnancy-related death, including hemorrhage, pregnancy-induced hypertension, and pulmonary embolism (Anachebe and Sutton 2003). According to the Centers for Disease Control report of Safe Motherhood, this represents a four-fold disparity in maternal mortality risk when compared to White women – 46.1 versus 12.4 per 100,000 live births – and is one of the largest racial disparities among major public health indicators (2008).

Many socially disadvantaged minority women find that reproductive health care that promotes healthy mothers and babies is unavailable, leaving them without many available choices (Dehlendorf et al. 2010, Roberts 1993, Rutherford 1992). Furthermore, poor women,

and especially poor women of color, find limited access to reproductive services and information, including information about the option of abortion since they disproportionately rely on federally funded family planning clinics for contraceptives and basic reproductive health services (Arons and Agenor 2010, Rutherford 1992). Many poor women and women of color live under circumstances that make it difficult for them to obtain early abortions (Dehlendorf and Weitz 2011, Nsiah-Jefferson 1989). Even with the availability of such clinics, one notable legislative policy, the Hyde Amendment, highlights the constrained choices that impede African American women's access to abortion through the denial of Medicaid funds for abortion (Arons and Agenor 2010, Nsiah-Jefferson 1989, Ross 2006c). This policy impacted significant numbers of women of color and disadvantaged women, causing delays in abortions while they raise the necessary funds to cover the costs (Arons and Agenor 2010, Boonstra and Sonfield 2000, Nelson 2003, Nsiah-Jefferson 1989, Ross 2006b). In cases in which women are required to raise the money needed for an abortion, the time they spend searching for funds makes it more likely that they will need a more costly and difficult second-trimester procedure (Fried 2000).

Prenatal care includes the range of health care services provided by hospitals, clinics, trained medical professionals prior to the woman giving birth. The functions of prenatal care are to improve pregnancy outcomes and decrease the likelihood of adverse events such as low birth weight and preterm births (Fiscella 1995). African American infants are twice as likely as White infants to be born to mothers who received late or no prenatal care (Rutherford 1992, Spong et al. 2011). Additionally, studies have found that White women are more likely to begin their prenatal care in the first trimester, whereas African American women tend to delay treatment until the second or third trimester (Alexander, Kogan and Nebukera 2002). When African American women receive timely prenatal care it may still be inadequate and contribute

significantly to the disproportionately high infant mortality rate of African American babies (Goldenberg et al. 1996, Johnson et al. 2007). Although prenatal care reduces these risks, limited health-care access and use cannot fully explain the disproportionate rate of maternal death for African-American women (Parham and Hicks 2005).

Unrestrained access to medical knowledge is crucial to the optimum maintenance of reproductive health and the power to make genuine choices about their reproductive health which is the *sine qua non* of reproductive freedom (Jones 2010, Rutherford 1992). Reproductive choice for financially disadvantaged women and women of color is hindered by numerous realities including lack of quality gynecological services, unnecessary reproductive surgery, including hysterectomy and other procedures resulting in sterility, inadequate informed consent to procedures, lack of information about sex, contraception and health, lack of culturally appropriate health service, as well as anti-abortion clinic violence and domestic violence (Jones 2010, Nsiah-Jefferson 1989, Washington 2006). Ultimately, the lack of access to proper reproductive health care and information enforces the right to have children, while denying the right not to (Roberts 1997).

### *Denied Motherhood*

The systematic denial of reproductive freedom has stained African American women's history in America. When state legislators and judicial officials deny a woman the right to bear children or the ability to maintain control over her reproductive capabilities, she is deprived of part of her humanity (Roberts 1997). The denial of reproductive freedom emerges through issues such as sterilization and limited access to reproductive health and decision-making. In the 1970s, between 100,000 and 150,000 poor women, half of who were African-American, were

sterilized annually under federally funded programs (Roberts 1997). For women of color, the line between helping to control their reproductive lives and coercing them to reduce the number of children has never been a clear one and continues to be an area of conflict and compromise.

### Compulsory Sterilization

Women of color have been subjected to systemic and widespread sterilization abuse for decades (Davis 1983, Nsiah-Jefferson 1989, Roberts 1997, Roberts 2000). Sterilization is not a phenomenon of the distant past. A recent study using data from the 2002 National Survey of Family Growth revealed that African American women were more likely than White women to have undergone tubal sterilization (Borrero et al. 2007). Sterilization abuse has taken the form of both blatant coercion and trickery and the subtle influences on women's decisions to be sterilized (Clark 1984, Nsiah-Jefferson 1989). Forced sterilization refers to instances in which the woman is unaware that she will undergo a sterilization procedure at the time of the surgery and only learned of the sterilization after the fact (Lombardo 2008). Forced sterilization has historically been used to enforce family caps under state welfare laws, and a history of racism that devalues women of color and portrays them as undeserving mothers (Hooton 2005). Coercive sterilization refers to two particular instances in which sterilization takes place. First, it refers to an individual who is legally unable to give informed consent, due to mental capacity or age. Secondly, it may involve an individual who is legally capable of giving consent but is deceived, compelled or coerced into being sterilized. Coerced sterilization is one of the most extreme forms of control over a woman's reproductive life and despite the repeal of sterilization laws; such coercion persists among advocates of sterilization for women requiring public assistance (Thomas 1998).

Because the victims of blatant sterilization have been primarily African Americans, Hispanic Americans, and Native Americans, this raises concerns that sterilization has eugenic overtones. Some doctors refused to deliver the infants of African American Medicaid patients unless they agreed to be sterilized after delivery (Roberts 1997). The Eugenics Movement as a whole was concerned with what was believed to be the “genetic fitness” of the population. Measuring genetic factors rather exclusively through social and behavioral characteristics, the Eugenics Movement sought to control reproduction of individuals of perceived inferior races, including African Americans. The U.S. government attempted to reduce the number of people on welfare by taking action to limit the transference of poverty from generation to generation (Roberts 1990, Ross et al. 2007). In particular, the Eugenics Movement centered around the goals of creating a supreme race, supporting the Birth Control Movement targeting African American women as unfit, and working to prevent their reproductive freedom (Lee 2000). By permanently denying women the right to bear children, sterilization enforces society’s determination that a woman is unworthy of motherhood. The end of slavery did not afford African American women any greater right to sexual autonomy and the disproportionate sterilization of this population was yet another manifestation of the dominant society’s devaluation of them as mothers (Roberts 1990, Roberts 1993).

Another method of sterilization is the hysterectomy, a medical procedure that surgically removes the uterus. Hysterectomies were performed on many African American women for non-medically indicated reasons and frequently without her knowledge or consent including ending a women’s childbearing potential. Although the practice was performed across the country, these procedures were so common in the South they were referred to as “Mississippi appendectomies” (Roberts 1990, Rodriguez-Trias 1982, Wilcox 2002). In efforts to link



contraception to welfare, African American women and economically disadvantaged women were disproportionately the targets of programs and legislative proposals in the United States promoting sterilization or requiring contraceptive use (Boonstra et al. 2000, Rodriguez-Trias 1982). Due to its long history, recommendations of hysterectomies may cause suspicion among African American women, even in more recent times.

### Long-Acting Contraceptives

A common reproductive choice for women who attempt to avoid pregnancy is the use of female contraceptives. Contraceptives are an empowering tool that women use to control their fertility as they deem appropriate. Population control on the other hand strips women of the ability to make fully informed decisions about their fertility and instead subjects women to policies and practices that control her reproduction against her will or without her full consent. Where contraceptives can be a positive woman-centered experience, population control never is (Scully 2004).

One of the most common long-acting contraceptives is Norplant. Norplant was approved at the end of 1990 and quickly became popular among public policy makers because of its simplicity. Specifically, for five years a woman only had to allow a health care provider to surgically implant the device in her arm to induce infertility (Gill 1994). Furthermore, a great portion of the early Norplant users experienced irregular, heavy bleeding that sometimes lasted for months and others had no period at all. Many suffered from severe headaches, nervousness, extreme weight gain, hair loss, menstrual bleeding, nausea, depression, and chronic blurred vision leading to permanent vision loss or blindness and tumors in the brain (Scully 2004). Similarly, Depo-Provera is a “set it and forget it” form of contraception because it regulates

fertility for three months, sending a constant stream of hormones throughout the user's body (Scully 2004). This method also has potential side effects including adverse effects on bone density (Pitts and Emans 2008, Westhoff 2003), irregular menstrual bleeding and weight gain (Berenson and Rahman 2009, Matson, Henderson and McGrath 1997), and a potentially increased risk of cervical cancer (McFarlane-Anderson et al. 2008). Furthermore, the limitations of these two contraceptives are that neither provides any protection against sexually transmitted infections and both are associated with decreased condom use (Martin et al. 1998, Scully 2004).

Much of the debate about Norplant and Depo-Provera use in the United States grew from concerns about racial bias in the provision of health care (Lee 2000). The unique characteristic of Norplant is that it removes virtually all control over contraception from the woman (Albiston 1994). One of the most salient problems with Norplant was that many physicians were trained to insert Norplant yet lacked the skills to remove it. While physician's removal skills have improved, many state Medicaid policies provide support for insertion but not removal (Arnoff 1996, Scully 2004). Thus when women desire to have the Norplant device removed, if they do not have funds for the procedure, they are held hostage, often at the discretion of providers and politicians. These long-acting contraceptives caused extreme controversy because they were perceived as a form of population control because of its targeting to African American, Latino, and Native American women (Albiston 1994, Roberts 1997). Two examples support these claims: the regular use of Norplant among African American women prior to FDA approval and courts mandating the Norplant device to be implanted in women convicted of drug or child abuse or as a condition of probation (Albiston 1994, Roberts 1997, Watkins 2010). With the exception of Asian American women, women of color have higher Depo-Provera usage rates than European American women (Volscho 2011). Young, low-income, African American and Native

American woman with lower levels of education have also been found to be more likely to be currently using Depo-Provera than similarly situated European Americans, Asian Americans, and Latinas (Volscho 2011).

Additionally, women frequently made the “choice” of using Norplant or Depo-Provera under pressure, thereby making these decisions not a choice but a consequence of coercion, particularly after giving birth (Roberts 1997). Tactics limiting women’s choices to only a few methods of contraceptives (e.g., sterilization, Depo-Provera and Norplant) or pressuring the use of these methods despite significant health risks, or denying women choices altogether, are viewed as attempts of population control (Scully 2004). Contraception decisions should be based on a woman’s health history, current health status, ability to access health care as needed, and lifestyle, rather than a health care provider in a position of power perceiving her as a problem because she is a woman of color or has an illness (Scully 2004).

### *Conspiracy, Suspicion & Discrimination*

While the early occurrence of slave breeding, rape, and sterilization laid a foundation for the distrust of programs directed toward sexuality, fertility and reproduction, in contemporary African American culture, belief in conspiracy theories may play a significant role in health care. Conspiracy theories influence a patient’s decision making in seeking health care, trusting providers, and making choices about health behaviors. Bird and Bogart (2005) conceptualized conspiracy beliefs as beliefs about large-scale discrimination by the government and health care system against a group (Bird and Bogart 2005). They explored conspiracy and discrimination beliefs in relation to contraception among a randomly selected sample of 71 African Americans. Specifically these authors explored (1) birth control conspiracy beliefs, (2) perceived group

discrimination, and (3) attitudes toward and perceived effectiveness of contraceptive methods. Among their sample, 36.9% agreed with the statement “doctors and nurses coerce African American women to use certain birth control methods” and 48.6% agreed with the statement “Whites want to keep the numbers of African American people down.” Between five to forty-nine percent endorsed the conspiracy beliefs regarding birth control. They also found their respondents reported perceiving discrimination when seeking health care for family planning or contraceptive services. Interestingly, those with stronger beliefs of conspiracy also held more negative attitudes toward contraceptive methods (Bird and Bogart 2005). Finally, these authors contended that their findings of conspiracy beliefs regarding birth control were similar to beliefs found among African Americans over three decades ago.

Actions and attitudes aroused suspicions among African Americans that family planning efforts were inspired by racist and eugenic motives, designed to eliminate African Americans as a race (Dula 1994). Certain segments of the African American community mistrusted the underlying intention of both private and government efforts with respect to contraception. Some African Americans in particular became skeptical of the increasing push for contraceptive dispersal in poor urban neighborhoods, accusing contraceptive proponents of promoting nothing less than “Black genocide” (Caron 1988). The infamous Tuskegee experiment is one of the most notable medical atrocities in American history, in which this 40-year study the United States Public Health Service withheld treatment from 400 impoverished African American men diagnosed with syphilis. However, little focus has been given to the women and children who were the invisible victims of the experiment. At least 50 unnamed women and children contracted syphilis from the untreated men. Their needs were ignored until 1975 when the

government approved treatment for 27 wives who tested positive for syphilis and 17 children and 2 grandchildren with congenital syphilis (Gamble 1997).

Additionally, negative interactions and counseling with health care providers have important implications for the health of individuals as well (Yee and Simon 2011). Several researchers have found that a significant percentage of patients report experiencing discrimination based on their race, socioeconomic status, sexual orientation or other factors when receiving health care (Rouse-Amett, Dilworth and Stephens 2006). It has also been found that experiences with discrimination can have adverse physical and mental effects (Bird and Rieker 2008, Rouse-Amett, Dilworth and Stephens 2006, Williams and Williams-Morris 2000, Yee and Simon 2011). In another study by Bird and Bogart (2005), they suggest that perceptions of discrimination may affect the interactions African American women have with the health care system and her receipt of family planning or contraceptive services. In a telephone survey of 500 African American women of reproductive age, the authors found that while the majority of women indicated they had seen a provider for family planning services, 2 of 3 women reported race-based discrimination when obtaining these services. The respondents spoke of experiences with providers that reflected stereotypes of African American women, such as assumptions about multiple sexual partners. They also touched on concerns of contraceptive safety and a broader historical view of birth control as a form of African American genocide (Thorburn and Bogart 2005). These authors suggest that future discussions surrounding unintended pregnancy, birth control, and HIV/AIDS risk in African American women should take into consideration the historical context of these issues, because African Americans may be more suspicious of certain contraceptive methods. Thus, considerations should be made for historical and current policies

and experiences within the health care system that may explain ways in which African Americans access and receive health care (Dula 1994, Jupka et al. 2008).

Dorothy Roberts' seminal work, *Killing the Black Body*, brought to light the socio-historical struggle for reproductive freedom by tracing the pathways from slave owner's economic vested interest in bonded women's fertility to the more contemporary attempts to coerce African American women and welfare mothers to accept Norplant and Depo-Provera (Roberts 1997). The horrific history of oppression that African American women have endured through the brutal exploitation of their reproductive labor coupled with prior negative experiences with health care institutions and personnel have led many African American women to distrust institutional recommendations, thereby putting these women at risk for unintended pregnancy, sexually transmitted infections, and compromised reproductive health (Mullings 2006).

### **Reproductive Health and Disabled Women**

Although most chronic conditions are disabling, clear lines distinguishing between chronic illness and disability continue to be blurred (Gabe, Bury and Elston 2009). Some have argued that society makes clear distinctions between the able-bodied and the disabled and that chronic illness and bodily states are separated from such structures (Gabe, Bury and Elston 2009). Nonetheless, symptoms and disability are indeed the principal outcomes of chronic conditions and become the focus of protracted personal and medical care (Verbrugge and Jette 1994). In short, in many instances, chronic conditions affect bodily functioning and daily activities and can lead to disability—conceptualized as the restriction or lack of ability to perform an activity in a normal manner (Nosek et al. 2001). Disability is generally categorized into three

broad categories: (1) communication, (2) physical, and (3) mental (Waldrop and Stern 2003). For the purpose of this dissertation, disability is narrowly defined as bodily limitations that restrict physical activities.

### *Discouraged Motherhood*

Medical providers treat disabled women as incapable of making their own choices, especially those choices involving sexuality and pregnancy (Kallianes and Rubenfield 1997). For most women choosing to bear a child is an unquestioned right, yet society insists that disabled women justify and defend their decision (Killoran 1994). To assume that childbirth is not a concern for women with disabilities denies their normal desires (Jackson and Wadley 1999). It also underlies the serious lack of consumer and clinical information about risks and precautions of pregnancy, labor and delivery for women with disabilities (Nosek and Simons 2007). Women with disabilities have reported that their mothering rights have been denied through subtle discouragement by doctors, professionals, and family members due to the assumption that they will breed more disabled individuals (Kallianes and Rubenfield 1997, Romano 1982, Volz 2006, Walsh-Gallagher, Sinclair and McConkey 2012). In extreme cases, providers have performed forced sterilization through unwanted and unnecessary tubal ligations or hysterectomies on disabled patients (Cole 1988, Volz 2006).

As part of a study on maternity, motherhood, and disability, Carol Thomas (1997) conducted interviews with 17 women having Crohn's disease, diabetes, asthma, Addison's disease, cerebral palsy, and systemic lupus erythematosus to explore their reproductive experiences (Thomas 1997). Participants were varied in terms of childbearing status, and included women who were currently pregnant, had no children, one child, and two or more

children. Participants expressed their desires, decisions and experiences of childbearing and parenting as intertwined with additional concerns stemming from the physical limitations they encounter, personal experience of living with impairment, and their knowledge about the possible effects of reproduction on their bodies. Secondly, women in the study spoke of the pressure they felt resulting from their disabled condition that often made them feel as though they had to demonstrate that they were, or could be, “good enough mothers.” The third key finding was the women’s experiences of receiving “unhelpful help” from health care and social workers, imposing suggestions from health care workers that were neither solicited nor desired. Thomas suggested this process served not to simply manage the pregnancy, but more-so to manage the disabled woman (Thomas 1997).

#### *Denied Reproductive and Sexual Information*

Women with illness or disease are frequently deemed asexual; therefore they are prone to ignore considerations of reproduction or sexual activity (Curry et al. 2009, Matthews 1983, Ray and West 1984). When a disabled female is denied her sexual needs and desires, she is being denied her basic humanity as well (DeLoach 1994). Nosek and Simmons (2007) identified several sources of sexual and reproductive health disparities among disabled women. Misconceptions about disabled women include that they are not sexually active, asexual, uninterested in sex, unable to take part in sexual activity, or are sexual “monsters” unable to control their sexual drives and feelings (Anderson and Kitchin 2000, Nosek and Simons 2007).

Another source of disparities for this population are the systemic barriers that ensue when physicians fail to offer reproductive health services or fail to consider women with disabilities as sexual beings or assume that sexuality is not a relevant or important issue. Many health care



providers are unprepared to discuss issues of fertility, conception, and pregnancy for disabled women (Philips and Phillips 2006). Again, numerous barriers exist that impact disabled women's prenatal and reproductive care such as provider attitudes, poor communication, knowledge of the conditions, and physical, structural factors such as limited time and resources (Becker, Stuifbergen and Tinkle 1997, Philips and Phillips 2006, Piotrowski and Snell 2007). Regrettably, disabled women report they are not generally afforded legitimacy and are unrecognized as having sexual desire – these serious claims of discrimination warrant attention by health professionals. Disabled women have also reported dissatisfaction with the lack of adequate counseling on sexuality, birth control, pregnancy, and childbirth from gynecologists and rehabilitation professionals (Asch and Fine 1988, Nosek et al. 2001).

A study by Becker, Stuifbergen, and Tinkle (1997) focused on how reproductive care could be improved for women with physical disabilities. These authors conducted in-person interviews designed to elicit information about birth control, pregnancy, sexually transmitted infections and barriers to quality services and suggestions for improvement. Ten women between the ages of 28-47 with various disabilities participated: four women had congenital impairments, one was disabled at 16, the other five were disabled in adulthood, all were White, with some college education, all were employed or attending college. The thematic analysis of the transcripts revealed barriers, facilitators, and issues regarding birth control, pregnancy, sexually transmitted diseases, menopause, aging, and sexuality. This study suggested that individual barriers to receiving appropriate reproductive care among women with disabilities may be attributable to the lack of knowledge about their bodies and sexual function and their difficulty in obtaining reliable contraceptive information (Becker, Stuifbergen and Tinkle 1997). Other barriers impacting participants' reproductive health included limited options for

contraception, health care providers' insensitivity, inaccessible equipment and facilities, lack of knowledge about disabilities, limited information tailored to their needs, and avoidance of regular gynecologic visits due to difficulty accessing these services (Becker, Stuijbergen and Tinkle 1997). Women with disabilities have also reported experiencing doctors not providing them with information on sexuality and birth control because of assumptions that they did not need it (Nosek et al. 2001).

For women with disabilities, the desire for freedom to bear children is no different than able bodied women and translates into the need for them to have equal access to reproductive services, including sexual health education and access to contraceptives (Kallianes and Rubenfield 1997). The lack of access to sexual health information can prove to be dangerous in that women with disabilities who have not received adequate information may not obtain necessary reproductive and obstetrical care, or appropriate information on protecting themselves from sexually transmitted infections (Kallianes and Rubenfield 1997, Sheppard-Jones et al. 2008). Women with disabilities may also fail to receive crucial information about domestic violence and sexual assault, which affects the population with disabilities at a greater percentage than the general population (Healey, Humphreys and Howe 2013, Kallianes and Rubenfield 1997). Because of these assumptions, many disabled women are likely to be restricted from opportunities that are readily available to nondisabled women (Lonsdale 1990). Some of which include dating, engaging in sexual behaviors, and experiencing motherhood (Asch and Fine 1988, Piotrowski and Snell 2007, Rintala et al. 1997).

Women with disabilities are often perceived as unfit mothers because some believe they are unable to cope with the demands of pregnancy, childbirth, and childrearing (Hwang 1997, Lonsdale 1990, Palombi 2012). They are also considered unfit because they are viewed as

incapable of contributing either physically, emotionally, or financially to a family (Asch and Fine 1988). This raises concerns for disabled mothers about maintaining their right to parent (Wates 1997). Research found that parents with disabilities experience prejudice about their rights or abilities to parent. In a national study of nearly 1,200 parents with disabilities, about 15% of the parents reported experiencing threats to their right to parent by having their children removed from the home (Kirshbaum and Olkin 2002). These threats contribute to a skewed sense of identity and promote feelings of mistrust of the health care system.

Women with disabilities are also deemed unfit because they are perceived as casting the burden of their care upon their children-, who are required to work as young caregivers. Being a young caregiver is portrayed negatively and is usually seen as the result of restrictions on the child's freedom, for example to social activities, friendships, employment opportunities, recreation, educational achievement and person growth (Aldridge and Becker 1994, Bilsborrow 1992, O'Neil and Platt 1992). Children of disabled parents are sometimes seen as victims and their parents are scrutinized for their values, choices, and even their right to parent at all (Keith and Morris 1995, Prilleltensky 2004).

Cultural stereotypes depict disabled women as asexual, unfit to reproduce, overly dependent, unattractive—traits that are generally removed from the sphere of true womanhood and feminine beauty (Garland-Thomson 2002). A woman with a disability is often treated as asexual and then viewed as an unfit lover and also assumed to be an unfit mother (Nosek and Simons 2007). The dominant stereotype of disabled women is the poster child, which refers to the practice of many disability-related charity organizations of using a child with a particular disability for charity marketing and medical campaigns (Blackwell-Stratton et al. 1988). The poster child portrays the image of the individual as cute, but not sexy: always the cared for, never

the caregiver (Blackwell-Stratton et al. 1988). These images are exploitive, designed to evoke pity in the nondisabled, and thus a desire to contribute money to the charity, while an unintended consequence extends the image from the philanthropic world into society-at-large (Ferri and Gregg 1998). Joanna Weinberg (1988) also suggested that women with disabilities are “locked in a perpetual adolescence” because of the strong societal taboos attached to their sexuality (Weinberg 1988: p. 274).

### **Reproductive Health and Women with Genetic Conditions**

Genetic risk has various consequences for women as bearers, carers and carriers of children (Hallowell 1999). Risk is a pervasive concept in the social and medical context of reproductive health and a central concept surrounding genetics (Kelly 2009). The concept of risk dominates the process of becoming a mother in the United States and is used to categorize women from the time of their first prenatal visit (e.g. high- and low-risk) (Lippman 1994). Women with genetic conditions are frequently compelled to engage in the medical “risk” discourse and are often told of the risks associated with motherhood and advised of these risks by health care providers (Hallowell 1999, Thomas 1997). A woman’s decision to conceive, abort, or bear a child with genetic disorders may be subject to questions of personal and communal accountability. As biomedicine tends to direct attention toward matters of prevention, popular standards suggest that a child is morally wronged when he/she is knowingly, deliberately, or negligently brought into being with a health condition likely to result in disability, suffering, or significantly reduced life choices relative to other children with whom he/she will grow (Davis 1997, Green 1996, Purdy 1995). So while a woman may not have control over her own

genetic occurrence, women can control the birth of a child who may inherit the condition; she may be required to make choices in the face of the fetus' genetic risk (Lippman 1994).

### *Tentative Motherhood*

#### Prenatal Testing

Prenatal testing affects pregnant women in various ways, but it especially affects those known to be at greater risk of genetic abnormality due to family history, age, ethnicity, etc. (Shakespeare 1998). Prenatal testing is performed to detect any fetal abnormalities and procedures include amniocentesis, fetoscopy, and ultrasonography. Prenatal testing provides a means to avoid the family distress and suffering associated with the unpredicted birth of babies with genetic disorders and malformations. Prenatal testing allows geneticists and obstetricians to offer the choice for abortion covertly, if not overtly, when the fetus has been found to have particular atypical characteristics (Lippman 1994). Definitions and expectations of normal pregnancies intersect with developments in prenatal diagnosis and a growing "ideology of risk" surrounding pregnancy (Lippman 1994). Autosomal disorders are of particular interest in reproductive planning as couples may be at increased risk for having a child with one of these disorders (Driscoll, Sehdev and Marchiano 2004).

Prenatal testing requires that women make decisions and then live with the consequences, a process which Barbara Katz-Rothman's interviewees described as tragic (1993). Findings from her interviews revealed that the investment in pregnancy with the question of 'genetic risk' renders women's relationships with their own pregnancies as 'tentative and fragmented' because the pregnancy cannot be fully accepted until "abnormalities" are ruled out by the tests (Katz-Rothman 1993). Rothman argued that prenatal diagnosis involved a process of "evaluating

disabilities, deciding which disabilities make life not worth living for the person, and also which disabilities demand too much or are beyond [the mother's/parents'] competence" (1993:160). Unfortunately, the burden of choice based on information provided by a prenatal genetic diagnosis will be disproportionately borne by women, since it is the expectant mother who will physically live out that decision through her body, whether through continuation or termination of a "risky" pregnancy. If the decision is made to have a prenatal diagnosis, and the fetus is shown to be affected, then a decision is made whether to terminate the pregnancy or to give birth to an affected child. These decisions are far from straightforward as there is more than one type of prenatal test and various risks associated with different procedures including the threat of miscarriage (Kazazian, Boehm and Dowing 1985). Moreover, women are faced with an interesting paradox in that the choice to undertake prenatal testing reinvests the very conditions and discourses (eugenic and obstetric) which may make screening seem necessary (Shakespeare 2011, Steinberg 1996). It has generally been assumed that women who reject prenatal testing or those who chose not to terminate following a positive result do so out of *a priori* opposition to abortion or a commitment not to devalue the lives of those with disabilities (Kelly 2009).

Petrou et al. (1992) investigated the uptake of prenatal diagnosis in 170 couples "at risk" of having children with sickle cell disease. They showed that the stage of pregnancy, type of sickle cell disease, and ethnic group influenced participants' choices. They described that half of the couples in which one partner had sickle cell disease chose to receive prenatal diagnosis. Participants also reported a greater acceptability of first trimester prenatal diagnosis. Women who were pregnant for the first time were least likely to request prenatal diagnosis. The direct experience of sickle cell disease within the family was also important: over 90% of the women who already had an affected child chose prenatal diagnosis. A common statement made by those

mothers was that they could not cope with the increased anxiety associated with having two affected children. Many of the women indicated that they would not consider terminating the current pregnancy because of sickle cell disease, but would have liked to know the diagnosis. A common reason given for declining prenatal diagnosis was fear of the procedure and the risk to the pregnancy, since miscarriage is an increased outcome for these women (Petrou et al. 1992).

Etchegary et al. (2008) investigated retrospective attitudes toward prenatal testing and screening decisions among 38 adult women who had recently delivered a healthy child at Ottawa Hospital. Of these 38, 16 declined screening and 22 accepted (Etchegary et al. 2008). Their analysis categorized women into having two main influences on their decisions: empathetic knowledge and embodied knowledge. In this study, embodied knowledge referred the personal experience with pregnancy or illness and empathetic knowledge drew upon family and friends' experiences with raising a child with a disability or screening procedures. They found that participants embodied and empathetic knowledge influenced their decisions about prenatal tests. However, those who declined screening placed more emphasis on empathetic knowledge and expressed not wanting to place any additional stress or grief on their family and friends. The participants who declined also expressed a more negative attitude toward termination and had fewer embodied experience with serious illness.

Chen and Schiffman (2000) also qualitatively explored attitudes toward genetic counseling and prenatal diagnosis among 15 adults with physical disabilities including spina bifida, muscular dystrophy, amyotrophic lateral sclerosis (ALS) and others (Chen and Schiffman 2000). The participants in this study viewed genetic counseling as either general information, a discussion of recurrence of risk/reproductive choice, or warnings about birth defects. Perceptions of prenatal diagnosis included preparation for having a child with special needs,

knowledge for pregnancy, detection of birth defects and confirmation of a healthy baby. One participant indicated that prenatal diagnosis was a means of allaying fears and stated “knowing takes some of the fear away. If you can get enough knowledge about something, it puts you in a better seat” (p. 146). Finally, participants did not view genetics as a mechanism for advancing eugenic ideals. Ultimately, these authors suggest that previous views on prenatal diagnosis have been primarily negative, and their findings suggest that while an individual may in fact oppose termination, she may still favor prenatal diagnoses and these two procedures are not mutually exclusive (Chen and Schiffman 2000).

While individuals with genetic conditions make autonomous decisions based on their risk, not often enough is it acknowledged that they draw upon various experiences, from multiple contexts (family, community, society) and are influenced by various competing discourses on their health (clinical, media, family) all of which influence their personal experiences and interpretations of genetic risk and screening (Vahabi and Gastaldo 2003).

## **Summary**

This section illustrates how various social locations and identities may work together to label women with sickle cell disease as unfit mothers for multiple reasons. This section provided an overview of the historical foundations, economic limitations, and discrimination experienced by African American women that may give rise to suspicions in health care in general and reproductive health care in particular. It also illustrates how women with disabilities may be discouraged from motherhood through the lack of reproductive information and how women with genetic conditions may experience pressure to terminate pregnancies. Women with sickle cell disease are an ideal population to sociologically study the nexus of race, gender, and genetic



illness. These social categories have rarely been considered together alongside issues of reproductive health care, particularly with regards to the woman's choice to be sexual, to bear children—even an illness-affected child—and to be seen as fit to mother (Kallianes and Rubenfield 1997).

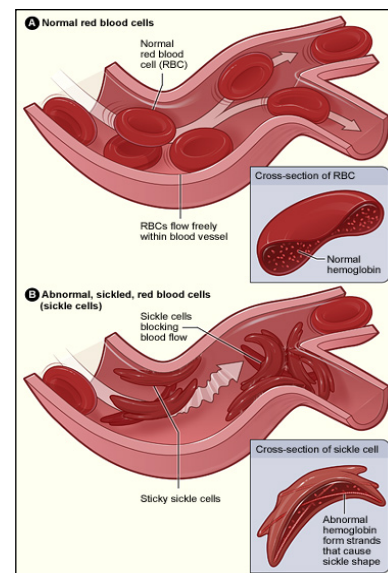
## SICKLE CELL DISEASE

Sickle cell disease (SCD) is an inclusive term for a group of autosomal recessive inherited blood disorders, called hemoglobinopathies. There are four major sickle cell disease disorders: sickle cell anemia hemoglobin S (Hb-SS), sickle beta-zero thalassemia (Hb-S $\beta^0$ ), sickle cell anemia hemoglobin C (Hb-SC), and sickle beta-plus thalassemia (Hb-S $\beta^+$ ) (Platt and Sacerdote 2006). The most common and severe form of sickle cell disease is sickle cell anemia (Hb-SS) (Brawley et al. 2008).

The disease is named “sickle” cell because of the abnormally shaped red blood cells that resemble the sickle, a farm tool with a curved sharp edge that is used for cutting wheat. Normal red blood cells (RBCs) are composed of hemoglobin A and are soft and round, which allow them to flow easily through blood vessels. For those with sickle cell disease, mutations in the hemoglobin gene (the main iron-containing oxygen-transport protein in blood) lead to the production of an altered form of hemoglobin—hemoglobin S (Hb-S)—which distorts the normal shape of RBCs into a sickle shape (Ballas 2002, Frenette and Atweh 2007).

Sickled RBCs are rigid and exhibit enhanced adherence to vessel walls, which obstruct the blood flow from the heart to organs and extremities, causing pain, infection and organ damage (Ballas 2002, Frenette and Atweh 2007, Platt and Sacerdote 2006).

For conditions that are inherited in an autosomal recessive pattern, a person needs to have two copies of a gene change in order to have the condition and receives one gene change from



**Figure 1.** Abnormal shape and blood flow in patients with SCD. **(A)** Schematic of normal and sickled red blood cells. **(B)** Schematic of normal blood flow (top) and restricted blood flow in individuals with SCD (bottom) Source: [http://www.nhlbi.nih.gov/health/dci/Diseases/Sca/SCA\\_Whatfs.html](http://www.nhlbi.nih.gov/health/dci/Diseases/Sca/SCA_Whatfs.html)

each parent (Nussbaum, McInnes and Willard 2004). Those affected with sickle cell disease have a 50% probability of transmitting sickle cell disease to their children if one parent has sickle cell disease and one has sickle cell trait (Hb-AS), and a 100% probability of transmitting the disease to a child when both parents have sickle cell disease (Platt and Sacerdote 2006). When one parent has the disease and the other parent has normal hemoglobin, all children will have sickle cell trait.

**Table 1.** Genetic Transmission of Sickle Cell Disease

<b>Pattern</b>	<b>Parent 1</b>	<b>Parent 2</b>	<b>Children</b>
<b>1</b>	Sickle Cell Disease (Hb-SS)	Sickle Cell Disease (Hb-SS)	100% Hb-SS
<b>2</b>	Sickle Cell Disease (Hb-SS)	Sickle Cell Trait (Hb-AS)	50% Hb-AS 50% Hb-SS
<b>3</b>	Sickle Cell Disease (Hb-SS)	Normal Hemoglobin (Hb-AA)	100% Hb-AS

The first introduction of sickle cell disease into the literature occurred in 1910 by Dr. James Herrick, a physician at the University of Chicago (Herrick 1910). Since then, probably no other medical condition has been so strongly associated with the concept of race (Bediako and Haywood 2009). Sickle cell disease currently affects more than 250 million people worldwide and includes people from a diverse range of racial and ethnic backgrounds (Bediako and Haywood 2009). Globally, the disease is found throughout Africa, Asia, the Caribbean, the Middle East, Europe, and the United States. In the United States, sickle cell disease is most common among African Americans and has long been perceived as a “Black disease” (Bediako and Haywood 2009, Elander et al. 2003, Nash and Telfair 1994, Wailoo 2001). Many have speculated that the sickle cell gene migrated to the United States and the Caribbean as a consequence of slavery which explains the high prevalence among Afro-Caribbean ethnic groups

(Hendrickse and Williams 1966, Serjeant, Singhal and Hambleton 2001). The exact prevalence of sickle cell disease in the United States is currently unknown, however, it is estimated based on 2008 U.S. Census reports and national newborn screening records that approximately 100,000 Americans have sickle cell disease and approximately 1,800 infants are born with the disease each year (Hassell 2010).

Over the past 30 years, life expectancy has improved dramatically due to early diagnosis, improvements in effective and comprehensive treatment, and the use of antibiotics, (Barakat et al. 2009, Driscoll 2007). Previously, the life expectancy estimate for individuals with Hb-SS was 14 years old; yet today the average life span reaches 42 years for men and 48 years for women (Platt et al. 1994). For those with Hb-SC the median mortality age is currently estimated at 60 years for males and 68 for females (similar to the general population of African Americans) (Nash and Telfair 1994, Platt et al. 1994). This data is somewhat dated and it is likely that advances in treatment over the last 19 years have improved survival rates even further. Despite medical advancements, the condition continues to be debilitating and life-threatening with a shorter lifespan than those unaffected by the condition (Brawley et al. 2008, Platt et al. 1994).

### *Sickle Cell Trait*

Those with sickle cell trait are healthy carriers of the sickle cell gene who have inherited one normal hemoglobin gene from one parent and the sickle gene from the other parent (Platt and Sacerdote 2006). Those with sickle cell trait are generally asymptomatic, however the trait has been found to be associated with sudden death, organ problems, and loss of fetus during pregnancy, and complications during strenuous physical activity and exercise (Connes et al. 2008, Mitchell 2007, Tsaras et al. 2009). More than two million Americans, again mostly

African Americans, have sickle cell trait (Hb-AS) (Brawley et al. 2008, Creary, Williamson and Kulkarni 2007). While sickle cell trait is not a disease, when both parents have the trait, there is a 25% chance with each pregnancy that the child will be born with the disease, 50% chance the child will be born with the trait, and a 25% chance the child will be born with a normal hemoglobin (Nussbaum, McInnes and Willard 2004, Platt and Sacerdote 2006). If only one parent is a carrier, there is a 50% chance of a child inheriting only one abnormal gene and being a carrier, like the parents (Table 2) (Nussbaum, McInnes and Willard 2004, Platt and Sacerdote 2006).

**Table 2.** Genetic Transmission of Sickle Cell Trait

<b>Pattern</b>	<b>Parent 1</b>	<b>Parent 2</b>	<b>Children</b>
<b>1</b>	Sickle Cell Trait (Hb-AS)	Sickle Cell Trait (Hb-AS)	25% Sickle Cell Disease 50% Sickle Cell Trait 25% Normal Hemoglobin
<b>2</b>	Sickle Cell (Hb-AS)	Normal Hemoglobin (Hb-AA)	50% Sickle Cell Trait 50% Sickle Cell Disease

### **Clinical Manifestations & Management**

Sickle cell disease is a multifaceted disease with a complicated symptomology and pathophysiology and unpredictable clinical course. The chief manifestation is intermittent and unpredictable episodes of severe pain, which occur when sickled red blood cells constrict blood vessels and capillaries and cause a reduction of oxygenated blood supplied to tissues (Steiner and Miller 2006). The vaso-occlusive pain episode is the hallmark of sickle cell disease and is the most distressing symptom to patients and leads to debilitation and impaired functioning in school, employment and other social contexts (Driscoll 2007). Pain episodes are also the most frequent cause of recurrent morbidity in Hb-SS and accounts for 70-90% of hospital admissions among those with sickle cell disease in the United States (Serjeant, Singhal and Hambleton 2001,

Solomon 2007). A pain episode may occur in nearly every parts of the body, the most commonly affected are bones, back, legs, chest, and abdomen and can be exacerbated by minor infections, a cold, sore throat, stress, fatigue, high altitudes, and abrupt weather changes (Ballas 2002, Danielson 2002, Yale, Nagib and Guthrie 2000). While length and severity are uncertain, pain is often based on the patient's general health condition, physiological and psychological state, pain coping mechanisms, and other medical complications or conditions (Smith et al. 2005). A single pain episode can last between 3 to 14 days and has been compared to that of terminal bone cancer pain (Elander et al. 2003, Smith et al. 2003).

Although pain is the chief manifestation, sickle cell patients also suffer from acute chest syndrome, a combination of respiratory symptoms including fever, cough, chest pain, and shortness of breath and in some cases hypoxemia (Vichinsky et al. 1997). Approximately 50% of patients who have sickle cell disease experience at least one episode of acute chest syndrome during their lifetime (Driscoll 2007). Infections also occur frequently due to splenic dysfunction, which can be life threatening in children under the age of three due to their immature immune system (Schnog et al. 2004). Lung disease (pulmonary hypertension) and the increased susceptibility to severe bacterial infections—meningitis, pneumonia, and septicemia—are all major causes of death among individuals with the disorder (Brawley et al. 2008).

Nearly 10% of all sickle cell patients will have a stroke at some point during their life, with the peak incidence occurring between the ages of 4 and 6 (Claster and Vichinsky 2003, Schnog et al. 2004, Steiner and Miller 2006). Strokes also occur within the blood vessels of the brain, limiting oxygen levels and causing weakness on one side of the body, headache, cranial nerve palsy, and speech impairment (Claster and Vichinsky 2003, Schnog et al. 2004, Steiner and Miller 2006). Some strokes can be so small they may go undetected, leading to

compromised cognitive and physical functioning. Additionally, individuals with SCD have decreased height, weight and body mass index, delayed sexual maturation, delay in onset of menarche and pubertal development when compared to those without the condition (Cepeda et al. 2000, Singhal et al. 1994). Other common manifestations of sickle cell disease include skin ulceration, aplastic crisis, silent cerebral infarcts, and organ damage (Platt 2008, Schnog et al. 2004). This disease can also lead to an increased risk of early death, failure to thrive, vomiting, liver disease, and mental retardation in untreated survivors of stroke (Lee et al. 2006).

### *Clinical Management*

There is no cure for sickle cell disease and therefore the condition requires on-going treatment. Treatment for this condition is complex and ripe with controversy as it mainly consists of opioids. The main purpose for sickle cell management is the prevention of pain and other complications and treatment of pain.

### Pharmacologic

Pharmacologic management of sickle cell pain includes three major approaches: non-opioid analgesics (Tylenol, ibuprofen, aspirin, etc.), opioid analgesics (codeine, morphine, oxycodone, etc.), and adjuvants (e.g., antihistamines, antidepressants, etc.) (Ballas 2002, Jacob 2001). Opioids are the mainstay of treating moderate-to-severe pain and are often associated with addiction and illicit drug use (Ballas 2007, Pack-Mabien and Haynes 2009, Shaiova and Wallenstein 2004). Antibiotics can be used to prevent infection in early childhood and treat infection in adults with sickle cell disease (Jacob 2001). Management also includes treatments for pain episodes and dehydration by using supplemental oxygen, non-steroidal anti-

inflammatory drugs (NSAIDs), and intravenous fluids (Smith et al. 2005). One of the premier causes of increase life expectancy, oral penicillin, is now administered during early childhood and has done much to improve and extend the lives of children with sickle cell disease (Falletta et al. 1995).

### Hydroxyurea

Hydroxyurea is currently the only FDA-approved disease-modifying therapy for sickle cell disease (Brawley et al. 2008). Hydroxyurea is taken orally and stimulates fetal hemoglobin production, raises hemoglobin concentration, increases the size of the red blood cell, lowers white blood cell counts, and decreases red blood cell intracellular dehydration (Hankins et al. 2005, Steinberg et al. 2003). This therapy is most often used with patients who have moderate to severe disease, as indicated by the number of painful episodes or occurrences of acute chest syndrome (Platt 2008). However, long-term use may lead to cancer, specifically acute leukemia, which may influence willingness to take the drug and adherence (Platt 2008). While use of Hydroxyurea has been found to reduce hospitalizations and pain episodes, it is currently not recommended during pregnancy as it has been found to have teratogenic effects which may increase the risk of adverse effects and fetal abnormalities (Brawley et al. 2008, Hassell 2005, Lanzkron et al. 2010).

### Blood Transfusion Therapy

Blood transfusion therapy is commonly used in sickle cell disease management in those severely affected individuals to lower the fraction of cells that contain the hemoglobin S and improve oxygen carrying capacity and/or prevent sickle-related vascular effects (Danielson



2002, Wayne, Kevy and Nathan 1993). Transfusions also help minimize or prevent disease complications such as acute chest syndrome, stroke, cerebrovascular disease, vaso-occlusive episodes, and other organ damage (Josephson et al. 2007, Wayne, Kevy and Nathan 1993). While a life saving measure, if not used carefully, transfusions are associated with iron overload, alloimmunization and viral infectious complications (Wayne, Kevy and Nathan 1993).

### Bone Marrow Transplantation

Bone marrow transplantation is the only potential curative treatment for sickle cell disease (Hoppe and Walters 2001). While bone marrow transplantation has been successful for treating sickle cell disease in select individuals, the mortality rate and adverse long-term side effects with this treatment have been generally high, especially in adult patients (Walters et al. 1996). Unfortunately, locating sufficient matched donors significantly limits the number of candidate patients for this procedure and only 14% of sickle cell patients have indications for transplantation with a matched donor sibling (Driscoll 2007).

### Alternative Therapies

Many alternative therapies methods are used to decrease the use of opioid and actually provide a more holistic approach to managing or eliminating the pain rather than simply riding patients of the perception of pain (Bodhise et al. 2004). Continuous opioid use is associated with problems of over-sedation, acute chest syndrome, and paradoxical effects (Shafer and Vichinsky 1994). Cognitive strategies including hypnosis, imagery, and biofeedback can be effective methods for pain reduction (Chen, Cole and Kato 2004, Sibinga et al. 2006, Telfair et al. 2004, Yoon and Black 2006). Some of the non-pharmacologic pain management options include heat

packs, relaxation, distraction, music, massage, therapeutic exercises, menthol cream rub, self-hypnosis, acupressure, and acupuncture (Ballas 2007, Bodhise et al. 2004).

### *Self-Management*

Those with chronic illnesses must assume a large part of the responsibility for managing their condition, which consists of self-care practices and routines that promote prevention and improve health (Thorne and Patterson 2000). Individuals with sickle cell disease are encouraged to take health promotion steps to prevent the onset of pain and promote their own health status (Platt and Sacerdote 2006). Some of these behaviors include drinking plenty of water, managing fever, getting enough oxygen, flying in unpressurized airplanes, getting plenty of rest, refraining from over-exertion, taking prevention medications appropriately, avoiding certain situations such as getting too hot or cold, and avoiding alcohol, tobacco and illicit drugs (Platt and Sacerdote 2006). These measures are just a few of the key principles of promoting health for a person with sickle cell disease.

### *Reproductive Health Outcomes*

The two most researched areas of reproductive health in women with sickle cell disease are pregnancy complications and acceptable contraception methods. Notwithstanding medical advances, women with sickle cell disease continue to experience worse pregnancy outcomes than women without the condition and there continues to be some degree of uncertainty concerning appropriate contraceptive methods. It well established that women with sickle cell disease face numerous pregnancy risks, complications, and adverse outcomes (Barfield et al. 2010, Chase et al. 2008, Hassell 2005, Howard, Tuck and Pearson 1995, Smith et al. 1996). Prior to 1972,

maternal and perinatal rates averaged 4.1% and 52.7%, respectively, however these rates have declined and in 2005 were reported as averaging 1.7% to 22.7% (Powars et al. 2005). The decreases in maternal and perinatal mortality may be the result of advances in medical care, improvements in transfusion medicine, and more frequent prenatal care. The increased risks of complications and mortality caused providers to recommend that women with sickle cell anemia become sterile, terminate pregnancies when they occur, or avoid pregnancy altogether based on known health risks (Fort et al. 1971, Fort and Morrison 1972).

There is an emerging body of evidence-based research on pregnancy outcomes for women with sickle cell disease (Serjeant et al. 2004, Mou Sun et al. 2001, Villers et al. 2008). Of note, these women are at increased risk for several adverse pregnancy outcomes. Mou Sun and colleagues (2001) reported that women with sickle cell disease (hemoglobin SS) were significantly more likely to need antepartum hospital admission (62%, often as a result of sickle pain crises, pyelonephritis, and anemia), deliver by cesarean section (34%), deliver an infant that was premature (45%) or low birth weight (46%), and experience a postpartum infection (22%) compared to the control group (Mou Sun et al. 2001a). Villers and colleagues analyzed data from the 2000-2003 National Inpatient Sample from the Healthcare Cost and Utilization Project to assess the maternal morbidity of pregnant women with sickle cell disease (Villers et al. 2008). The authors identified 17,952 deliveries to women with sickle cell disease in the United States during this time-period. Similar to Mou Sun and colleagues, the authors reported a higher cesarean delivery rate in women with sickle cell disease as compared to controls (31% vs. 25%,  $p < 0.001$ ). Moreover, they experienced a higher mortality rate (72.4 vs. 12.7 deaths per 100,000 deliveries). Unlike previous reports, this study found that when compared with control subjects, women with sickle cell disease had higher rates of infections and pregnancy-related

complications such as preeclampsia, placental abruption, preterm labor, intrauterine growth restriction, and genitourinary tract infection (Villers et al. 2008).

More recently, Barfield and colleagues (2010) conducted a retrospective study comparing pregnancy outcomes between women with sickle cell disease and women with no hemoglobinopathies (Barfield et al. 2010). Both cohorts of women were of African descent and residents of the state of Massachusetts, with a live birth greater than 20 weeks and greater than 350g. The study used the Massachusetts Pregnancy to Early Life Longitudinal (PELL) Data System to examine perinatal outcomes for these populations between 1998 to 2006. The study yielded a total of 663 deliveries and found that fetal demise was twice as likely among SCD deliveries relative to deliveries to women with no reported hemoglobinopathies. The authors also found preeclampsia, lung disease, and heart disease were reported more often among women with sickle cell disease compared to deliveries to women with no reported hemoglobinopathies, while no differences were found for diabetes, hypertension, kidney disease, or eclampsia. Over 58% of deliveries to women with sickle cell disease were covered by public insurance yet nearly 26% of the deliveries had less than adequate prenatal care utilization. This study suggests that women in this population continue to experience major risk-factors for pregnancy and delivery-related complications including higher risks of fetal death, preterm births, low weight births, cesarean delivery and induction of labor (Barfield et al. 2010).

Numerous concerns and misconceptions exist surrounding potential complications and disease exacerbations due to the use of contraception among women with sickle cell disease (Howard, Lillis and Tuck 1993, Legardy and Curtis 2006, Manchikanti et al. 2007). Much of this uncertainty is due to the lack of useful and clear guidelines and conflicting messages regarding contraceptive use among this population (Chase et al. 2008, de Abood et al. 1997,

Foster 1981, Ladipo et al. 1993). The use of combined oral contraceptive pill has found to be associated with increased thrombotic risks, while progestogen-only pills, injectables, and implantables have resulted in concerns for possible clinical or hematological complications. Other documented research cautions against the use of copper intrauterine devices (Howard, Lillis and Tuck 1993, Koshy and Dorn 1996). In a recent Cochrane review of steroid hormones for contraception in this population, Manchikanti and colleagues (2007) state that Depo-Provera appears to be a safe contraception option and may reduce sickle pain crises, but that more well-designed randomized controlled trials are needed. The authors only included a trial by De Ceulaer that reported that affected women who were on Depo-Provera were 77% less likely to report a painful sickle crisis over a six-month period (DeCeulaer et al. 1982, Manchikanti et al. 2007).

This gap in knowledge of the complete reproductive health experience for women with sickle cell disease was further stressed in a small body of research on contraceptive choices for adolescents with chronic diseases. Kimberly Heroux (2003) and Gittles and Strickland (2005) explained that there is a lack of information on identifying effective contraceptive options for medically ill adolescents who may be initiating sexual activity. In a review of the literature, Heroux (2003) described the challenge of promoting contraceptive counseling in adolescents with the concurrent medical management of a chronic illness. Some medications may alter the effectiveness of hormonal contraception; thus, Heroux reviewed the literature and clinical recommendations for this at-risk population. For adolescent girls with sickle cell disease, Heroux stated that recommendations vary widely given the uncertainty on the magnitude of risk for venous thromboembolism in oral contraceptive users with sickle cell disease (Heroux 2003). Gittles and Strickland (2005) echoed these findings and argued that, while adolescents with the

disease may be chronically ill, there is evidence to suggest that their experiences with sexual activity mirror their healthy peers (Gittes and Strickland 2005, Suris et al. 1996).

There is a paucity of evidence-based research on family planning practices for women with sickle cell disease (de Abood et al. 1997, DeCeulaer et al. 1982, Howard, Lillis and Tuck 1993, Manchikanti et al. 2007). Again, this gap is critically important as the unintended pregnancy rate for women with sickle cell disease may be higher than in the general population (Howard, Lillis and Tuck 1993). Howard and colleagues first reported on this disparity in 1993 in an analysis of 156 women with sickle cell disease in North London (Howard, Lillis and Tuck 1993). Interviewers asked participants about their menstrual, obstetric, and gynecologic history and current and past contraceptive use. The authors found that the average age at menarche was 15 years and that of the 207 pregnancies reported, 133 were unplanned (64%). Moreover, 45% of participants had used a combined oral contraceptive at some time. The use of the progestin-only pill (20%), intrauterine contraceptive device (19%), and Depo-Provera (17%) was much lower but may reflect contraceptive patterns of that study period. When asked about pregnancy counseling they had received, 36% of respondents indicated they were advised not to become pregnant by their medical provider. However, only three participants indicated this advice had or would have influenced their pregnancy plans.

Samuels-Reid et al. (1984) collected sexual and menstrual history, contraception behaviors, pregnancy, and general demographic data from 52 patients with sickle cell disease and 80 patients without sickle cell attending two family planning clinics at Howard University and George Washington University (Samuels-Reid, Scott and Brown 1984). These authors found that 39% of the sickle cell group reported being sexually active compared to 81% of control group with age of first sexual relationship at 17 years old. Thirty-three percent of sickle

cell group (SCD) reported use of some contraceptive method compared to 66% of controls and only 30% of sickle cell group had used any contraception during most recent sexual encounter whereas 64% of controls had used contraception. Of the contraception methods reported 39% of sickle cell group used the birth control pill while 86% of control group used this method. Among the sickle cell group in particular, 23% used a diaphragm, 15.4% used an IUD, and 23% used foam. Only 38% of the sickle cell group and 49% of controls reported unplanned pregnancies, while 55% of the SCD group reported using no contraception at time of unplanned pregnancy versus 35% lack of use among controls. The method of delivery varied between the two groups with 46% of the sickle cell group and only 18% of control group having caesarian sections (Samuels-Reid et al 1984). While this study is dated, the results indicate that while women in the sickle cell group reported less sexual activity, they were older at time of first encounter, which would provide additional time for reproductive health education.

A much more recent study conducted by Knight-Madden and Barton-Gordon (2009) also explored the prevalence of contraceptives usage in women with SCD and factors affecting their use (Knight-Madden and Barton-Gooden 2009). Similar to the Samuel-Reid study, they used a quantitative questionnaire to capture demographic, obstetric history, sexual activity, desire for pregnancy, contraceptive type, reason for non-usage, and beliefs about contraceptive use and pregnancy in women with SCD. A total of 132 women between the ages of 20-28 were recruited; the median age was 24 years old. The questionnaire results revealed that 83% reported having been told of the risks of morbidity and mortality associated with pregnancy. Among the sickle cell group, 75% had been pregnant at least one time, of those 72% had at least one live birth, 25% had at least one miscarriage and 4% had still born infants or elective abortions. Forty-eight percent of women in the study had used at least one contraceptive method during the

past 3 months. From greatest to least, women (or partners) used condom (39%), intramuscular depot medroxyprogesterone acetate injection (28%), oral contraceptive pill (22%), withdrawal (12%), tubal ligation (6%), the IUD (2%), and emergency contraception (1%). None of the participants reported using an implant, rhythm method, or a diaphragm. Among the 68 non-contraception users, 52% reported they did not use contraception because they were not sexually active, 15% expressed a desire to become pregnant, 18% indicated a fear of potential side effects, 16% had the belief that they were unable to conceive, 12% expressed that they did not like contraceptives, 10% had health concerns, and 2% had partners who did not like contraceptives (sum of percent greater than 100 because more than one selection was allowed). Women in the study reported their use of contraceptives was associated with sexual activity, not desiring to become pregnant, and being in a relationship. Women who declined to use DMPA cited excessive vaginal bleeding and the fear of injections as reasons for their choice (Knight-Madden 2009).

O'Brien et al. (2011) reviewed Michigan Medicaid claims of 250 adolescents with sickle cell disease, aged 13-21 over a period of 20 months. In this review they abstracted data for procedures and pharmacy claims to establish pregnancy and contraception use. They review found claims for hormonal contraception among 20 patients, the most common was DMPA (N=12). They also found 64 patients had at least one pregnancy during the study time period and 16 had two or more pregnancies, of these 59 were among patients aged 13-18 (O'Brien et al. 2011). These results indicate more pregnancies than contraception use among this insured population.

The most recent practice bulletin on hemoglobinopathies in pregnancy issued by the American College of Obstetricians and Gynecologists (ACOG), and summarizing much of the



literature presented above, advocated for a multidisciplinary approach in the management of pregnancy for women with sickle cell disease (2007). Specifically, they encourage an ongoing discussion between the obstetrician, hematologist, and anesthesiologist involved in the patient's care during the perinatal period. Given the presence for painful crises during pregnancy and an increased risk for adverse pregnancy outcomes, the ACOG stressed the need for coordinated care.

### Other Reproductive Issues

The biomedical model of sickle cell disease perceives the condition as a major health threat to African Americans and a disease that should be avoided if possible (Meyappan 2001). Thus, biomedical discourses have focused on preventing the transmission of the disease by suggesting that statistical probability be used as the basis of deterring parents from passing the trait or disease onto their child (Fort et al. 1971, Kenen and Schmidt 1978, Markel 1992). It also focuses on treatment and prognosis of the disease and the elimination of the disease through selective reproduction (Meyappan 2001). Linus Pauling, the scientist who discovered the molecular basis of sickle cell disease (1968), suggested:

There should be tattooed on the forehead of every person a symbol showing possession of the sickle-cell gene...[so that] two young people carrying the same seriously defective gene in a single dose would recognize the situation at first sight, and refrain from falling in love with one another. (1968:269)

The issue of moral judgment has generally been confined to discussions of voluntary health risks, particularly people's lifestyle choices or behavior (Hallowell 1999, Pauling 1968). However, more recently it has been observed that individuals not only have a responsibility to avoid voluntarily exposing themselves and others to health risks, but also may be seen as bearing some responsibility for their genetic risks (Kenen 1994, Lupton 1995a, Steinberg 1996). Moral

judgment may also include issues of blame or causality. Blame within the social construction of illness occurs, in some instances, whereby the disease is considered preventable or controllable yet still contracted. Thus certain people are blamed for their own condition which may incorporate a moral judgment about how the condition was contracted and pre-existing hostility toward the group most affected by it (Bayer 2008, Deacon 2006, Scambler 2009). The moral taint associated with a stigmatizing condition may cause some suffers to deny their health status, a situation that can lead to the further spread of a genetic condition.

Responsibility and blame are both important concerns in the context of reproductive choice. Downing (2005) illustrated the complexity of reproductive decision-making in families facing Huntington's Disease and suggested that accepting, modifying, or avoiding genetic risk is an emergent and jointly negotiated process (Downing 2005). Additionally, Steinberg (1996) argues that women in particular are seen as bearing the responsibility for genetics risks. She observed that genetic discourses construct women as "the bearers of nature's defects" or "genetic transmitters" and as such, they are seen as, almost single-handedly, bearing the responsibility for passing on their own and their partner's genes (1996:267). Previous research has found that mothers of children with sickle cell disease have been blamed for knowingly conceiving and giving birth to children who suffer physically (Burnes et al. 2008, Hill 1994b, Jenerette and Brewer 2010). However, little work has been done exploring similar experiences among women with sickle cell disease rather than sickle cell trait.

Genetic responsibility generally consists of three dimensions: (1) knowing about the self for self, (2) knowing about the self for others, and (3) knowing about the self to oblige others to know (Etchegary et al. 2009). These dimensions have implications for test decisions, family relationships and other family members desire to know (or not know) and to act (or not act) with

respect to their own genetic risk (Arribas-Ayllon, Sarangi and Clarke 2008). Moreover, several aspects of genetic responsibility arise within the context of the family: gendered responsibility, reproductive choice, and genetic testing of children (Arribas-Ayllon, Sarangi and Clarke 2008). Genetic responsibility has become a key factor for understanding how genetic risks reshape choice, identification, and obligation within families. Women are traditionally viewed as gatekeepers and transmitters of family information (Richards 1996).

Practices and belief systems that hold mothers fully responsible for the good of the child and the safety of the family go back at least to the Enlightenment (Badinter 1981). In America, the Eugenics Movement embraced the theory that intelligence and other traits were genetically determined and therefore inherited. Eugenicists held women directly responsible for the genetic make-up for their children. Eugenicists argued that unfit women would not willingly limit their reproduction because they lacked the mental ability to comprehend the issues and avoid seduction and, like the Jezebel, appeared incapable of exerting restraint on her capacity for impure breeding (Ettorre 2000, Ettorre 2002). Proponents alleged that many social problems could be eradicated by using eugenics through the enforcement of sterilization laws, thereby preventing the reproduction of genetically unfit individuals (Allen 1999). Eugenic goals concentrated on weaning out undesired characteristics by denying certain individuals with undesired traits the right to marry as well as the right to carry, birth, and rear children (Waxman 1994).

Society scrutinizes, judges, and censures decisions by parents who decide to bear children with potential genetic abnormalities. Parents decide whether to be tested as a carrier or to conceive when there is a family history, or positive carrier status for certain genetic conditions, whether to submit to prenatal screening or to continue the pregnancy of a nonviable fetus

identified as having a genetic anomaly (Shepherd 1995). When society determines that certain choices are irresponsible, it has a range of options, one of which is judging those parents to be morally irresponsible in their use of genetic information. As a result, these parents feel their requests for assistance are not respected (Green 1996). The goal of reducing genetic disorders in the population may be based on a desire to reduce human suffering or reflect an economic concern that the genetic disorder is costly. An even more damaging script is one that elevates eugenics to a level in which the offspring are expected to reach an ideal level of human functioning (Charo and Rothenberg 1994). Ultimately, the diagnosis of a disease-producing genetic trait suggests that those with the trait should avoid passing the disease on to a child by genetic screening of fathers, undergoing prenatal testing, selective abortion, or forgoing parenthood altogether.

### *Partner Testing*

In the context of genetic conditions, both partners must be a carrier of the gene in order to reproduce a child with the condition. Parents must first have access to an understanding of their genetic information. Then they must seek to obtain the trait status of the prospective partner. If the affected person has a partner who is a carrier, then she or he may have other choices when it comes to having children. It may be complicated for a carrier to face her potential reproductive decisions because sexual and reproductive behaviors are governed by complex biological, cultural, and psychosocial factors.

The balance of power within intimate relationships is linked to sexual and reproductive health in three primary ways: (1) directly, (2) through its relationship with violence between partners, and (3) through its influence on the use of health services (Blanc 2001, Gillespie 1971).

The power in sexual relationships refers to the relative ability of one partner to act independently, to dominate decision making, to engage in behavior against the partner's wishes, or to control the partner's actions (Pulerwitz, Gortmaker and DeJone 2000). Gender-based power relations can have a direct effect on the ability of partners to acquire information relevant to their reproductive health, their ability to make decisions related to their health and the ability to take action to protect or improve their health of those who depend upon them (Blanc 2001). Women who discover their fetus may be disabled or will be disabled consequently face many pressures to terminate the pregnancy. According to Tait (1986), the concept of "pro-choice" in the process becomes reduced to choosing between having a "healthy baby" or a "defective child" (1986:452). The control women exercise over the risk or safety of their sexual practices is constrained by the confusion of their ideals of sexuality with their expectations of romance, love, and caring (Tait 1986). Women's strategies for engaging in safer sex develop within social contexts characterized by gendered power inequalities, sexual hierarchy, and male dominance (Holland et al. 1992).

In a study of 34 adult women with sickle cell trait, 15 did not find out their partner's status prior to becoming pregnant (Anie, Berger and Asgharian 2003a). Reasons given for not finding out their partner's status fell into two categories: the awkwardness and sensitivity of asking their partner to be tested and a lack of awareness of the availability and importance of testing. One participant with the experience of sickle cell disease—through caring for a child with the condition—thought that testing was important and would expect her daughter to ask her own partner to be tested. Women who found it difficult to ask their partner explained that discussing sickle cell trait was not considered part of "normal" conversation. Some believed that asking could provoke problems within the relationship and it was viewed as "dangerous ground." Also,

participants suggested that asking or having a dialog would imply the woman wanted children with their partner and often women did not want to ask before reaching a natural state of discussing having children. Reasons respondents gave for not having prenatal diagnosis were because of the risk of miscarrying and the thought of having to make a decision about abortion if they found that the fetus was affected. Some women also mentioned that prenatal diagnosis was not an option because it was offered too late into their pregnancy. Despite the risk of disease to offspring, none of the participants questioned their role as a mother. Nevertheless, at least six women who previously had a child with SCD considered the possibility of not having any more children (Anie, Berger and Asgharian 2003a).

One of the most relevant studies on this topic found that female African American carriers of the sickle cell trait tended to “obfuscate” medical information (Hill 1994b). That is, they obscure, confuse and confound the information almost subconsciously in order to protect their reproductive autonomy. Nonetheless, women in this study found that it could be very difficult for them to talk about their carrier status with partners in advance of becoming pregnant. It was often easier to take the risk of giving birth to an affected child than to initiate discussions, which could expose them to the risk of rejection and the possible loss of opportunity to reproduce. Providing genetic information to these women did not limit the risk of transmission of disease to offspring. African American women were seen by the author as placing a strong value on motherhood yet they were not in a position to make active empowered choices regarding it. Furthermore, the postnatal implications for mothers include the additional responsibilities of attending to their own health and medication regimens, dealing with the physical symptoms of SCD that may impede parenting, preparing for future child care, and coping with guilt about passing the condition to the child (Hill 1994b).

## **Summary**

The literature outlined above illustrates the clinical complexities of sickle cell disease. The lives of individuals with this condition are punctuated with pain and they may often encounter multiple barriers to effective treatment, which may be fueled by racial, economic, and health-related stereotypes. Having this condition may also limit perceived physical and psychological ability to maintain or pursue relationships, employment or education goals. Moreover, women with this condition face numerous reproductive health considerations and complications, and African Americans have a double burden since they are weighted by the intersecting identities of gender, illness and race.

Recent increased life expectancy of individuals with SCD calls new attention to issues of the psychosocial aspects of reproductive health and choices that have previously been ignored in the literature. The unpredictable and recurrent nature of sickle cell pain, sociocultural stereotypes, and the use of opioids for treatment present significant challenges in the delivery of health care (Jacob 2001). The close association of African American women with sickle cell disease coupled with multiple sociodemographic factors may cause providers to develop preconceptions about patients based on their membership in racial and economic status groups, which may contribute to these women receiving less than appropriate health care.

**CHAPTER 3**  
**THEORETICAL FRAMEWORK**  
**SOCIOLOGY OF THE BODY**

Sociology of the body emerged as sub-discipline of medical sociology to examine the role of the body in the social world by drawing attention to how bodies are assigned meaning, used to define the self, and are socially controlled and regulated (Nettleton 2001). This sub-discipline has been used to illustrate how the body has been commodified and used as form of personal expression and the development of identity (e.g., tattooing, cosmetic surgery, piercing, etc.) (Nettleton 2001, Pitts 1988). Sociology of the body involves the study of the embodied nature of the cultural representations of the human body, the social nature of performance, and the reproduction of the body and populations in the social structure (Turner 2004, Turner 2009). Turner (2004) argues embodiment is:

not a static entity but a series of social processes taking place in the life course. Embodiment is a life process that requires the learning of body techniques such as walking, sitting, dancing, and eating. It is the ensemble of such corporal practices, which produce and give a body its place in everyday life... Embodiment is the mode by which human beings practically engage with and apprehend the world (2004:71)

Traditionally, three dominant approaches exist within of the sociology of the body framework: naturalistic, social constructionist, and phenomenological. The naturalistic approach focuses on explaining human actions and social differences in terms of their biological predispositions (Nettleton 2006). As a natural or biological entity with specific physiological characteristics subject to natural processes of aging and decay, the body is never just a physical object since it is shaped and influenced by society creating a unique relationship between the natural body and society (Shilling 1993, Turner 1996). Chris Shilling (1993) suggested the body



“is not simply constrained by or invested with social relations, but also actually forms a basis for and contributes towards these social relations” (Shilling 1993). He also suggested that the naturalistic body has been used as a justification for the subordination of women, minorities and other socially marginalized groups.

The social constructionist approach challenged the naturalistic approach by demonstrating the role social forces play in the creation, organization, and regulation of the body and the ways through which social meanings are attached to human bodies (Nettleton 2006, Shilling 1993). Based on this approach, bodies are socially constructed, no different from the evolution of historically changing modes of production and consumption, rather believed to be the culmination of key biological features (Freund 1998). Bodies are also socially constructed through individuals’ perceptions and experiences which are based on cultural norms and mores which define appropriate behavior (Wainwright 2008). Using this approach, bodies are assigned meaning based on social perspectives and norms in the society in which they live. Furthermore, certain bodies have particular social or cultural meanings attached to them, which compel individuals to perceive meanings of an illness that are socially stigmatized, contested, and medically unexplainable which also influence the way they experience the illness (Turner 2009).

The phenomenological view distinguishes between the lived body and the biological body. The concept of the “lived body” was developed by the French philosopher Maurice Merleau-Ponty in his *Phenomenology of Perception*, which argued that the body is a location of meaning and identity as well as a material entity, which is experienced within society (Merleau-Ponty 1962). He indicated:

We are in the world through our body, and ... we perceive that world within our body. ... [T]hus by remaking contact with the body and with the world, we also rediscover ourselves. (1962: 206)

Merleau-Ponty's perspective involves two main aspects: body as subject and body as object. The body-subject examines the individual's negotiation of societal rules in dealing with the body and is understood as both active and passive. The body actively questions the world in terms of the cultural schemas, which it has actively acquired rather than passively accepting messages from the world (Crossley 1995). For example, perception of tattoos, beauty or what it means to be overweight (anorexia) etc. Research inspired by this idea of the lived body and lived experience has been important in demonstrating the intimate and necessary connections between body, experience, and identity (Crossley 1995, Nettleton 2006). The body-object purports that the relationship between society and the individual is established through training, disciplining and socializing the body to adopt societal values concerning the body (Crossley, 1995). Thus, society defines, shapes, and limits the body. As both subject and object, the body is both a producer of society as well as a product of society.

Besides these three approaches to sociology of the body, individuals find meaning in their experience. Meaning is embedded in our experience within the world and is not separate from either the embodied experiences or the world itself (Waskul and Vannini 2006). Betsy Fife (1994) posited that meaning consists of two fundamental and linked dimensions: self-meaning and contextual meaning. Self-meaning refers to the perceived effect of the event on various aspects of one's identity, while contextual meaning refers to the perception of an event based on social circumstances that surround it. Fife states that meaning is not static. Self-meaning will change as the individual grows and brings new experience to the situation. Contextual meaning will also change as the individual moves in and out of social environments (Fife 1994).

## **The Body and Feminism**

Feminist scholars contend that the body is as much a cultural entity as a biological one and even physiological processes such as menstruation are frequently culturally constructed and assigned gendered meanings (Kuhlmann and Babitsch 2002). Feminists consider the body to be biologically sexed which has been categorized and treated within a patriarchal society in a manner that limits a woman's life chances (Lorber and Moore 2002). The feminist perspective suggests that the body is a location of meaning and identity in addition to a material entity, with unique social and physical experiences (McDonnell et al. 2009). Many feminist writings on the body have also adopted the work of Michael Foucault highlighting the construction and regulation of women's bodies in and through medical discourse and health care settings by invoking his concept of power and the various ways individuals are constrained within society (Eckermann 1997, Harding 1997). Foucault (1978) asserted that "power is not an institution and not a structure; neither is it a certain strength we are endowed with." Instead, he defines power as "a complex strategical situation in a particular society" (p. 93). For Foucault, the body is a site of the manifestation of power relations and it is managed by ideological constraints and everyday practices (Foucault 1978).

In the 2002 seminal work *Gender and the Social Construction of Illness*, Judith Lorber and Lisa Moore describe how menstruation has been socially constructed as a medical condition in a number of ways that include pathologizing women's emotional and bodily states. Using the biomedical model, menstruation transformed from a natural bodily process to an illness requiring treatment thereby providing justification for the production of medical intervention that either suppress or delay or suppress menstruation. The association of menstruation as a social problem and health concern served to maintain notions of idealized femininity during menstruation,

encouraged women to monitor their bodies through medical surveillance, and allowed pharmaceutical companies to promote medical treatment for menstruation (Lorber and Moore 2002). The modern trend of menstrual suppression represents an example of neo-medicalization of women's bodies with two effects: erasing female difference and promoting the patriarchal ideals of personhood as controlled and contained (Lippman 2004).

Another area of focus of women's bodies is pregnancy and childbirth. Pregnancy is also an illustration of embodiment. During pregnancy two separate entities exist, a woman and a fetus, within the body of the woman. Thus, the pregnant body is not completely separate from the self and is different from but not inseparable from the self (Gadow 1980). The physical growth and movements of the fetus within the mother's body depicts a notion of separateness. The fetus' presence is not detached from the mother, but is part of the mother's lived experience of her pregnant body. The view of a woman and her fetus as separate beings perpetuates the view of the fetus as patient and the woman as a mere container. This realization causes the use of surveillance and monitoring at the expense of the mother's self-determination.

Barbara Katz Rothman (1998) argued that of the various stages of motherhood, pregnancy is probably the most intense form of mothering, as women host their babies *inside* their bodies and shape them *with* their bodies. Much of Katz Rothman's work has illustrated how pregnancy affects women's lives and how women develop a social and not just a biological relationship with their children even prior to childbirth (Katz Rothman 1998). During pregnancy and childbirth, the primary medical assumption is that this is a time of risk and danger (Parry 2008, Sagrestano and Finerman 2012). This assumption shifts the view of pregnancy and childbirth from a natural and normal occurrence to one that requires scientific monitoring. From a feminist perspective, the medical involvement during pregnancy can be seen as a form of social

control – an interruption to women’s bodily autonomy which entitles medical professionals access to the body (Westfall 2006).

In a modern patriarchal society, the pregnant woman often experiences a loss of control. The medicalization of women’s bodies and experiences is perpetuated by removing the natural process from the comfortable home to the clinical hospital. Prior to becoming a medicalized event, pregnancy was an entirely private and female matter that did not require medical supervision (Sagrestano and Finerman 2012). When a woman enters the hospital to give birth, she is less likely to experience a purely natural childbirth, more likely to be offered/given drugs, and more likely to have an invasive medical procedure, such as an episiotomy or a Caesarian section.

### **The Body and Risk (Embodied Risk)**

Risk and the body are important concepts in understanding reproductive health. Two types of risk have dominated the risk literature, environmental and lifestyle risks (Gabe 1995, Lupton 1995b). Environmental risks have traditionally included factors such as pollution, toxic chemicals and nuclear waste which externally imposed, and serve as an indication that an outside agent has influenced a person (Kavanagh and Broom 1998). Lifestyle related risks include activities such as smoking, exercise and diet and are the result of certain activities in which individuals engage (Kavanagh and Broom 1998).

Anne Kavanagh and Dorothy Broom (1998) suggest a third category of risks<sup>2</sup>: embodied or corporeal risk. They distinguish embodied risk from lifestyle or environmental hazards in that this type of risk is located within the bodies of individuals. They further suggested that embodied risk simultaneously positions individuals either in a current illness state or as a sign of possible

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<sup>2</sup> These categories of risks (environmental, lifestyle and embodied risks) are not mutually exclusive.

future disease. Therefore embodied risks define who a person is rather than what they do or what is done to them. With embodied risks, a part of one's body poses a threat to the self, resulting in dissociation between body and self. Imposing a threat from within the body, embodied risks have the potential to define who a person is as opposed to what they do (e.g., lifestyle-related risks) or what is done to them (e.g., environmental and occupational risks). Finally, embodied risk is most often managed via self-surveillance (Kavanagh and Broom 1998).

Although risk discourse tends to be deeply embedded in predictability and statistical principles, estimates remain inherently uncertain. In the case of embodied risk, the risk is internalized and experienced as a state of being (Gifford 1986). Embodied people mindfully resolve pragmatic problems with intention and purpose in social encounters that are situated within broader social, cultural, and institutional settings (Koenig and Stockdale 2000, Waskul and Vannini 2006). The embodied risk experience is similar to the experience of living with disease in that the ways in which a person experiences risk is dependent on her personal experiences and her familiarity with the illness (Chalmers and Thomson 1996). In their research on the embodied risk and genetic burden, Barbara Koenig and Alan Stockdale (2000: 130) state:

How will women understand "risks" that literally reside within them, in their genes, over which they have little control, and which they may already have passed on to their children? Will breasts and ovaries be experienced as potential time bombs, harboring the early stages of cancer, in need of constant surveillance?

As a phenomenological approach, embodiment helps us understand how individuals understand risk information and create meaning about risk. Further, with this approach, bodies are contextualized within the lives of individuals and the complex relations along a spectrum from the biomedical to the social (Roberts 2002). For example, the biomedical approach to risk provides a rational and universal way of preventing unwanted outcomes fostering an individual

approach to lifestyle risk. Conversely, social science examines the strategies developed by lay individuals to deal with risk and uncertainty in their lives (Burton-Jeangros 2011). Genetic risk is an embodied risk and considers certain bodies as potentially dangerous and may result in a person to experience their body as “other” (Kavanagh and Broom 1998, Robertson 2000). The knowledge of certain genetics may cause the person to perceive their body as possibly dangerous (Polzer, Mercer and Goel 2002). This type of risk warns the individual of potential future illness, susceptibility to disease itself, and creates awareness that the body is separate from the self.

In matters of reproduction, Barbara Rothman (1986) noted that the burden of risk disproportionately rests upon the female body, whose reproductive processes are already viewed with suspicion within dominant obstetric discourse. The notion of genetic risk thus interfaces with already established notions of maternal risk (Katz-Rothman 1993). Under this guise, although both the father and mother influence heredity, as bearers of children, women are constructed as the carriers of heredity, holding women liable for choosing to give birth to afflicted children, and allowing the deterioration of the population (Caplan 1989, Ettore 2000). Concepts and ideas utilized in reproductive genetics appear to exert more limitations on women’s than men’s bodies. The process of conception and gestation is internal to the female body, and the reproductive body represents processes that are unique to females (Ettore 1999). Again, women also bear the burden for the decision to have children, especially when they are aware of genetic risks which may jeopardizing the quality of the life of potential offspring. In this way, it is the mother who bears the ethical responsibility for society (Novas and Rose 2000).

Embodiment can also enter into reproductive health discourse in an attempt to explain matters of risk assessment. Emily Abel and C.H. Browner (1998) and Thomasina Borkman

(1979) provide the framework of experiential versus expert knowledge, which are used by individuals to assess risk and make health decisions (Abel and Browner 1998, Borkman 1979). Experiential knowledge has been conceptualized by Borkman (1979) as knowledge that is based upon the experiences of an individual and is highly valued because it has been acquired through the individuals' direct interaction with the physical, social and intellectual world (Borkman 1979: 450). Abel and Browner further suggest there are two types of experiential knowledge: embodied and empathetic. Embodied knowledge refers to personal perceptions of bodily experiences and sensations (e.g., pregnancy) and empathetic knowledge is derived from close association with others living with a particular experience. Embodied knowledge also refers to the subjective perceptions of bodily experiences and sensations (Abel and Browner 1988). Empathetic knowledge derives from a close association of with others living with a particular experience perhaps through care-giving (Abel and Browner 1998). Using this framework, research tends to draw a distinction between personal knowledge and expert (health care professionals) knowledge regarding perceptions of genetic risk, and unfortunately views individuals as passive recipients of risk information rather than active agents in their health care (Bakker et al. 2001, Cox 2003, Koenig and Stockdale 2000).

## **Summary**

The sociology of the body and embodied risk are important theoretical frameworks for this study because sickle cell disease may pose perceive themselves as having an embodied risk during times of reproductive health. Focusing on a woman's bodily processes and how others attempt to regulate her reproduction is a key contribution to the existing literature in this area. This study touches on matters of the body and how bodies with illness are viewed, as well as the



attempts by medical science to regulate, monitor, and place these bodies under surveillance. To date, limited research exists exploring the experiences of women with sickle cell disease, and even less research focuses on how women with sickle cell experience reproductive health care and decision-making and the ways in which race, gender, and illness may influence the meaning, priority, and agency they give to this area of their lives and their approach to achieving optimal reproductive health.

## CHAPTER 4

### RESEARCH METHODOLOGY

The purpose of this research was to explore the reproductive experiences and identities among women with sickle cell disease. This study will focus on reproductive health experiences with professional health providers, contraception usage, preparation for conception, navigating disclosure and testing conversations within intimate relationships and the trajectories of motherhood. This chapter describes the methodological approach to this study including sampling, targeted population, data collection, and data analysis.

#### *Methodological Strategy–Phenomenology*

Phenomenological approaches to the body and embodiment use thick descriptions of lived experiences that reveal meaning in the life worlds of the individuals who live them (Waskul and Vannini 2006). Phenomenology was founded by the German philosopher Edmund Husserl (1959-1938) and is a paradigm used to explore and describe the meaning of a unique experience (VanManen 1990). It is based on an inductive approach that focuses on describing (rather than explaining) the life worlds of those being studied and the ways in which a phenomenon has been experienced and the meanings individuals construct of their lived experience (Creswell 2003, Omery 1983). Phenomenological researchers are driven by the desire to understand the ways in which people experience their world, how they see a given phenomenon instead of preconceived theoretical constructs and research hypotheses (Creswell 2003, Omery 1983). Descriptive phenomenology focuses on descriptions of peoples' experiences and the meanings attached to them, rather than the interpretations, rationalizations,

and speculations about the causes of their experiences (Koch 1995). This method of inquiry is particularly suited for this study since participants report their perceptions when describing their lived experiences with reproductive health. Further, this is one of the few occasions in which this topic has been examined among women with sickle cell disease.

### *Black Feminist Standpoint Theory*

One of the most dominant qualitative inquiry approaches used in research with women is the standpoint perspective which according to Smith asserts that “the notion of a standpoint of women doesn’t stand by itself as a theoretical construct; it is a place to begin inquiry” (1992:91). This approach focuses on the everyday experiences of women not as universal but recognizing the diversity of women’s experiences (Smith 1992).

Black Feminist Standpoint Theory is defined as ideas that are produced by Black women that clarify a standpoint for Black women (Collins 2000a). According to Patricia Hill Collins, Black Feminist Standpoint Theory acknowledges that knowledge is the sum of two perspectives: first, the taken-for-granted knowledge shared by members of the group, and second the declarations from experts who are part of the group and express the group’s standpoint (Collins 1986). Black Feminist Standpoint Theory further asserts that African American women occupy a unique standpoint based on their subjection to both racism and sexism (Collins 2000a). Indeed, women’s diverse social locations influences how they experience being a woman as they occupy multiple locations and identities, which shape their experiences, opportunities and decision-making abilities. However, while women share similar physical and biological events (e.g., menstruation, childbirth, menopause, etc.) that affect their health and well-being, they frequently

differ in how they experience and create meaning from these events based upon their social locations (Martin 1987).

As a methodological theoretical construct, Black Feminist Standpoint Theory comprises four fundamental tenants:

- (1) *Valuing women's experiential knowledge through their lived experiences.* Collins argues that only those men and women who experience the consequences of a phenomenon can select topics for investigation and methodologies used. Black feminist epistemology then begins with connected knowers, those who know from personal experience.
- (2) *Using dialogue in assessing knowledge claims.* Collins suggests that when at least two subjects come together, knowledge is based on perception, there is no objective existence apart from lived experiences, and knowledge emerges through dialogs.
- (3) *Implementing the ethics of caring.* Collins argues that all knowledge is intrinsically value-laden rather than believing that researchers can be value-free, and would thus be tested by the presence of empathy and compassion. She further asserts that it does not require the separation of the researcher from her or his own experience nor does it require or assume that it is possible to separate our thought from our feelings.
- (4) *Implementing personal accountability.* Collins claims that because knowledge is built on lived experience, the assessment of knowledge is a simultaneous assessment that precipitates through the filter of an individual's character, values and ethics. This approach states that all knowledge is based upon beliefs, which implies personal responsibility.

Black Feminist Standpoint Theory places the experiences of Black women at the center of analysis through interpretive frameworks that extend beyond demonstrating that African American women are capable of creating specialized knowledge, but they are also able to create new ways of thinking about that knowledge (Collins 2000b). This framework also acknowledges that Black women in the United States are not a homogeneous group. Thus, it would seem appropriate that the reproductive health of African American women be rooted in this ideology which has long asserted its commitment to improving the position of this population (Collins 2000a, King 1998, Nelson 2003). Accordingly, much of the work of reproductive health among

women of color highlights how race and class work together to shape and restrict reproductive choices (Cook 1995, Pine and Law 1992, Ross et al. 2007).

This study used Black Feminist Standpoint ideology as a point of inquiry which supports the use of qualitative methods as inviting African American women to share the stories of their experiences (Collins 1986). It also aimed to give voice to the lives and expressions of African American women and position them as informants who are not simply talked to but speak for themselves (Collins 1986). Several key dimensions ground Black Feminist Standpoint Theory including: (1) Black women in the United States participate in a dialectical relationship linking oppression and activism; (2) wisdom gained from experience is highly valued; (3) action and thought inform one another in ongoing dialogue; (4) Black women intellectuals from all walks of life (not only academia) have contributed to Black feminist theory; (5) Black feminist and social justice projects are intimately connected; and (6) Black women's struggles are part of the wider struggle for human dignity, empowerment, and social justice (Collins 2000a). This study was designed to uncover the voice of African American women, particularly those with SCD, in order to illuminate how the "web of stigmatization" works to shape their perception of and experience with reproductive health care. In addition, this study was designed to explore how women with sickle cell disease approached health rather than illness, which also fits into this paradigm as it presumes an image of African American women with SCD as being empowered and healthy rather than victims who are sick.

### *Research Questions*

**How do women with sickle cell disease think about and experience reproductive health?** That is, how do they perceive the type and quality of care they receive concerning their reproductive health? What importance do they give to their reproductive health? What priority does their reproductive health have in

their lives? What behaviors do women with sickle cell disease engage in that they believe help maintain their reproductive health? What impact does having sickle cell have on their reproductive lives including desires for motherhood and intimate relationships?

**How do race, gender, and genetic illness affect the reproductive lives of women with sickle cell disease?**

**What social, environmental, and cultural factors influence the ability of women with sickle cell disease to either seek or receive reproductive health care?** That is, what sources of information, advice and guidance do women with sickle cell use to learn about reproductive health?

### Method of Inquiry

#### *Data Collection*

Qualitative approaches are well suited for investigating the human experience and meanings individuals give to social events, situations and activities, and allow researchers to pay particular attention to the subjective nature of the experience (Denzin and Lincoln 2005). The unique ability of qualitative research to focus on experience and meaning is central to exploratory studies, which focus on relatively understudied topic in new areas. Qualitative research seeks depth rather than breadth and is used to learn about how and why people behave, think, and create meaning. Moreover, this method of inquiry provides a voice for participants, raises their consciousness, and advances an agenda for change that may improve the participant's lives (Creswell 2003).

This study used a qualitative approach of semi-structured in-depth interviews to explore how women with sickle cell disease experience reproductive health, which included various sub-categories of sexuality and sexual behavior, motherhood, pregnancy, contraception use, and intimate relationships. According to Seidman (1991), phenomenological interviews are structured in a three-stage process of (1) establishing the context of the participant's experience,

(2) constructing the experience, and (3) reflecting on the meaning these experiences hold for the participant (Seidman 1991). The semi-structured interview technique is optimal for collecting data on individuals' personal histories, perspectives and experiences, particularly when sensitive topics are being explored, while allowing interviewees to answer direct questions and offering their unique perspective. This interview style also provides the opportunity for synchronous communication and the ability for the researcher to provide comfort and react to visual and non-visual cues of respondent distress (Opdenakker 2006, Sturges and Hanrahan 2004).

These methods illustrate the common thread that exists among qualitative inquiry and phenomenology. A qualitative approach is being used due to the lack of existing literature on this topic with the hope of shedding light on reproductive health among women with sickle cell disease. These approaches emphasize include focusing on capturing the participants' perspective, enlisting the participant as the expert knower, describing the participant's experience from their own perspective and searching for the meanings individuals give to their particular experiences.

### Participant Sampling

Lincoln and Guba (1985) suggested that sampling within a qualitative study should be "based on informational, not statistical, considerations...to maximize information, not facilitate generalization" (1985:202). The inclusion criterion for this study was the following: identify as an African American, a medical diagnosis of sickle cell disease, female, and over the age of 18. The targeted population was not limited according to socioeconomic status, insurance status, marital status or parity. The attempt was made to recruit a diverse sample through recruiting from multiple types of locations (e.g., medical clinic, community organization and the internet).

Participants for this project were recruited using the non-probability and snowball sampling methods. The sampling method was non-probability in that I targeted participants from one gender (female), a specific medical condition (sickle cell disease) and from specific locations, rather than the general public. Snowball sampling was used to generate chain referrals by asking members of the target population under study to provide names, and telephone numbers of other members of the targeted population (Adler and Clark 2003).

Sampling in qualitative research does not attempt to meet requirements for representativeness and proportionality or achieving adequate numbers for “statistical power” for analyses, however the aims are to narrow sampling strategies in phenomenological studies based upon experiences of the phenomenon under investigation (Lincoln and Guba 1985). This strategy is further supported by Colaizzi’s idea that in order to best understand a phenomenon it is important to include individuals who have actually experienced it (Colaizzi 1978).

### Human Subjects Approval

I received approval from the Wayne State University (WSU) Human Subjects Review Committee prior to the implementation of this project (Approval # 104611B3E). Women who were selected agreed upon a meeting time and location that allowed for privacy and the ability to allow the conversation to audio-recorded. Before beginning the interview, women gave their permission for the interview to be tape-recorded. I reminded every woman that their participation was limited to one interview, and they were informed that they were not required to answer any question that made them feel uncomfortable. Women were reassured their identities would remain confidential. Women were given an information sheet detailing the study as well as confidentiality guidelines and contact information for further and future informational about



the study. To maintain confidentiality, random numbers were assigned to each participant's demographic questionnaire. Confidentiality was maintained by changing names to pseudonyms. These pseudonyms were used in all written records. The electronic data collected for this project was stored on a password-protected computer and paper data (e.g., demographic questionnaire) was stored in a locked file in my home.

### Recruitment Locations and Strategy

The primary recruitment location for the study was the University of Michigan sickle cell clinic, a pediatric clinic services over 200 patients with various hemoglobinopathies. This clinic provides comprehensive care including psychology, nutrition, and access to social workers. The recruitment process was facilitated by the Clinic Director who wrote a letter of support providing legitimacy to my study. Based on the inclusion criteria, the Director mailed the recruitment flyer, introductory letter, along with a cover letter in November 2011 and then again January 2012 to all eligible patients meeting the study inclusion criteria. As further reinforcement, recruitment flyers were also distributed during weekly clinic visits and to any new patients who had not received either mailing. A total of eleven women were recruited from this location, ten with direct contact with the location and one woman was recruited from another participant.

The other primary recruitment location was the Sickle Cell Disease Association of American (SCDAA)–Detroit Chapter. This chapter, under the direction of the legendary Charles Whitten, M.D.<sup>3</sup>, was one of the initial chapters to emerge into what has now become a national organization. The SCDAA promotes awareness and education and provides free services to

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<sup>3</sup> Dr. Whitten was among the first to develop and insist on newborn screening for sickle cell disease, which is now performed worldwide. In 1971, he formed the Sickle Cell Detection and Information Center in Detroit, the most comprehensive community program in the country. In the same year, he facilitated the creation of the National Association for Sickle Cell Disease, which now has over 80 member organizations.

persons with SCD and their families, such as genetic counseling and genetic testing. I received approval from the WSU Human Subjects Review Committee to use the Association as an additional recruitment location in March 2012. In April, interviews started to pick up due to the assistance of the SCDA. Prior to receiving this approval I experienced a lapse in recruitment. The SCDA-Detroit Director extended her support based on their established relationships with the target population, interest in the topic, and available staff to assist with the research project. In addition to distributing my recruitment flyers, she also asked staff members to contact potentially eligible participants and provide them with my contact information. Eight participants were recruited from this location; one contacted me via email, the other seven made contact via telephone.

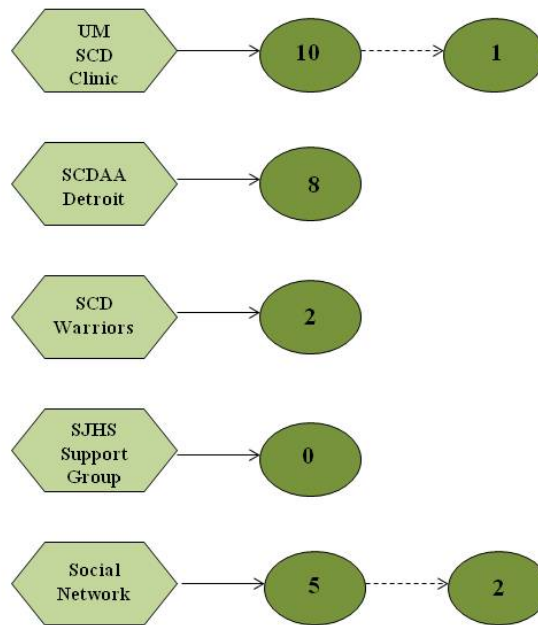
The Sick Cell Warriors website ([sicklecellwarriors.com](http://sicklecellwarriors.com)) also served as a recruitment location. This is a supportive website with over 3,000 members. The site's slogan is "A Community of those Living, Loving and Surviving Sick Cell Disease" and is owned by a Registered Nurse who also has sickle cell disease. While I sent her the flyer and approval notification in November 2011, after several attempts to re-contact her during December and February 2012, the announcement did not get posted until mid-February 2012. The owner of the Sick Cell Warriors posted information about the study as well as my contact information on the website. Instead of posting the flier, she posted the contents of the flier, in narrative form, on the website under the "SC Research" section of the site. However, no mention was made about in-person interviews or state of Michigan residency. Two participants were recruited from this location.

Another recruitment location I used was a sickle cell support group sponsored by the St. Joseph Mercy Health System-Oakland. Shortly after the support group moderator received the

flyer I contacted her again and she informed me that the support group took a hiatus for the winter and would not resume again until April 2012. After receiving the flyers, the organizer of the support group distributed flyers at their monthly meeting and placed them in the Emergency Room. This location did not yield any participants.

All participants were given fliers and asked to pass them along to any other women with sickle cell disease over the age of 18. I also obtained seven interviews through personal connections. Professional colleagues and close friends were provided with flyers and my introductory letter in an effort to gain additional access to a wider network of women with sickle cell disease who may not be under the care of a physician or involved with the SCDA. A total of 45 women volunteered to be interviewed for this study, 28 were interviewed and the other 12 were not interviewed because of hospitalizations, a death in the family, and several canceled to care for children who had become ill. Follow-up with these women was difficult and I felt once the initial interview was canceled they may have lost interest. The other five women who volunteered lived out of state and were unavailable for an in-person interview. I responded to their emails letting them know that at that time I did not have approval to conduct telephone interviews outside of Michigan, yet if I did get approval I would like to contact them. I kept them as possibilities if I could not obtain enough in-person interviews. I did not end up using those contacts. Also, because I recruited women from locations that specifically target individuals with sickle cell—either seeking medical treatment or education and support—my sample is not representative of all individuals with sickle cell disease and may not be a complete description of the reproductive experiences of women with sickle cell disease, but a direct result of the recruitment locations.

Figure 2. Recruitment Diagram



The interviews were conducted during the period of November 2011 through May 2012. I traveled approximately 2,200 miles to and from the 28 interviews. Women lived between 4.3 and 143 miles away and the average distance was 44.3 miles. Because of the distance, it was important that I confirm with women prior to departing. Each of the 28 interviews lasted approximately between 45 minutes to 90 minutes, with the majority taking more than one hour. Twenty-three interviews occurred in participants' homes, four at public libraries, and one at a local coffee shop. On several occasions the interviews started before I turned on the digital recorder. Women sometimes started telling me their stories either when we spoke on the phone to schedule the interview, or when I was getting settled into their home or on one occasion the ride to the coffee shop. Within two months of completing the initial interview, I had conducted seven interviews. There was a lapse in recruitment, which gave me time to reflect on the data I had collected and I believe improved the quality of the remaining 21 interviews. During the last

four interviews I felt that I reached theoretical saturation—I used these final interviews to confirm previous findings.

One of the difficulties I experienced in securing interviews was scheduling the interview too far in advance. I realized that it was best to conduct the interview soon after talking to women. When interviews were scheduled too far in advance, women would forget about it, their telephone number would no longer be valid, or they were may have been hospitalized. While scheduling interviews soon after making contact worked in most cases, one attempt did not. I had an interview scheduled with one woman, but when I called to confirm before departing for her home, she informed me she was out of town and asked if we could re-schedule, which we did. Again, I called to confirm before departing and this time she didn't answer. Finally, I called her one more time and she asked if I could "come now" and I said yes, but it would take me 40 minutes to get there. I made it to her home in 30 minutes and her mother answered the door and said she was not there. I explained who I was and I had just spoken to her daughter less than an hour ago, but her mother didn't offer any additional information and I decided not to pursue this interview further. On my way home I retraced my steps to see if there had been something during our conversations that would make me think she may not want to do the interview. All I could think of was the voicemail she had left saying, "I saw your flyer, I want to do this."

Another strategy I used was not giving up after the initial attempt to reschedule missed appointments. I realized that while this interview was at the top of my priority list, many participants had a different set or new set of priorities. For example, one woman had rescheduled the interview several times and after numerous unsuccessful phone contacts and voice mails, we finally made contact. She apologized for not being able to be interviewed and explained that she

had recently been diagnosed with cervical cancer and was dealing with the psychological impact of this diagnosis and preparing for surgery in two weeks.

Overall, the recruitment process was much more difficult than I imagined considering the multiple recruitment locations I had identified. In the beginning recruitment was very slow and although participants contacted me, I still faced barriers to securing actual interviews (e.g., illness and cancelations). However, in the end, the delay in interviewing actually benefited the quality of data I was able to collect.

### The Interview Process

The interview guide was developed based upon key concepts identified during a systematic review of the literature on the reproductive health of African American women, disabled women and women with genetic conditions. The questions were open-ended with follow-up probes to encourage elaboration and to ensure the full understanding of the experience has been captured. During the course of the interview, more sensitive topics were introduced as rapport and trust were established. I also used a feminist style of interviewing which seeks to minimize hierarchical nature of the research process. I attempted to conduct interviews as conversations, rather than formal interrogations. During each interview I maintained flexibility regarding the structure of the interview in order to record the context of their responses.

### *Interview Guide*

Participants were asked questions to describe their past and present experiences of reproductive health within the context of socially excluded and marginalized groups (e.g., race, gender, and genetic illness). Probes were used to extrapolate specific details of the experience.

Particularly, questions were asked regarding their experiences more broadly, as well as sources of knowledge of sexual health as well as identify sources of advice and information women with sickle cell disease use to learn about their reproductive health and how sexuality and reproductive health are understood and experienced. Questions were asked to determine participants' desires for motherhood and experiences with pregnancy (including abortion), including preconception desires for pregnancy, preparation and readiness (e.g., employment, emotional preparation, and readiness of other children), effort exhausted to either achieve or prevent pregnancy, desire for a child with their partner, and relationships with others. I asked questions about access to reproductive health care, and their ability to exercise agency in their own reproductive health decisions. Access and agency represent the social context in which healthy, sexuality, and reproduction are experienced and acted upon (Price and Hawkins 2007). Participants were probed about influential factors such as experiences with health care providers, family and intimate partners. Reproductive health and decision-making are embedded in social relations and social institutions that operate from the macro- to the micro-level (Price and Hawkins 2007). Additionally, I asked questions regarding the participants' life course considerations and social circumstances which included family dynamics and social support, and perceived life-chances (Santelli et al. 2003). These questions were aimed at extrapolating experiences related to sexuality, fertility, reproduction and health that may be influenced by a range of race-, gender- and illness-specific factors, such as relations of power and control within intimate relationships, household and family structures, and economic and cultural ties.

Although I collected over 52 hours of data on topics different than what is reported here, for the purpose of this dissertation I only present data from discussions related to reproductive

health care, messages from family and providers about reproduction, and participants' experiences with prenatal and partner genetic testing.

### Demographic Questionnaire

Participants were also asked to complete an end-of-interview questionnaire to capture sociodemographic information such as educational level, age, income, and use of hospital services, which were used to stratify participants. The questionnaire collected general information on medical and reproductive histories to gather disease severity and parity. Using a quantitative survey nested within a qualitative study enabled me to better describe between- and within-group similarities and differences based on demographic categories.

### Participant Motivations

Women were appreciative that I was interested in studying sickle cell and specifically women with sickle cell. For the most part, participants indicated they participated in the study because they were thankful that I was interested in or cared about sickle cell disease or they wanted to be supportive of someone furthering their education. Specifically, one participant indicated, "If somebody is willing to put in the time and the effort, then I need to be willing to tell my story so that the next person doesn't necessarily have to go through everything that I went through." Another stated, "Here's a young black woman trying to finish her doctor degree. Let's do that." These sentiments caused quite a few participants to refuse to accept the \$10 token of appreciation I offered them. I began putting the \$10 into a thank you-card so they would accept it. Admittedly, only three participants informed me they participated simply because of the monetary incentive. These three reported being in the lowest household income category on



the demographic questionnaire. After I told one participant about the \$10 incentive, she stated, “I wish it was \$20!” I jokingly replied, “Me too!”

### Interruptions and Distractions during the Interviews

The interruptions that occurred during the interviews were due to the environment, others in proximity, and participants’ emotions and fatigue. Interviews in public places sometimes proved to be more difficult simply because of the personal nature of the topic. In one interview occurring in a public library on a Saturday morning, this facility was so small and busy we were forced to sit in a room where people frequently traveled in and out. Another interview was in a coffee shop and I suspected this would keep her from speaking freely.

Interviews were also difficult when other people were around. For example, when participants had small children in the home who were curious about what “mommy was doing” or “who the lady was,” they would at times interrupt the interview or their presence would keep women from openly discussing their reproductive histories in front of them. Younger participants were often compelled to invite their parents to sit in on the interview, probably because they were very much accustomed to having their parents around to assist in answering questions regarding their health. In these instances, parents only stayed for the first few minutes of the interview during which questions pertaining to illness experiences were asked, which did not influence the data collection in any way.

On several occasions participants became emotional when telling their stories. One because of the burden of the illness, and another because of the emotions she felt when discussing her friends’ concern for her and her inability to attend school due to her illness. When

participants became tearful, I stopped the interview and often offered compassion by touching their hand or forearm. I paused the interview until they let me know they were ready to continue.

With three interviews I got glimpses of fatigue when the participant's speech slowed or their eyes became glazed. When this happened I acknowledged that I thought they were becoming tired and asked if they could continue. They always said they could, but I let them know I would attempt to wrap-up the interview and made sure to only ask pertinent questions. Because I ensured to ask pertinent questions this did not impact the data analysis.

### Leaving the Field

Looking back, I realized that although the "interview" was officially over many participants remained engaged in the research process and continued to reveal very important information about themselves and their experiences. In some cases I asked for permission to turn the recorder back on and in other cases I simply wrote detailed notes about these conversations immediately after leaving the interview location.

Also, I found it difficult to abruptly bring such a personal and in-depth conversation to a close and sometimes the interview came to an end before the participants were ready for me to leave. Once I realized this was happening I decided to linger for about 10-15 minutes for small talk and follow-up questions either the participant or I had. The lingering would include women sharing articles about them in the paper, recent family portraits, wedding albums, old letters from previous physicians, or sharing stories about other interviews they had given about their disease. On several occasions, I received phone calls or text messages after I had left their homes, simply thanking me for talking to them.

It was important for me to have a journal in which to capture these post-interview conversations and to take time to reflect on how the interview went and unique occurrences (Ortlipp 2008). After each interview I wrote about personal thoughts and initial impressions on what I had seen, heard, and felt during the interview. I also recorded the time of day, who was present or within close proximity of the interview, and the characteristics of the room or environment.

Upon reviewing these notes I began to realize that it wasn't always what was said that told the story, but the manner in which the story it was told. "Listening for voice" and "voice in conversation" are the additional components the researcher must address. In these steps, the researcher pays attention not only to what the research subject, the "actor", says with words, but also to what the actor says with body language and with silences. Sometimes women would use humor or a joking tone to talk about difficult situations or their voices would get low and sad and between their words I could hear them say, "It's been hard, but I'm okay." Realizing this made me value the data I received even more, knowing that it came at the price of such difficult experiences. I left a resources sheet that included contact information for a support group and the Sickle Cell Disease Association of America (Appendix E).

### *Data Analysis*

This study used a descriptive phenomenology approach which favors thick description and close analysis of the lived experiences to understand how meaning is created through embodied perception (Creswell 1998). My analysis followed the six steps of the Colaizzi's data analysis method (Colaizzi 1978, Koch 1995).

*Step 1 Reading each transcript for accuracy and significant statements.* Each interview was fully transcribed by a hired transcriptionist and then I reviewed the transcript alongside the audio-file for accuracy. I read each transcript in order to become familiar with the data.

*Step 2 Extracting significant and research relevant phrases.* This step consists of returning to the transcripts and extracting phrases or significant statements that pertain to the phenomenon under investigation. I generated an initial list of concepts and themes by reading the data and creating as many relevant codes as possible. I placed all transcripts into a qualitative software program, NVIVO<sup>®</sup>, to help with data management. This allowed me to (1) further analyze the data units within each code and (2) review each data unit within each code organized by participant and specifically on the topic of reproductive health, health behavior, and activities. When developing a new code in NVIVO<sup>®</sup> I also provided descriptions that explained what they represented to ensure accurate themes. This was the second phase of the analysis conducted to extrapolate common elements that described their unique experiences.

*Step 3 Formulating meanings and Step 4 Organizing formulated meanings into clusters of themes.* During these steps, Colaizzi says that meanings are derived and formulas developed which explicitly describe each significant statement; the data must be allowed to speak for itself. I then sorted the codes by participant, genotype, parental status and age group to explore whether these social locations were an indication of similar or disparate experiences. Each of the above steps were repeated for each data set and organized to illustrate an aggregated meaning.

*Step 5 Exhaustively describing the investigated phenomenon.* The descriptive step in the process emphasizes viewing a person as one representative of the world in which they live. Based on this step, three main themes emerged from the analysis of the interviews which focus on several reproductive stages and activities: (1) reproductive health care experiences which

includes participants' experiences navigating optimal care amid their provider's knowledge in caring for women with sickle cell disease and illustrates how participants found themselves managing a gap in knowledge between their gynecologist and hematologist regarding their reproductive health care; (2) discouraging reproductive messages which described the ways in which participants were discouraged from having biological children; and (3) responding to reproductive risks in pregnancy and childbirth associated with having a genetic condition, particularly being categorized as high risk pregnancy and negotiations of prenatal and partner testing. These themes and the theoretical foundations on which they were based are discussed and analyzed in the upcoming pages. These themes were primarily derived from the questions: "In any ways do you think having sickle cell may impact any of these reproductive issues: Who do you see for your women's health issues? Things like pelvic exams, birth control, things like that? What kinds of conversations have you had about prenatal testing? What types of conversations have you had about genetic testing?"

*Step 6 Describing the fundamental structure of the phenomenon.* Colaizzi (1978) proposed formulating exhaustive descriptions of the investigated phenomenon. He suggested that these descriptions be considered as an indisputable indicator that identified statements represent the fundamental structure of the data. My analysis suggests that participants' possessed an ongoing awareness of the influence having a genetic illness has on their reproductive behavior. The analysis also revealed subtle differences in experience between symptoms, genotype, and parental status.

One essential component of phenomenological methodology is believing that the consciousness is what humans share, an assumption that self-reflection and conscious "stripping" of previous knowledge, help to present an investigator-free description of the phenomenon, the

assumption that adherence to established scientific rigor ensures description of universal essences or eidetic structures, the assumption that bracketing ensures that interpretation is free of bias (Koch 1995). To accomplish this, I maintained a journal of reflections about the interactions that I observed through the data collection process to create an audit trail and enhance the credibility of the findings. I used this journal to capture my reactions to participants and collected data and to make explicit my evolving assumptions that might influence the analysis and interpretations. With the journal, I also documented anecdotal impressions of the research sites, reactions to responses of participants, and the time lapse between each interview and reflections on the data collection process.

### *Data Checking*

The findings of this research were confirmed using three validation methods as an assurance that the emergent themes represent the authentic expression of the participants (Miles and Huberman 1994). First, I performed rich data collection, by conducting in-depth interviews that were detailed and varied to provide a full and informative picture of the participant's circumstances and conditions and transcribe the interviews verbatim transcripts rather than simply depending on notes to ensure a full description is provided for analysis. Secondly, I conducted an iterative analysis process, which involved repeated contextual reading of the original transcripts (Forman et al. 2008, Maxwell 2004, Strauss and Corbin 1990). Third, I maintained a journal of reflections about the interactions that I observed through the data collection process to create an audit trail and enhance the credibility of the findings. This was used to capture my reactions to participants and collected data and to make explicit my evolving assumptions that might influence the analysis and interpretations.

Even though I have a somewhat complete knowledge of sickle cell disease, I always remembered that the real experts in this study are the participants (Collins 2000). For example, when during the eligibility phase I wanted to confirm that women had sickle cell disease and not sickle cell trait, or when I asked about what type of sickle cell they had, women attempted to educate me as if I was asking for information rather than clarification. In these cases I simply listened rather than letting them know that I already knew what they were telling me. Understanding the different types of sickle cell disease and the genetic transmission patterns is a complicated process and I was also careful not to challenge what they told me, even if it contradicted what I believed I knew. When I doubted what I was told, I simply asked them to repeat it to ensure they simply had not misspoken.

I worked hard to establish rapport and to make women feel as comfortable as possible. I was asking women to talk to me about very personal topics and had to get to that portion of the interview in a very short amount of time. I am a 40-year old woman who does not have sickle cell disease. I was never asked about my status and I never offered. I simply informed women I interviewed that I was in graduate school in Sociology and this project was for my dissertation.

### *Sample Characteristics*

Much of the demographic information on the sample derives from the demographic questionnaire each participant completed at the end of the interview about their social, medical and reproductive histories. Specific information about their experiences was derived from conversations with participants before, during or after the interview and field notes taken after each interview.

### Sociodemographic Characteristics

The sample consisted mostly of women between the ages of 20 and 39, with ages ranging from 18 to 52 (see Table 1), and from two primary recruitment locations—the University of Michigan Sickle Cell Clinic and the Sickle Cell Disease Association of America. Women recruited from the clinic were younger, with ages ranging from 18 to 27. The clinic primarily provides care to pediatric patients and has a limited adult patient population. On the other hand, the Association provides services to parents of children with sickle cell disease or adults with the condition, therefore those recruited from this location were older, with ages ranging from 24 to 44. Women recruited from my social network were closer to my own age (40 years old), with ages ranging from 30 to 49.

The household income of the sample was similar. Over half of the participants reported household incomes below \$25,000 and that they received Supplemental Security Income (SSI) (see Table 3). SSI is a government program that aids people who are either over 65 or disabled and have low income and limited resources. Participants who did not receive SSI were employed full- or part-time, or were full-time students.

There was limited variation among the sample in terms of marital status: 21 participants were single—20 never married and one divorced—five were married, and two lived with a partner (See Table 3). Similar to marital status, the sample was quite similar in terms of their educational attainment. The sample consisted of two current high school students, four high school graduates or equivalent, 18 with some college, and four college graduates, three with bachelor degrees and one with a graduate-level degree (see Table 3). Many participants shared their challenges completing every level of education (elementary through post-secondary) due to frequent absenteeism and lack of understanding from educators of the nuances of the disease.



Participants who were successful in their educational endeavors benefited greatly from the attentive support of parents who ensured they received missing work from teachers, obtained a tutor when necessary, and advocated for their removal from situations that would impact their health (e.g., outdoor recess in the winter, excessive running in gym, etc.).

The employment status among the sample was also very similar and most of the participants reported being currently unemployed (see Table 3). Unemployment was most often illness related, either from the inability to secure employment should they inform potential employers about their condition during an interview or the ability to sustain employment as a consequence of frequent absence from work. Furthermore, the lower household income of the majority of the sample may also be a reflection of unemployment and marital status since 21 women were single (never married or divorced<sup>4</sup>).

Living arrangements are often influenced by age, marital status and/or income. The seven women who lived with their parents were younger and either high school or college students. The remaining women in the sample had varied living arrangements: seven lived alone, eight lived with partner or husband, and seven lived alone with their children (see Table 3). The majority of women who lived alone received SSI and were unemployed (only one was employed). The women who lived alone with children reported household incomes of less than \$25,000, were between the ages of 30 and 39 and also received SSI. Participants who lived with a boyfriend or partner (with or without children) had higher incomes, although most were unemployed, many still reported not having enough money for basic expenses (see Table 3).

Based on these characteristics, the women in sample were relatively similar. On average, the participants were single, had low household incomes, received SSI and had less than a college education.

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<sup>4</sup> Of note, two women living with a partner reported household incomes of less than \$25,000.

**Table 3.** Sociodemographic Characteristics

	N (%)
<b>Age (Mean Age = 30.39)</b>	
18-19	2 (7.1)
20-29	12 (42.9)
30-39	10 (35.7)
40-49	3 (10.7)
50-59	1 (3.6)
<b>Household Income</b>	
Less than \$25,000	19 (67.9)
Between \$25,000 and \$49,999	4 (14.3)
Between \$50,000 and \$74,999	1 (3.6)
Between \$75,000 and \$99,999	2 (7.1)
Between \$100,000 and \$149,999	1 (3.6)
<b>Supplemental Security Income (SSI)</b>	
Yes	19 (67.9)
No	9 (32.1)
<b>Marital Status</b>	
Single, never married	20 (71.4)
Single, divorced	1 (3.6)
Living with partner	2 (7.1)
Married	5 (17.9)
<b>Living Arrangements</b>	
Living alone	7 (25.0)
Living alone with children	6 (21.4)
Living with partner or husband	8 (28.6)
Living with parents or guardian	7 (25.0)
<b>Level of Education</b>	
High school student	2 (7.1)
High school graduate or equivalent	5 (17.9)
College student	5 (17.9)
Some college	12 (42.9)
Undergraduate college degree	3 (10.7)
Advanced degree	1 (3.6)
<b>Employment Status</b>	
Student (high school or college)	7 (25.0)
Unemployed	12 (42.9)
Employed part-time	7 (25.0)
Employed full-time	2 (7.1)

### Medical Characteristics

It was important to capture the medical history and illness characteristics of the participants in order gain some insight into the extent to which their illness may influence their daily lives and reproductive health experiences. Of the 28 women interviewed for this study, 17 had sickle cell anemia hemoglobin S (Hb-SS), nine had sickle cell anemia hemoglobin C (Hb-SC), one had sickle beta-zero thalassemia (Hb-Sβ<sup>0</sup>), and one had sickle beta-plus thalassemia (Hb-Sβ<sup>+</sup>) (see Table 4). The genotype of the sample may have been influenced by the higher prevalence of Hb-SS and Hb-SS in the population and the characteristics of two primary recruitment locations—UM Sickle Cell Clinic and SCDAADetroit Chapter. Nine of the 10 women recruited from the UM clinic had Hb-SS and five of the eight women recruited from the SCDAADetroit had Hb-SC. Because Hb-SS is considered the most severe form of sickle cell disease, it often warrants closer medical management through the care of a physician. However the primary aim of the SCDAADetroit is to promote education, awareness and support, thus it not surprising that those with more severe forms were recruited from a medical clinic.

While Hb-SS is known to be the most severe form of SCD, people with other types of SCD also experience illness symptoms. I asked participants if they had any other illnesses in addition to SCD, as having multiple chronic conditions may impact their reproductive health. I also asked participants during the past 12 months how many pain crises requiring hospitalization they experienced in order to gauge not only the frequency of their pain but also the severity of their illness experience. People with sickle cell tend to exhaust every effort to manage their care at home before seeking care from a medical professional. The frequency of pain episodes requiring hospitalization during the past 12 months varied among the sample, from 0 to 20, within the past 12 months. The majority of participants reported having at least one other illness

(see Table 4). Those who experienced more pain crisis were mostly women with Hb-SS who had an illness in addition to SCD.

Health insurance is an important factor in managing a chronic illness, particularly one that requires multiple medications and specialty medical care. All participants possessed some type of insurance and only two reported a lapse in their insurance at some time during adulthood (see Table 4). Notwithstanding insurance coverage, several participants lamented over the amount of their unpaid medical bills and the ensuing stress from their inability to pay them.

Genotype and having another illness seem to have a role in the amount of pain and frequency of hospitalizations among this sample. More women in the sample had Hb-SS, experienced 1-5 pain crises in the last twelve months and did not have another illness in addition to sickle cell disease. Women who reported not being hospitalized for pain during this time period were mainly women with Hb-SC who did have another illness. Because of the limited time frame in which I asked, I may have insufficiently captured the severity of illness during the participant's lifetime. Moreover, those with sickle cell disease have a high level of functionality while still in severe pain and therefore even what I observed may not have fully captured the severity of their illness.

**Table 4. Medical Characteristics**

	N (%)
<b>Genotype</b>	
Hb-SS	17 (60.7)
Hb-SC	9 (32.1)
Hb-Sβ <sup>0</sup>	1 (3.6)
Hb-Sβ <sup>+</sup>	1 (3.6)
<b>Other Medical Conditions (N=12)</b>	
Heart conditions (e.g., murmurs, CHF, etc.)	5 (41.7)
Lung conditions (e.g., pulmonary hypertension, acute chest syndrome, etc.)	4 (33.3)
Brain conditions (e.g., epilepsy, etc.)	3 (25.0)
Other	4 (33.3)
<b>Number of Pain Crises Requiring Hospitalization During Last 12 Months</b>	
None	6 (21.4)
1-5	14 (50.0)
6-10	5 (17.9)
11-15	0
16-20	2 (7.1)
21 or more	1 (3.6)
<b>Type of Insurance</b>	
Medicaid	18 (64.3)
Medicare	9 (32.1)
HMO Insurance	5 (17.9)
Private Insurance	4 (14.3)

### Reproductive Health Characteristics

As previously stated, reproductive health encompasses the full range of the reproductive cycle (e.g., contraception, conception, pregnancy, childbirth, abortion) and includes various reproductive challenges (e.g., egg donation, surrogacy, reproductive technologies, etc.) (Ross 2006a). Therefore, to best capture the full spectrum of these experiences, I have divided this section into three disparate categories: bodily experiences, reproductive health behavior and pregnancy and childbirth.

*Bodily Experiences*

There were only slight differences in how participants reported their reproductive bodily functions—menarche, menstruation, and menopause. Monthly menstrual cycles among women in the sample varied, in regard to when they began, whether they continued, and the overall experience. Participant's age of menarche may provide some insight into the variation in reproductive bodily functioning. Much of the existing literature reports individuals with SCD experience delayed sexual maturation, onset of menarche and pubertal development (Cepeda et al. 2000, Singhal et al. 1994). Age of menarche among women in the sample ranged from 11 to 20 and the average age was slightly older, 14.04 years old, than the average age for African American females, 12.09 (Anderson and Must 2005). Genotype may influence age of menarche, since 14 of the 17 women with Hb-SS experienced menarche at age 13 and younger, while five of the nine women with Hb-SC experienced menarche the age of 11 and younger (see Table 5). The two women with Hb-thalassemia also experienced menarche over the age of 13.

Twelve women reported they no longer had a monthly menstrual cycle, three of these had experienced menopause and one reported having a hysterectomy in an effort to resolve ongoing menstrual cycle difficulties (see Table 5). Further, four women attributed the absence of their monthly cycle to the type of birth control they were using, and four women had no clear understanding about why they no longer had their cycle (see Table 5).

I specifically collected data on pain associated with menstrual cycles, uterine fibroids, ovarian cysts, stillborn birth, infertility, and miscarriage because these are among the difficulties associated with sickle cell disease. Only 11 women reported having at least one of these reproductive difficulties. Of these women, nearly all had Hb-SS and over half had given birth to a child (see Table 3).

In summary, women in this sample who started their menstrual cycles at age 14 or later were more likely to have Hb-SS and were less likely to report a reproductive difficulty (see Table 5), while those beginning menarche between the ages of 11-13 mostly had Hb-SC and reported having at least one reproductive difficulty. Women who did not report any reproductive difficulties continued to have their monthly menstrual cycle (see Table 5).

### *Reproductive Health Care Seeking*

I also explored the actions taken by participants regarding their reproductive health. One key component of reproductive health is seeking care from an obstetrician/gynecologist (OB/GYN). Of the 28 participants, 22 reported having an OB/GYN and 21 reported a recent visit to their OB/GYN (see Table 5). Women gave various reasons for not recently visiting an OB/GYN: their reproductive health was currently being maintained by their primary care physician, they were a virgin and considered it unnecessary to see an OB/GYN, they simply had not “gotten around to it,” and one participant had recently undergone a series of negative interactions in her efforts to conceive and decided to “take a break” from reproductive health care.

Among women with sickle cell disease, while the use of combined oral contraceptive pills has been found to be associated with increased thrombotic risks, progestogen-only pills, injectables, and implantables also raise concerns for possible clinical or hematological complications and others have cautioned against the use of intrauterine devices (Howard, Lillis and Tuck 1993, Koshy and Dorn 1996). Women reported using a variety of contraceptive methods (see Table 5). Of the 11 women reporting not currently using contraception, seven were

not currently sexually active, one wanted to have a child, and three believed they were unable to conceive due to failed attempts to become pregnant (see Table 5).

Since contraception use is in part associated with sexual activity, I placed women in the following categories to explore their contraception use: women who were sexually active and single (N=12), sexually active and married (N=7), not currently sexually active (N=5), and never sexually active (N=4). Single women who were sexually active, were more likely to always or sometimes use condoms, whereas married women used condoms sometimes or never during sexual intercourse. Two of the women who had never had sexual intercourse explained that they used contraception for proactive reasons: one to help regulate her menstrual cycle and the other had contraception impressed upon by her aunt in order to circumvent a teenage pregnancy. In this sample, nine women reported using contraception as an intentional strategy to control menstrual cycle difficulties.

Overall, the sample was similar in seeking care and consultation for reproductive health issues and the use of contraception. Most women sought care from an OB/GYN for some aspect of their reproductive health and were using some type of contraception, although the specific type varied.

### *Pregnancy and Childbirth*

Rather than simply looking at experiences of motherhood, I felt it was also important to capture the reproductive variations in the experience of pregnancy. Therefore, I categorized women based on whether or not they had ever been pregnant, rather than their parenthood status (see Table 5). This allowed me to acknowledge women who had been pregnant, yet had not given birth due to an abortion or a miscarriage—two potentially distressing reproductive



experiences. Of the 28 participants, seventeen participants reported having been pregnant.<sup>5</sup> Two women were pregnant at the time of the interview, one with her second child and the other with her third. Six women reported terminating a pregnancy either voluntarily because of the lack of financial stability or due to emotional preparedness for parenthood or involuntarily due to parent enforcement.

Among the 13 women with live births, the age of first child ranged from 17 to 35, with an average age of 22 years old (see table 5). Three had one child, five had two children, four had three children, and one woman had four children, with children's ages ranging from 16 months to 28 years old (see Table 5). Of the 13 mothers in the sample, eight indicated they breastfeed their children. Several women attempted unsuccessfully to breastfeed, others stated they did not breastfeed because of a medical condition, and a few never tried to breastfeed.

As important as it was important to capture decisions to give birth, it was also important to capture decisions to purposefully bring an end to their ability to reproduce. Six reported having planned tubal ligations, most to avoid future pregnancies and the physical "toll" of pregnancy on their bodies, and one indicated regrettably agreeing to a tubal ligation under duress following the birth of a stillborn child.

Their pregnancy experiences varied based on genotype and age. Of the 11 women without children who had never been pregnant, eight had Hb-SS and were mostly under the age of 29. Additionally, more women with Hb-SC had live births and were younger at menarche than women who had never given birth (see Table 5).

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<sup>5</sup> This number represents whether participants reported being pregnant (yes/no) and not the total number of pregnancies among the sample.

**Table 5.** Reproductive Health Characteristics

	N (%)
<b>Age of Menarche (Mean Age=14.04)</b>	
11-13	14 (50)
14-16	10 (35.7)
17-19	3 (10.7)
20 and above	1 (3.6)
<b>Regular Menstrual Cycles</b>	
Yes	16 (57.1)
No	12 (42.9)
<b>Menopause</b>	
Yes	4 (14.3)
No	24 (85.7)
<b>Reproductive Difficulties (N=12)</b>	
Vaso-occlusive pain associated with menstrual cycles	6 (50.0)
Dysmenorrhea <sup>6</sup>	5 (41.7)
Uterine fibroids	2 (16.7)
Ovarian cysts	1 (8.3)
Stillborn birth	2 (16.7)
Infertility	1 (8.3)
Miscarriage	5 (41.7)

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<sup>6</sup> Pain during menstruation that interferes with daily activities.

Reproductive Health Care Seeking	
	N (%)
<b>Currently Have An OB/GYN</b>	22 (78.6)
Yes	6 (21.4)
No	
<b>Reason for Most Recent OB/GYN Visit (N=22)</b>	
Annual pap smear	15 (68.2)
Contraception consultation	5 (22.7)
Pregnancy care and delivery	2 (9.1)
<b>Types of Birth Control Ever Used<sup>7</sup></b>	
Birth control pills	12 (42.9)
IUD	7 (25)
Contraception condom	11 (39.3)
Contraception patch	3 (10.7)
Contraception ring	1 (3.6)
Depo-Provera	16 (57.1)
Rhythm method	1 (3.6)
None	3 (10.7)
<b>Last Time Used Contraception During Sexual Intercourse (N=27)</b>	
Never	7 (25.0)
0-3	11 (39.3)
4-6	1 (3.6)
7-9	1 (3.6)
10-1 year	7 (25.0)
<b>Reason for Not Using Contraception (N=11)</b>	
I am not sexually Active	7 (25.0)
I want to have a child	1 (3.6)
I don't believe I can conceive	3 (10.7)
I don't like contraceptives	0
<b>Frequency of Condom Use During Sexual Intercourse (N=27)</b>	
Never	7 (25.0)
Sometimes	8 (28.6)
Always	12 (42.9)

<sup>7</sup> Total number is greater than N=28, participants were able to check all that applied.

Reproduction	
	N (%)
<b>Reproductive History<sup>8</sup></b>	
Never Pregnant	11 (39.3)
Pregnant-Miscarriage or Abortion	4 (14.2)
Pregnant-Delivery	13 (46.4)
<b>Types of Delivery (N=13)</b>	
Caesarian Section	3 (23.0)
Vaginal	9 (69.2)
Natural	1 (0.7)
<b>Age of First Child (Mean Age =22.38) (N=13)</b>	
19 and under	7 (53.8)
20-25	3 (23.1)
26-30	2 (15.4)
Over 30	1 (7.7)
<b>Number of Children (N=13)</b>	
None	15 (53.6)
1	3 (10.7)
2	5 (17.9)
3	4 (14.3)
4	1 (3.6)
<b>Breastfeed Any of Your Children (N=13)</b>	
Yes	8 (61.5)
No	5 (38.4)

### Summary

Overall the sample is similar across sociodemographic categories. However, in terms of reproductive health experiences, behavior activities, and birth trajectories there is some variation. While the reproductive health diversity within the sample allowed me to make some assumptions about different types of reproductive health experiences, there was too little variation in employment, income or marital status to make any assumptions regarding the influence of these social characteristics. Of note, two women were not officially diagnosed with SCD until they were adults, which also made the perceptions of their lifetime experiences and reproductive health decisions different from those diagnosed as a child. Since, the majority (N=17) of the

<sup>8</sup> Participants may have experienced more than one of these options.

sample had Hb-SS and nearly all (N=20) experienced more than one pain crisis requiring hospitalization. I conclude that the women in this sample have a clear picture of what it is like to live with sickle cell disease.

## CHAPTER 5

### RESPONSES TO DISCOURAGING REPRODUCTIVE MESSAGES

*I've heard we shouldn't have kids.  
We're still normal, regular women in my opinion. ~Jada*

The focus of this chapter is the discussion of participants' resistance to discouraging reproductive messages and the various types of reproductive agency they used to pursue their reproductive desires for biological children. Some of the agentic responses included seeking medical expertise, exercising their right to reproduce, becoming informed about their reproductive capabilities, and drawing upon personal experience. In this study, reproductive agency refers to the ability to exercise autonomous choice when selecting health care models and providers (Unnithan-Kumar 2004). In the context of pregnancy and prenatal care, reproductive agency includes "ideas, actions, thinking and planning in the domain of human reproduction" (Unnithan-Kuman 2004: p. 6).

This chapter specifically describes participants' responses to three categories of discouraging reproductive messages: health concerns, genetic transmission, and misinformation. Nearly all the women in this study (N=23)<sup>9</sup> encountered at least one discouraging reproductive message from family members or health care providers. Fourteen of the twenty-three women were discouraged from having a biological child because of the burden of pregnancy and childbirth on their bodies. Eleven participants were discouraged from having a child with sickle cell disease. Four participants were told they could not conceive children because they had sickle cell disease (See Table 6). Only five of the 28 participants in the study were not discouraged from having biological children.

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<sup>9</sup> Discouraging messages are not mutually exclusive and many participants received more than one discouraging message.

**Message: Don't Have Children, Its Too Dangerous**

Half of the women in the study (N=14) provided detailed descriptions of the discouraging reproductive messages they received from their health care providers or family members due to concerns of for their physical health associated with pregnancy and childbirth. Nearly all of these women (N=13) had the more severe form of sickle cell disease (Hb-SS) and more pain crises requiring hospitalizations within the past 12 months. The concern that these women may experience fatality is consistent with research, since apart from general health concerns related to sickle cell disease, pregnancy and childbirth are two contributors of mortality among women with this condition (Mou Sun et al 2001; Villers et al 2008). Women with sickle cell disease have been found to experience higher mortality rates during childbirth than women without the condition (72.4 vs. 12.7 deaths per 100,000 deliveries) (Mou Sun et al 2001; Villers et al 2008).

The sections that follow describe participants' responses to the discouraging reproductive message not to have biological children because it was too dangerous: two participants decided not to have children out of concern of the chance they could die, the other 12 made other decisions and instead sought an alternate source of information, based their decision on their own bodily experience with sickle cell disease or decided to leave their fate in God's hands.

*I Understand the Risks, But It's Still My Choice To Make*

Seven participants indicated being told of a "50/50 chance" of death with childbirth. Two participants were unwilling to take this risk and decided to forgo having children. Verlean, a 40 year-old woman, also decided not to pursue having a child because of the fear of fatality with childbirth, which she witnessed firsthand.

[PR: *Do you have children?*] I was told not to, it was a 50/50 chance. [PR: *A 50/50 chance of what?*] That some women survive birth and some women don't when they have it [sickle cell disease]. There's a bunch of people with sickle cell that have been blessed with a wonderful, beautiful child and are still here in this world doing good. My sister had a baby, she had sickle cell—the full one—and she gave birth. The situation is kind of hurtful. She passed when she gave birth. So it's just like, if you have a child, you have that risk. How are you going to be there for that child when you're gone? I am blessed with a nephew and I'm blessed with four God-children.

Verlean viewed becoming pregnant as making a choice between life and death and decided she was unwilling to risk death while attempting to have a child. These odds of surviving childbirth were very real for Verlean because she knew women with sickle cell disease who had experienced both life and death during childbirth. Verlean was concerned with her own fate and the fate of the child should she not survive childbirth. She also considered the burden having a child would put on her family because she was frequently hospitalized and knew someone else would bear the burden for caring for her child. Verlean lost both her sister and her mother, who also had sickle cell disease, due to other non-reproductive complications. Because of her knowledge of these experiences and her close relationship with these women in her life, she decided to not bear children.

Another participant, Mya, a 33 year-old woman, shared her experience of being told, “not to have none.”

I was told not to have no kids, that it was 50/50 that you will die or the child might die so I was scared of having kids. I was not even about to even set myself up for that type of failure. I was like, no, no, no. [PR: *Tell me a little bit about that conversation.*] I talked to him [her hematologist] about it a while back and they're like, “You're trying to have kids?” I'm like, “No, I'm just asking.” [PR: *What were you asking about?*] Like, would it be a hard time? They said, “50/50 and the older you get, we advise that you not, because it would just be harder on your body” and stuff like that. So I'm like, “Oh, okay.” I was just listening to what they [were] saying. Now that I'm getting older, I know the older you get the worse the timing and everything and my doctor [hematologist] was like, “No, I don't think you should be trying to have any right now.” I'm like, “I'm not, I was



just seeing.” Now, I don’t even want no kids for me. I don’t want none. I spoil my nieces and nephews.

Mya’s reproductive decision was based on the worsening health she was told would come with age. The information she received caused her to view pregnancy and childbirth as a choice between life or death and an activity that would jeopardize the adult life she had achieved. As Mya got older, she remained curious about the possibility of having children and with some trepidation, she “checked to see” if her health had improved enough to pursue having a child. Thus, her decision to forgo having biological children was not necessarily a final decision and was contingent on the status of her health. Upon having this discussion with her hematologist and with his words of discouragement, she resolved to end her reproductive pursuits. Similar to women who delay childbearing or are infertile, not having children is typically a temporary decision and continues to be contemplated over their lifetime. Like Verlean, Mya did not oppose the discouraging message that fatality may be an outcome of childbirth, and used it as a self-imposed barrier to motherhood since both decided to forgo having children.

The other twelve women who were discouraged from having children due to concerns for their health also recognized the potential risk of pregnancy and childbirth, yet made a different choice from Mya and Verlean. Joyce, a 25 year-old woman, did not specifically inquire about her reproductive capabilities, but she was still discouraged from having children by her hematologist.

When I was 15, he [hematologist] was like, “We can just do a hysterectomy right now,” when I was having all the issues with my cycle. He was like, “Let’s just do a hysterectomy.” I’m like, “Hold on. I might want to have kids at some point.” He was like, “Let’s just do the hysterectomy now. You won’t have a cycle anymore and then we don’t have to ever worry about it again.” He’s like, “Well you’re not going to have kids.” This was my doctor who at the time felt like he was my father. Because when you have sickle cell anemia you and your doctor are talking every day. So this doctor said, “You’re not going to have kids. If something happened to you because you got pregnant, I would never be able to

live with myself. You're not having kids." Me and my mom were like, "No. At some point I may be healthy enough to bear a child, so we're not going to kill that whole dream."

Recognizing the finality of a hysterectomy, Joyce exercised agency by readily rejecting her provider's recommendation and held on to the hope that she would be able to have children. Instead of following this recommendation, Joyce decided that her health during adulthood would determine whether or not she would have children. When I asked her how she felt about the recommendation not to have children, she stated:

I didn't take it badly because you have to realize that I had a long relationship with this individual. Like I said, having sickle cell anemia I have to be "there" with my doctor. I have to be one-on-one. I have to know that you care more than just about your paycheck. This is a doctor who asks me about my family. He says, "Oh, what do you have going on? Oh, what do you need?" You know, even outside the medical part of it. I didn't take it badly. He really thought that he was looking out for me. But at the end of the day that's my choice.

Joyce felt this particular physician was committed to maintaining her health and their interactions had been filled with compassion allowing her to trust his intentions. Her trusting relationship with this provider allowed the message to be received and rejected without animosity. In this situation, her trust was the result of cooperative behavior that had developed over time and through frequent interactions. Joyce respected her provider's concern for her beyond sickle cell disease; however, she believed the decision of whether or not to have children was hers to make.

I have friends who have sickle cell and have children. My one friend, she had a really hard time. She was never sick before she had her baby. Once she got pregnant, she got super sick and she has been that way ever since. It all depends about your own personal experience with the illness. As far as I'm concerned, I feel like I'm too sick to physically carry a baby. I do want children and I am thinking to myself that adopting may be my best strategy for doing that. In fact, I was just talking to my mother about that yesterday. I think that I want to do that sooner, rather than later. I think that I'm ready now.

Over the past ten years, Joyce's menstrual cycle problems had been resolved. Now at the age of 25, she still questioned her physical ability to bear a child and was considering adoption as a route to motherhood. Like Mya, Joyce based her decision of whether she would be able to bear children on her embodied experience living with sickle cell disease and continued to hope her health would improve. Joyce was determined not to allow her health condition to prevent her from becoming a mother. Her mother had adopted five children, family members who originally were destined for foster care; therefore the idea of adoption was a familiar solution for her maternal desires.

Jada, a 23 year-old woman, was looking forward to having a child. Unfortunately, she experienced a long and disappointing journey securing medical assistance to fulfill her reproductive desires. Jada was born with a ribcage that was not fully closed and with a heart that contained three holes, she had her first grand mal seizure at the age of seven, and her blood was 98% sickled. Her reproductive agency began with her initial step toward conception when she stopped using birth control, saying "[I want] to get it to get out of my system. I wanted a kid." Jada also experienced several miscarriages and estimated having a total of "five or six" in the past three to four years. Thus she determined the condition of her health would dictate whether she would have a successful pregnancy and exercised agency by seeking advice from several obstetrician/gynecologists to learn what she could do differently to improve her health.

I went to this one doctor and I'm like, "I want kids. I've always wanted them and I should be able to have them." That's how I feel. She asked, "Well are you taking any preventative measures to keep from getting from getting pregnant?" I told her "No." She goes, "Are you trying to kill yourself?" She said, "You know this is a death sentence, right?" I was like, "What?" She goes, "This is a death sentence and if you get pregnant I will write a prescription for an abortion." I just grabbed my stuff and walked out because I didn't know what else to do. [I thought,] "You're not going to touch me. You're not going to continue to talk to me like this."

Despite having numerous miscarriages and being told that having a child was a “death sentence,” Jada remained determined to have her own child. This physician attempted to assume control over her right to have a child and instead Jada was seeking a physician that would work with her. Ultimately, Jada felt that the physician’s perfunctory response was simply another rejection of medical assistance because of her health condition.

After such a negative encounter with an extremely strong message of potential fatality, Jada continued to resist this message and maintained her pursuit for having a biological child and found another obstetrician/gynecologist.

I scheduled another appointment and *this* doctor was even worse. I went in, same thing [as with the first doctor]. [As a] new patient, he [physician] goes through the medical history. He goes, “Wow! This is a lot...” Before we could finish he goes, “This is a lot! How many medicines do you take?” At the time I think I was taking like 21 pills a day. He goes, “Well you do know that all of this will kill your child, right?” He goes “Hmmm.” Like he didn’t believe me, like, “Hmmm.” I was just like, “What the?” He got to the question, “Why are you here? Are you using any protection?” I said, “No! Because I want a baby.” He said, “Do you know how much it’s going to take to have a baby? We’re going to need a team of 20-some-odd doctors.” I said, “And your point is what? I’m coming to you beforehand to see what I need to do to make sure that I am as healthy as possible.” This is him, he killed me literally, [he said,] “Well I don’t feel comfortable being your OB/GYN, but I can be your primary care doctor.” I said, “Why is it that you’re not comfortable?” He said, “Because this isn’t a case I’m willing to take on. It’s too high of a risk.” So, now you’re worried about your reputation instead of helping somebody? That’s the impression I got from it.

This attempt to find a health care provider willing to help her have a biological child was also unsuccessful. While the message she received from this physician was that having a baby was possible, he was unwilling to put forth the necessary effort and take the risk to make it happen. To Jada, the benefits of having a biological child far outweighed the risks and by seeking preconception care she felt she was taking the necessary steps to minimize these risks. Additionally, because of this physician’s unwillingness to provide her with reproductive health care, Jada refused to allow this person to have authority over any aspect of her health care. In

neither encounter did the physicians appear to take into consideration Jada's desire to pursue having a child. While it was within the physician's right to decline to assist Jada in her pursuit due his knowledge of her case, it was the manner in which the message was delivered that caused her to have such negative feelings.

Nonetheless, Jada continued to assert her right to have a child despite having sickle cell disease.

I'll find a doctor that will help me eventually. I feel like it's something wrong and if it was any other regular woman that has been trying to get pregnant for this long they would consider saying "Well you need infertility treatment" but they won't do that with me. [PR: *Have you asked for those?*] Yes. [PR: *What happened?*] The doctor said that she doesn't feel comfortable doing it. She doesn't feel comfortable!?! That's what I get a lot. [PR: *What about infertility treatment doesn't she feel comfortable helping you with?*] Because she doesn't feel like I should be pregnant. [PR: *How does that make you feel?*] I get so mad and it takes a lot for me to get mad. How dare you tell me that I don't deserve to be a mom! I told Dr. [hematologist] and he goes, "Just hang in there, we'll find you a good doctor to help you out." He's like, "It's crazy. You're going to have a baby, so don't worry about it."

Being told not to pursue having biological children caused Jada to question whether she received the same reproductive support that she would if she were a "regular woman." She also specifically resisted any notions of the opinions of others regarding who should be able to reproduce and who should not, but felt it was her decision to make. This is very similar to what was presented in Chapter 2, that physicians often fail to offer women with disabilities reproductive health services. For example, these physicians were unwilling to suggest alternatives that would increase her odds of bearing children, such an infertility treatment which could in some sense be considered the denial of treatment.

Although Joyce and Jada were both discouraged from having children, they had disparate reactions to this message. Joyce had a long relationship with the doctor who told her "not to have kids" and felt this statement was made purely out of concern for her health and genuine concern

for her. Therefore while she opposed his recommendation, she still paid close attention to his concerns for health and years later recognized that she might not be healthy enough to endure pregnancy and childbirth. Unlike Joyce, Jada was interacting with new physicians with whom she had not established a relationship and who only knew about her “on paper”. Thus their recommendation that she forgo having biological children caused her to become very upset. She interpreted this message as being told she did not “deserve to be a mom” rather than a doctor’s genuine concern for her health. Also, because Jada was purposefully inquiring about ways she could improve her health, she further concluded that this message was not related to her health, but their opinions of who should be able to reproduce. It is important to note that Joyce received the discouraging message at the age of 15, when she was not actually pursuing pregnancy, while Jada received this message during her current pregnancy pursuit.

Both Joyce and Jada were close in age, lived independently with the emotional support from their families, had health problems beyond sickle cell disease, and experienced various health problems throughout their lives. Both women stated they wanted their providers “to be in the war” with them, and exhaust every possibility in managing their care. In particular, Jada recalled her mother telling her “it took a team of doctors to keep her alive” at birth, yet her current providers were unwilling to take these measures.

Another agentic response to this discouraging message was to seek information to confirm validity. Faith, a 19 year-old high-school student, described being discouraged by her hematologist from having children while seeking his advice about her ability to survive pregnancy.

I went to the doctor because I wanted children and I don’t just want to get pregnant and end up dying giving birth. I asked, “Am I allowed to reproduce?” They told me no. [PR: *Who told you no?*] Dr. [hematologist] and a couple more doctors that I don’t know. [PR: *What did they say?*] That I shouldn’t because of

my chronic sickle cell disease and the things that come with it, like severe chronic chest problems or whatever I could die from going through labor. [PR: *How did that make you feel when they told you that?*] I was a little upset but I wasn't worried about it because I wasn't ready for no kids. [PR: *How long ago did they tell you this?*] About three years ago. [PR: *What did they suggest you do?*] Not have kids. I've looked it up myself. [PR: *Where?*] Online. I looked up my disease and if I can have kids or not and what should I do and stuff like that. I just wanted to know with my disease how should I take care of it [pain crisis] if my medicine doesn't work when I'm pregnant. That was the hard part. [PR: *What was hard?*] Finding stuff on what you can do.

At the age of 16, this message held little meaning for Faith because she was not ready to have children. However, as she got older she was unwilling to allow her reproductive desires to remain unfulfilled and exercised reproductive agency by investigating her reproductive capabilities. Information is one way to individuals regain control over their lives to compensate for physical limitations. Faith did not accept the definitive response to her inquiry about having children and sought information online about how to manage her condition while pregnant.

Nia's mother, Vivian, was concerned about her health and discouraged her from having biological children by suggesting she adopt instead. Nia, a 23 year-old woman, resisted her mother's message and exercised reproductive agency by taking Vivian with her to the hematologist to hear first-hand that it was safe for her to have a child. Nia was very close to her mother and referred to her as "the hero of everything." Her mother was a constant source of support and encouraged her to overcome the barriers of her condition and pursue her life goals. Therefore Nia earnestly sought her mother's approval when she decided to have a biological child.

When I was younger I was told, "If you have sickle cell you shouldn't have kids. You need to adopt." [PR: *Who told you that?*] My mom. Dr. [hematologist] made her feel a little more comfortable about it [having biological children]. So I think it [talking to her hematologist] was only to make her feel a little more secure about my life and me wanting to bring kids into the world. I do want my own kids. Me and Dr. [hematologist] and her [her mother] talked about it a lot because he's delivered babies from sickle cell patients and it's been such a success,

everything's OK, so that's good to know. [*PR: Whose idea was it to talk to Dr. [hematologist]??*] Mine. I brought it up because me and my mom were just having a conversation and she's like, "Oh, I think you should adopt." I said, "No, I'm not adopting. I don't want to adopt." She's like, "Okay, if it comes down to it, I'm saving you, not no baby."

Understanding the risks to both mother and child, Nia's mother would choose to save the life of her daughter at the expense of her grandchild. Her mother's perspective was shaped by Nia's long family history of sickle cell disease. Both Nia's mother and her grandmother had milder forms of sickle cell disease with fewer symptoms. In some cases, the death of a family member from the disease brings to bear the possibility of death and caused participants to be discouraged from pregnancy, as with Verlean above.

It's only because her brother passed when he was young and she saw him always in pain and he died at a very young age. He had sickle cell. She saw him suffer every single day. He was in pain every single day, every holiday, every birthday. Everyone she has known—as far as her family and friends—didn't make it long once they had a child.

Here Nia also acknowledged multiple sources of reproductive influence, her mother as well as other family members. Nonetheless, like Faith, Nia decided to use information seeking as a strategy to confirm her safety during pregnancy and childbirth. I also interviewed Nia's mother, Vivian<sup>10</sup>, a 52 year-old woman, who stated that she told Nia to adopt. I asked Vivian about this advice, and she replied not only from the perspective of Nia's mother, but also as a woman who had experienced having her own biological children.

I told Nia to adopt because it's a strain on your body. With Nia having SS, which is the chronic disease, I tell her no. There are medications out there that can help you—especially the Hydroxyurea they say is really good. Even though I know the medications are more advanced, I would just adopt. Even though you might marry somebody who don't even have trait or disease and it's a 50/50 chance, I would consider adopting first. If that's not what you want to do, then you have to look at your life span. Are you going to have time to spend with your child?

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<sup>10</sup> This was the only mother-daughter pair I interviewed, making them fairly unique in my sample.



Vivian was quite concerned that Nia's chronic condition would worsen due to pregnancy and childbirth and wanted Nia to carefully consider the possibility of fatality. By suggesting adoption, Vivian felt she was suggesting an alternative and safer path for Nia to become mother. Vivian had apparently already heard Nia's refutations—that there were advanced medications and she would not purposefully seek a disease- or trait-free partner—nonetheless, she remained adamant that Nia should adopt.

Well, the only reason why [I felt it was fine for me to have a child] is [because] my fetal hemoglobin is high and Nia's [hemoglobin] is low [and] I did not have as many crises as she does. She started off [having crises] at 12 months on up. I'm healthy.

Vivian attributed her belief that Nia should not have biological children to Nia's more severe experience with sickle cell disease. Vivian emphasized the chronic nature of Nia's symptoms, which suggests that when women exhibit more severe forms of sickle cell disease, family members may suggest foregoing pregnancy as a precautionary measure.

Whether or not participants decided to forgo having children, pursue having children or postpone having children until they felt they acquired better health, they still made these decisions themselves and exercised agency in ensuring they made the most informed decision possible.

### *It's in God's Hands*

Three participants indicated that their safety throughout pregnancy and childbirth had already been determined by God. Sydney, a 24 year-old mother, was discouraged from having a child by her mother and hematologist because they felt it could jeopardize her life. Because of these discouraging messages, she was hesitant to tell her mother about her pregnancy.

I'm sitting at the table and my momma started yelling real loud and I just started crying. I'm like, "Oh, my gosh." Then she pulled the sickle cell thing in. [She

said,] “You don’t know how it’s going to affect you.” Dr. [hematologist] said, “You shouldn’t have no baby because you might not make it. You can’t take these medicines while you’re pregnant.” I’m like, “Oh, my gosh, this is really...this is a big risk.” She just made me feel so bad. No, no one decides whether you should have children no matter what. When I was 18 they [her doctors] told me they didn’t want me to have a kid. [PR: *Why not?*] Because of the sickle cell [and] the problems that could happen. I believe there is a God and that we don’t have the last say. So even though the doctors said that, it did scare me a little because I was like, “Dang!” But they don’t got the last say.

Sydney’s mother was concerned that she would be unable to take the necessary pain medication. Sydney’s mother attempted to reinforce what she heard from Sydney’s hematologist about the risks associated with pregnancy, to support her discouraging message by saying, “Dr. [hematologist] said.” This statement drew upon the physician’s medical expertise as a source of valued and trusted information and reaffirmed the medical risks associated with pregnancy and childbirth. Sydney was very much aware of the “problems that could happen” during her pregnancy, yet she recognized her right to make her own decision whether or not to have children. Sydney turned to faith to support her decision to continue her pregnancy by explaining that because she was able to conceive, a “higher being” had destined a safe pregnancy and a safe birth. Sydney’s narrative illustrates the multiple sources attempting to influence her reproductive behavior, including her provider whom she respected and her mother whose opinion she valued was her own perspective for her reproductive behavior.

Similar to Sydney’s mother, Zora’s father had been told of the dangers of childbirth with sickle cell disease. Zora, a 37 year-old participant, had numerous health problems brought on by sickle cell disease including a coma, brain damage, temporary memory loss, and nine grand mal seizures.

My father was one that would definitely ask questions if he didn’t know which route to take. He did a lot of questioning because he wanted to understand it [sickle cell disease]. I’m thankful for that. He was there. My daddy was told that if I ever got pregnant I would die. [PR: *Who told him that?*] He was told that at

the [Hospital's] Sickle Cell Clinic when I was younger because of how much I had gone through.

Zora, and six other women in my sample, explained that their parents had no prior knowledge of sickle cell before having a child with the condition. Zora, for instance, said, "They never heard of it until they were told I had it." With parents' unfamiliarity with the medical trajectory of sickle cell disease and the ongoing health challenges, participants' parents paid particularly close attention to providers' recommendations and were protective.

When I got pregnant, my father didn't want me to have the baby because of all the complications that can occur. I understood that but still I'm going to do what I want to do, because I just believe that our life is already mapped out for us and if it's meant for me to die then it's going to happen. He wouldn't even talk to me for the whole nine months he was so scared. I wasn't really worried. I didn't know my mother and father had so much fear. I didn't know but he came down to the ICU when I opened my eyes and I saw him and that was when they were first taking the tube and everything off and he ran in and said, "My baby!" That's when he held my hands and told me, "I didn't want to lose a daughter to gain a grandchild." I said, "Daddy, you should have told me that. You could have talked to me about this." I didn't know why that was why he was being so mean to me.

Zora's father became withdrawn when she shared the news of her first pregnancy with him. Similar to Sydney's mother, Zora's father did not want her to continue the pregnancy and for both of the parents of these women their pregnancies were tentative. Not until after her son was born—following a coma, nine blood clots, and a stay in intensive care—did Zora come to understand the reason behind her father's reaction. While her father and others were afraid, Zora's belief that her destiny had already been determined offered her comfort about her decision to have children. Zora's story illustrates her first realization of the origin of her father's fear. Despite knowing how involved her father had been in her medical care and had been told about the medical risks of childbearing with sickle cell disease, Zora did not understand (or had not consciously thought about) the deep impact this would have on her father.

Gwen, a 22 year-old woman, was discouraged from having children by her mother and sister due to their concerns for fatality.

They [her mother and sister] said I can die from giving birth and then it's nine times out of ten that the child wouldn't make it. They didn't try to boost me up. I'd rather experience it for myself than to go by what somebody is telling me. They tried to bring me down. I don't listen to it because God got a plan for everybody. I don't listen to it. If it's not meant for you to have kids, you'll find that out. But I know one day I want to be a mother. So it's like I can't listen to them. I have to go by my own feelings.

Gwen's reproductive desires were in opposition to her mother and older sister's recommendation that she not have biological children. She acknowledged the potential fatality of sickle cell disease and childbirth, yet felt that her mother and sister should have encouraged her to pursue what she wanted in life, perhaps because they served as a source of support in other aspects of life (e.g., caring for her when she is sick, motivating her to get back in school, etc.). Even knowing the odds and having important adults in her life instructing her that pregnancy was medically unwise, Gwen believed this decision would be determined by the status of her health and God—not her family. These three women made it clear that God would determine their fate, not family or health care professionals.

Family members and health care providers' concerns for participants' lives were apparent throughout the interviews. One participant, Sophia, provided a clear illustration of how in times of crisis, health concerns may be given priority over women's reproductive desires.

One thing that tends to happen with sickle cell females is pregnancy really takes a toll on our body. I was engaged once and I had gotten pregnant. Actually that was one of the things that sent me into the coma about five months into the pregnancy. It was just really weird waking up and I knew something was different. They [her family] told me that the doctor told them it was between me or the baby. My whole thing was I believe in life choice. I said, "What am I going to tell God when he asks me about this?" And she [her mother] said, "Well, I'll be standing right there and I'll tell Him I chose life for her?" [PR: *What are you saying?*] Well, when my mother was saying that she chose life for me it was her decision. [PR: *What happened?*] When I was in a coma they took the baby.

My parents signed for it. I'm Catholic, and in the Catholic faith they don't believe in abortion. [PR: *Is that how you view that?*] Yeah, I did.

In this instance, Sophia was denied the opportunity to exercise agency and achieve her reproductive desires and regulate her pregnancy while unconscious. Sophia questioned her mother's decision because it was in opposition to her preference for "life-choice." Not only did the health professionals prioritize Sophia's life over her child's, so did her mother. For Sophia, this experience brought to light the importance of having a living will to ensure her reproductive and life decisions, are honored when she is unable to make them for herself.

If you're going to have children and you have this disability, you need to have a [living] will. You just have to. Somebody needs to know your wishes if you're incapacitated. It's telling them to resuscitate you; it's telling them who's going to be taking care of your affairs while you're out.

### *Summary*

The 14 participants who were discouraged by their family members or health providers from having biological children were among those who experienced more pain and had multiple comorbidities (e.g. stroke, acute chest syndrome, seizures, etc.). This suggests that, while in many cases the individual voicing discouragement was speaking out of legitimate concern for the participant's life, that person still did not give enough attention to the participant's reproductive desires and her freedom to decide for herself. Most participants resisted the message that they shouldn't have children because of their health; however, only four of these women had made the decision already and actually delivered children at the time of the interview. Participants without children and who had decided to forego having them also spoke about their close relationships with nieces and nephews and god-children who may indicate a form of alternative mothering, replacing that of having biological children.

Although being discouraged from reproduction because of their health caused participants great angst and some tension between their family members and providers, participants still employed reproductive agency to pursue their desires and do what they felt was right for them. Participants believed the decision whether or not to have children should be made based on the condition of their health and belief in God's will rather than having sickle cell disease alone. These women recognized and accepted the risks and even potential danger to their lives amid pregnancy and childbirth, but felt they were being responsible by doing their own research, seeking health clearance with physicians, and paying close attention to their bodies and health status to guide their decision-making. Ultimately, those that opposed the message did so based on their desire to make an autonomous and informed choice.

**Message: Don't Have a Baby by Nobody with Sickle Cell**

In addition to being discouraged from having biological children out of concern for their health, nearly one third (N=7) of the participants indicated they were discouraged from reproducing with a man with sickle cell disease or sickle cell trait. This message was a more implicit way of ensuring these women would not transmit sickle cell disease to their child. For example, Mya indicated that while growing up, her hematologist "didn't like us [patients] to associate with other sickle cell patients in the office because he thought we might start dating."

*Of Course I Wouldn't Have a Baby with a Man with Sickle Cell*

Six women indicated that this message influenced their relationship formation and they exercised agency by intentionally avoiding having a partner with either sickle cell disease or

sickle cell trait. As a young woman Gabrielle, a 36 year-old mother, used this message as a guide for her future reproductive behavior.

I didn't think I would have a baby with sickle cell of course because I didn't think my husband had the trait. Of course, I would not have mated up with anyone that had the trait. Two bad genes is only going to give a bad gene. I can't give off a good one because I only have two bad. [PR: *How did you even know to ask your husband about it?*] Because my family told me, "Don't have a boyfriend with the sickle cell trait or disease." So I knew that much. Because I knew my mother and father both had the trait and that's how I ended up with the disease. So they did teach me that. Like, "You can't have a boyfriend [with sickle cell]. You have to find out their medical history, if they have sickle cell" and stuff like that. So that I did know. I knew I was going to have kids. Nobody said I couldn't have kids, they just said that I couldn't have kids with someone else who had sickle cell.

Her family instructed her not to have a boyfriend with sickle cell disease—with the understanding that casual relationships have the potential to escalate into intimate relationships. Through her family's careful explanation of the genetic transmission process, Gabrielle interpreted her reproduction as contingent upon making sure her partner did not have either sickle cell trait or disease. Gabrielle followed this instruction and was diligent about not dating a man with sickle cell. For instance, she asked her ex-husband to be tested at the local hospital while they were still dating and before pregnancy. However, once her son was born with sickle cell disease, they discovered her husband's test result was a false-negative. This experience caused Gabrielle to be even more agentic with her next partner's genetic testing by taking him to the sickle cell clinic where they "test for everything."

In her youth, Jada had also been instructed to discover her partner's sickle cell status prior to reproducing.

I understood really early that if I wanted to have kids it should not be by a person that has sickle cell disease and that my child *is* going to be born with the trait. [PR: *Who told you that?*] Dr. [hematologist]. They of course have to tell us that you need to make sure the child's father doesn't have the trait or sickle cell disease. If he has sickle cell trait and you have sickle cell disease, do you want to

take that risk? Because you know you have to pass on one of your genes and one of his genes, so if I have the disease of course I'm going to pass it on.

Similar to Gabrielle, Jada framed her reproductive future based on whether or not her partner had sickle cell trait or disease. For Jada, this message was simply a form of necessary patient education for her as a woman with sickle cell disease not to have a child with the condition. Therefore she viewed it positively and willingly internalized this message as a road map used for reproductive partner selection.

Joyce, her family, and her doctors had discussed in great detail how she came to have sickle cell disease. Having this knowledge she refused to date men who had sickle cell disease to ensure she would not pass the disease onto a child.

I have actually had guys with sickle cell try to talk to me and I'm looking at them like, "You do realize that there is no way possible for us to be in a relationship past a friendship?" They're like, "We can be together. We just won't have kids together." I'm thinking to myself, well, that's part of what I want. I don't want a relationship and not be able to have a child. Then it won't work either because you're sick [and] I'm sick, so when you're sick I'm going to be taking care of you [and] when I'm sick, you're going to be taking care of me. What type of life are we really going to have? Somebody has to be well at some point. So, that doesn't work.

Due to these influential conversations with her family and providers and her own embodied experience, Joyce was willing to limit her partner selection, but she was not willing to limit her relationships to those in which having a child was not an option. In her mind, taking care of a child was an experience she desired; however she fully realized the effort and energy required. Additionally, her decision not to dating men with sickle cell disease extended beyond having a child with sickle cell disease. She expressed concerns about the quality of life she and her partner would have and questioned their ability to physically care for the child in times of sickness.



Joyce and Jada are participants who received different discouraging messages, from different sources, yet still exercised agency in pursuing their reproductive desires. All three of these women were very knowledgeable about how sickle cell is transmitted and the likelihood of their children having the condition. Much of what they learned came about because they were the only ones in their families to have the condition and their parents had taken the time to educate them. This reproductive information was therefore viewed in large part as a form of education, as evidenced by Jada's comment that "they did tell me that" and Gabrielle's comment "I knew *that* much." This information was presented as a road map of how not to proceed and each of these women, along with three others, indicated they were determined not to follow in this direction.

#### *You Can't Help Who You Love*

Only one participant was resistant to the message not to enter into a relationship with men who had sickle cell disease or sickle cell trait. Yvonne, a 23 year-old college student stated, "My mom told me, 'No! Don't marry nobody with sickle cell!'" However, Yvonne believed that love cannot be controlled by a set of rules.

You can't help who you meet and who you love and I guess that if I met somebody and I did find out that they had the trait of sickle cell, then, depending on how much I love that person you just have to make it work.

In Yvonne's opinion, adhering to this message would be based on the type of relationship and the feelings she may have developed for the other person. Yvonne held very specific ideals about love, marriage and family. She was planning to remain a virgin until marriage and had not seriously dated.

**Message: Don't Bring No Baby Here with Sickle Cell Disease**

In addition to the more implicit discouraging message not to have a child with a man with sickle cell trait or sickle cell disease, one quarter (N=9) of the participants indicated they were discouraged from having children because of the possibility that the baby would be born with sickle cell disease. For example, Raven, a 39 year-old mother of two son's with sickle cell disease, indicated that "people be like, 'With sickle cell why would you want to have a baby anyway?' Who wants to have a baby with sickle cell?" Raven had two sons with sickle cell disease and did not believe that having sickle cell disease was a tragic occurrence and felt happy to have them.

In addition to her concerns for Nia's health, Vivian was also concerned about Nia genetically transmitting sickle cell disease to her child.

I just don't think it's fair for you to have a child and you have sickle cell and it's a chance that they will have it too. I just don't like it. Wasn't no way Nia should have been here. I got my tubes tied right after Nia came out. I'm like, "I'm not bringing another baby here with sickle cell." I said [to her obstetrician], "Do you know how bad it is having sickle cell?" I'm not going to say that now because she's a blessing. I had my brother [die from sickle cell disease]. I didn't want to bring [another] baby here with sickle cell disease. So that was my choice.

Vivian indicated that she didn't believe it was "fair" for someone to knowingly have a child with sickle cell disease. Prior to her pregnancy, Vivian was under the assumption that her husband was not a carrier of sickle cell trait and therefore she did not knowingly make the decision to have a child who may have sickle cell disease. Vivian illustrates her commitment to not having another child with sickle cell disease by taking the preventative measure of having a tubal ligation. Vivian's story highlights the delicate balance of family members telling their children not to have children who may also have sickle cell disease.

*That's the Way It Has to Be*

Six participants responded to the message not to have a child with sickle cell disease by enacting their own diligent behavior, three of whom decided to forgo having biological children. Gina, a 25 year-old woman, grew up in foster care and referred to herself as “a ward of the state”. Due to her experiences with multiple foster care homes, she never received appropriate guidance or instruction regarding reproductive issues and stated, “With the foster parents that I've dealt with, they didn't teach me anything. I guess. They assumed that I already knew it so it wasn't like a mother sitting down or a grandmother sitting down teaching you.” Throughout her life she only maintained contact with one of her three siblings, her oldest sister, who continued to visit and inquire about her well-being. Her sister was also the person who discouraged her from having a biological child.

A couple of years ago when I was undecided, we [she and her sister] were debating about it, like spatting about it, and she thinks, it would be torturous to put someone else through this [sickle cell disease]. My sister thinks that it would be a disjustice [*sic*] to my child because I had the pre-knowledge on what his or her life is going to be like and it's not good, so why would I go ahead and do that? So at first I was against it and I was like, “Well, why should I have to not have kids just because I have this disorder? That takes away my chances at being a parent? That's not right.” But now I agree. Now that I am older, I understand that sometimes that's the way it has to be.

Gina's initial response was to reject this message as an imposition of her right to become a parent, yet later she viewed this message as her responsibility to prevent the “disjustice” of knowingly passing along sickle cell disease to someone else. As the one person in her life who provided her with any reproductive guidance, Gina was influenced by this message and later decided not to pursue having biological children. Gina's sister felt that because Gina had the experiential knowledge of living with sickle cell disease, this should have sufficiently deterred her from taking the chance of having a child who could possibly also have this condition.

When I started becoming sexually active at 20, and I'm like, "I can't *be* like everybody else because I'm not *like* everybody else so I have to take extra precautions. I can't have accidentally have a baby." [PR: *What were the extra precautions?*] I have taken all the precautions in the world, even taking the morning after pill. I have taken that about three times, you know, with accidents and things. So, yeah, I have not had to get an abortion.

Upon making the decision to avoid having a child with sickle cell disease, Gina began to view herself as being different from other sexually active women. Once she became sexually active, Gina held that her reproductive capacity was overshadowed by her genetic responsibility. Therefore, she exercised reproductive agency by taking extra precautions to avoid having a child with sickle cell disease, and even considered termination.

For Imani, a 49 year-old woman, the message she received from her mother included various reasons why she should avoid having a child with sickle cell disease.

My mother said, "Don't date a man if he has sickle cell or if he's a carrier because that's going to be a huge weight on your child. That can determine whether your child is going to suffer for the rest of their life or it's going to determine whether your child is just a carrier." Now my cousin [who also has sickle cell disease], she has four children. Me, I chose the...I guess I would say the coward's way out, because I didn't want to cause the baby suffering. I've got enough nieces and nephews. I wasn't going for that 'cause I had suffered so much. I couldn't see rolling the dice and saying, "Oh, guess you got it. Now you got to suffer through just like I had to suffer through." I couldn't see it and had my mother known, she wouldn't have gotten pregnant.

Imani viewed her decision of not having children as the "coward's way out," suggesting that to have a child would require a level of bravery she did not possess. Neither of Imani's parents was aware they were carriers of the sickle cell trait and Imani was told if her mother known that sickle cell could be passed to her offspring, she would have opted not to have children. Having been told this, Imani felt that those who know they have the potential to have children with illness should forego having biological children. Similar to Mya and Verlean above who were

unwilling to risk their health for childbearing, Imani redirected her maternal efforts toward her nieces and nephews and chose not to have her own children.

Mya worked at a clinic for people with chronic illnesses and met a woman with five daughters, all of whom had sickle cell disease.

I met a lady that came through my job with five daughters with sickle cell disease. She's like, "When one is sick, the other is sick." I'm like "Duh!" I'm like, "You and your husband know ya'll got the trait and you sat here and had five daughters and one may be sick and the other one may be sick." She's sitting there complaining, "When one gets out the hospital, I have to go because another one is in there." I'm like, "What did you think was going to happen?" They are sick and they are so cute. I'm like, "You don't understand the pain they go through. You have the trait. Ain't nothing really happening to you on a regular basis. Yea, they're going to be sick back to back to back."

Mya decided not to have children because of the risk of fatality and childbirth, even though she wanted children. She thought it was irresponsible for this mother to choose to have five daughters knowing she and her husband were both carriers of the sickle cell trait. Mya attributed this decision to the woman's lack of the embodied experience or a physical understanding of what it is like to live with sickle cell disease. Mya's strong opinion of this mother demonstrated her belief that those with genetic conditions should exercise responsibility in their reproduction and not have children who will have sickle cell disease and may explain how she arrived at her decision not to have children.

### *I'd Rather Be Here Than Not Be Here*

Only three participants resisted the discouraging message of having a child due to genetic transmission. In addition to Gwen's family concerns about her having a child because her health, they also discouraged her from having a child that may be born with sickle cell disease.

My mom and my older sister, they told me I shouldn't try to have a child when I got sickle cell because I wouldn't want my child to grow up with sickle cell. So they tried to talk me out of it.

Growing up, Gwen's said her parents told her "that I was the gifted child because when I was born, I was supposed to die." Having received this message of being "gifted" and surviving to the age of 22, it may have been difficult for Gwen to then accept being told not to have a child who would have sickle cell disease—since she beat the odds, her child would beat the odds.

Similar to Gwen, Yvonne was another woman in the study who received discouraging reproductive messages for more than one reason. In addition to concerns of reproducing with a partner with sickle cell disease, Yvonne's mother also instructed her to avoid having a baby with sickle cell disease.

She [her mother] said, "You received sickle cell from your father and I because it was a genetic thing. I had a trait, he had a trait and if you marry someone who has a trait or you marry someone who has sickle cell itself your children could potentially have it." The reason why I said I thought it would be selfish is because, some people may say like, "Well I'd rather not be here than be here doing all this suffering." But, I know me and personally I would rather be here regardless. Then again it's like we [she and her siblings] wouldn't be here. Surprisingly I'd rather be here with my life than be like, "Oh, my God, he has the trait, let's not have kids!" I'd rather be here than not be here. You're here because somebody gave you a chance. I wouldn't want nobody to think I'm selfish. Like, "Wow, that's really selfish of you knowing that your child could have this disorder but you still want to have kids." And people who impose their opinions and judgments on us [people with sickle cell disease], I don't think that's right. So, regardless if I have sickle cell or not, it's just a blessing to be here. I don't look at sickle cell disease like, "Oh, my God, it's just the worst thing ever."

Yvonne viewed having a child with sickle cell disease differently than her mother. While Yvonne did not intend to have a child with sickle cell disease, she stated she would not allow this possibility to deter her reproductive desires. Yvonne anticipated she would face social scrutiny and moral judgment if and when she should she have a child with sickle cell disease. She felt somewhat guilty for wanting her own children, regardless of whether they have sickle cell

disease or not. Yvonne based her desires for a biological child on her own gratitude for having the “chance” at life—even with sickle cell disease.

### *The Strength of the Discouraging Reproductive Message*

As the above narratives illustrate, the message that women “shouldn’t have children” arises from a variety of important sources—physicians, parents, and other close family members. It is so commonplace during participants’ upbringing that it colors their reproductive decision-making. This message not only influenced some women (N=3) to forgo having biological children, it also influenced women to express a sense of relief over a spontaneous miscarriage (N=1) or consider terminating their pregnancy (N=2). Jewel, a 41 year-old mother of four, highlighted how being told that she should not have children influenced her immediate reaction to her first pregnancy and while she had originally believed this to be true, an unplanned pregnancy caused her to realize the myth behind the message.

I found out that I was pregnant and it was a scary feeling. I wanted to get an abortion because I knew the stories about people with sickle cell having kids. They would say you’re not supposed to have kids when you got sickle cell. [*PR: Who told you that?*] That’s what I remember hearing as a kid when it came to sickle cell, [that] I’m not supposed to have kids. It’s one of the things that you’re not supposed to do. My [older] cousin [who also has sickle cell disease] didn’t have any [kids] and a lot of people I know with sickle cell disease don’t have kids. Even when I go down to the Sickle Cell Center, I hardly ever see anybody come to the clinic with kids. [*PR: How did you decide you weren’t going to have an abortion? That you were going to have the baby?*] I never got the money to get rid of it. Actually I had no choice but to have it at that point. After so long it was just too late to do anything. [*PR: How did you feel after you gave birth to your first son?*] I felt like a lot of things they say about sickle cell is a myth because I know a lot of people with sickle cell that don’t have any kids, none whatsoever, and want kids, wish they had kids. So I feel like I’m blessed.

Unfortunately, Jewel did not realize the rumor she had heard was not true until after she had her first child. While Jewel did not explicitly state the meaning she gave to hearing that she should

not have children, she internalized this information by seeking termination because of this message. Ultimately, because of the lack of financial support from the father of the baby, Jewel was unable to have the initially desired abortion.

### *Summary*

Twelve women received the discouraging reproductive message concerning genetic transmission. These findings mirror existing literature that has found that women with disabilities have reported that their mothering rights have been denied through subtle discouragement by doctors, professionals, and family members due to the assumption that they will give birth to more disabled individuals (Kallianes and Rubenfield 1997, Romano 1982). As a social body, there is a collective interest in ensuring the future health of society, which makes the issue of reproduction and more specifically the connection between genetic disease and reproduction a matter of importance.

In this study, participants received two separate messages aimed at preventing them from having a child with sickle cell disease. The implicit message was to avoid having a partner with sickle cell disease and the explicit message was to avoid having a child with sickle cell disease at all costs. Eight of the participants agreed with either of the two messages and four women agreed with both messages about avoiding genetic transmission. More women in this study agreed with the explicit message mainly due to their embodied experiences living with the condition and their desire to avoid subjecting another person to their own experience. These participants illustrated that even agreeing with this message was a form of reproductive agency in that they adopted specific strategies to ensure they did not have a child with sickle cell disease.



Two participants, neither of them had children, opposed this message and contended that while sickle cell disease is difficult to live with it was not a horrible fate.

### **Message: Women with Sickle Cell Disease Can't Have Children**

Four women in the study were told they could not have children as a result of having sickle cell disease. Rather than being told they should not have children, which suggests a moral decision, the message that they are unable to have children is suggestive of a physical inability.

#### *I Believed Them*

Only one participant, Ivy, a 27-year-old mother of three, initially believed the misinformation about her ability to bear children.

I was always told because I had sickle cell I couldn't have children so I was kind of confused in the beginning [of her first pregnancy] because I thought I couldn't have children. [PR: *Who told you that?*] My grandmother told me that and I remember while we were at my appointment at [Hospital], the same nurse who used to give me information, she also told me there was a chance that I would not be able to have children. They were wrong. [PR: *How did you feel when you realized you were pregnant?*] I was more nervous than excited. [PR: *About what?*] Just about everything because I really thought I couldn't have children so it was more what is going to happen? [PR: *Before your first pregnancy, was there any reason why you weren't on birth control?*] I was always told I couldn't have kids so there was no need for me to be on birth control. [PR: *Any other reason?*] No. I was told I couldn't have children so I never even thought about birth control, that's the only reason.

Ivy was the only person in her family with sickle cell disease and her grandmother was unfamiliar with the condition and depended on health care providers to educate her on how to care for Ivy. Having received this misinformation from her grandmother, who raised her as well as a health care provider, Ivy initially believed she was unable to have children and therefore did

not use birth control. Since this was her first pregnancy, she was confused and nervous after realizing she was pregnant, which hindered her ability to be excited about her pregnancy.

*I Knew That Was Horse-Monkey*

Unlike Ivy, who did not realize she could have children until she became pregnant, three women in the study rejected the message that they could not have children. As women with a physically-imposing condition, they had some doubt whether or not they were physically capable of becoming pregnant or bearing a child. Hope, a 25 year-old woman, was told by her mother that women with sickle cell disease could not have children.

I wish she [her mother] had of talked to me about pregnancy instead of telling me that sickle cell patients can't have kids. [She told me] that I can't have kids because I have sickle cell. That's what she told me. Instead of telling me that, I wish she had talked to me in a sensible way, like, "Well, you can have kids. It's fine to have kids." Instead of me going to my doctor and asking my doctor, "Well, is it alright for me to have kids and what will happen if I have kids?" I had to get it from my doctor. My mom should have told me all the information that Dr. [hematologist] told me. I dropped the subject and I never brung [*sic*] it up again until when I had got pregnant with my son. [*PR: What did she say when you told her?*] She was like, "Okay. Are you sure you want to have the baby?" And you know, she just asked me stupid questions at the time, but I said, "Yeah." Then she just dropped the subject.

Hope had also been given misinformation about her reproductive capabilities as a woman with sickle cell disease. Because she desired to have children, she decided to confirm this information with her hematologist. Young African American women often look to their mothers as reliable sources of information about reproduction and reproductive health care (Warren-Jeanpiere 2006). However for many parents of children with sickle cell disease, they do not always share the embodied experience of sickle cell disease (most have sickle cell trait) and thus may not possess the sought after information or a comprehensive understanding of reproductive abilities or limitations. While the intent of Hope's mother's message is unclear, even after

receiving clearance from the hematologist, her mother continued to question her decision to continue with the pregnancy perhaps out of an underlying concern of her health.

For these three women, knowing another woman with sickle cell disease who had children served to counter the message that they physically incapable of having children. Gwen indicated, “I know TBOZ from TLC<sup>11</sup> got sickle cell and she got kids.” Pearl’s mother also had sickle cell disease, not trait, which provided her with evidence to counter the message that she could not have children.

All the time I heard we couldn’t, not shouldn’t. I heard we could not. [*PR: From who?*] It didn’t matter. My mother had sickle cell disease so I knew they [people who said she couldn’t have children] didn’t know what they were talking about. I heard it from just people in general and people in the medical profession. I heard a lot of nurses say, “I thought sickle cell people couldn’t have kids.” So I didn’t hear “shouldn’t,” I heard “you could not.” But there wouldn’t be all these people out here with sickle cell if that was the truth, so I knew that was horse-monkey.

In addition to hearing from laypeople that women with sickle cell disease could not have children, Pearl heard this message from health care professionals. However, unlike most other women in the study whose mothers had sickle cell trait, Pearl’s mother had sickle cell disease, which provided her with the evidence that what she was being told was untrue.

Katrina, a 30 year-old mother, had another female family member with sickle cell disease who had given birth.

I have one cousin, she’s in her forties and she does have two kids. Other than that I’ve never talked to anyone until I was pregnant and it was a nurse who assisted me and she was like, “You’re going to get through this. You’re going to be fine.” She had sickle cell and she was like, “I didn’t think I could have kids so I adopted and then I had three of my own.” That really encouraged me.

Katrina’s conversation with another mother with sickle cell disease offered her reassurance about her own pregnancy. The women above illustrate that believing the message caused them to 1) not use contraception and 2) contemplate adoption. Yet, knowing another woman who had

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<sup>11</sup> TLC is a well-known R&B group.

already gone through the experience served as a source of social support. Researchers have specifically advocated social support interventions for individuals with sickle cell disease based on the observation that ethnic minorities tend to rely more on respected lay-persons for health information than medical professionals (Holmes, Hatch and Robinson 1991).

### *Summary*

Only a few women in the study had been told they were unable to bear biological children because they had sickle cell disease. One woman believed this message to be true because it came from two trusted sources—her health care provider and her grandmother. For the other women who were given this message, having personal knowledge seemed to help them disregard the misinformation they received, give them the power to overcome fear and doubt, and pursue their desire of having children. While this message was based on misinformation, even among health care providers, it illustrates how women must be able to validate the information they are given, regardless of the source.

### **Conclusion**

This chapter illustrates the multiple discouraging reproductive messages participants received as well as their resistance to or accommodation of the message and a range of agentic responses. This chapter also highlights the complexity of the discouraging messages in that they were delivered at varying stages of reproduction, from multiple sources and for different reasons. Some participants received multiple discouraging messages throughout their reproductive lives—from the time they reached reproductive age until their mid- to late-thirties.

The fourteen women in the study who were discouraged from having a biological child due to concerns for their health were also among those who experienced more pain requiring hospitalization during the past 12 months. At the time of the interview, only two of these women decided they were unwilling to risk their own lives to have biological children. Participants were physically unable to ignore having sickle cell disease, as they often experienced symptoms, thus instead of being influenced by the advice or guidance of others, participants used their embodied knowledge of living with sickle cell disease to determine whether or not to have children.

Eight of the women without children indicated their plans to have children in the future because they were unwilling to sacrifice the experience of giving birth and having a child. Aja explained this by saying,

I've been told that I could harvest my eggs but then I was told that there was not a guarantee that they would survive the freezing, nor can I afford to do it. And that if I do a bone marrow transplant, chances are that I won't be able to have kids at all, so I decided to at least having a baby first and then do it. Because I feel like I give up so much being sick, but that's the one thing that I'm not willing to give up.

Women in this study were not as concerned about the fatality associated with pregnancy and childbirth as they were about passing sickle cell disease on to their children. Six of the seven women in the study who were told they should not partner with someone with sickle cell trait or disease used this message to influence their relationship formation and choose their partners accordingly. Six of the nine women who were told not to have a child with sickle cell disease agreed with that message and were diligent in ensuring this did not happen. Of the eleven women who received either of the discouraging genetic messages, seven were the only member of their family with sickle cell disease. Thus, participants were willing to be selective in their reproductive partners in an effort to avoid having a child with sickle cell disease—even to the point of avoiding dating men who had sickle cell trait or disease altogether. Whether

warnings about the potential risk to their lives originated from a close family member or from a provider, most all women in this study were determined to have children if they desired them. Interestingly, women in the study were occasionally unable to identify the specific source of their discouraging reproductive message and simply stated that a generic “I heard it” or “they said,” which suggests the normative nature of these messages.

Sickle cell disease is an illness with very unpredictable symptoms and for these women reproduction was one aspect of their lives that many felt they could control. This attitude is reflective of Rotter’s idea of locus of control that refers to the degree to which people perceive that the outcomes of the situations they experience are under their control (1966). This control is influenced by either the effort one exhausts or environmental forces that are beyond one’s control (Rotter 1966). Thus some participants believed their decisions whether or not to have a child and whether or not they would have a child with or without sickle cell disease was within their control; however their survival of pregnancy and childbirth was not a situation in which they had as much control. Some participants also expressed spiritual locus of control, which reflects the belief that a higher power has control over one’s health outcomes (Debnam et al. 2012). The type of spiritual locus of control described by some participants in this study favors the passive dimension and consists of a belief that, because only a higher power is in control of health outcomes, there is no reason to engage in health promoting behaviors (rather than the active dimension which suggests that a higher power affords an individual to be empowered about health behavior or collaborate with a higher power to stay in good health) (Debnam et al. 2012).

Only four participants were told that they were incapable of having children and they soon realized this to be misinformation, either from a personal experience knowing a woman

with sickle cell disease or by inquiring about their reproductive capacity with a medical professional. Nonetheless, as Ivy illustrated, this message has the potential to place women at risk for unplanned or unwanted pregnancies.

Women in the study were particularly vulnerable to the influence of others through the power of discouraging messages. Suggesting that participants should not have children suggests an ideal outcome and the expectation that these women will make “responsible” choices by foregoing childbearing or limiting their intimate relationships with men who had sickle cell disease or trait. Several women had medical comorbidities in addition to sickle cell disease (e.g., heart disease, kidney disease, acute chest syndrome, etc.), which further encouraged family members and providers to question their ability to physically endure pregnancy and childbirth. Some even were told that they were incapable of having children. Women’s reproductive decisions could be affected in various ways, depending on the strength and source of message.

Most participants resisted the discouraging messages they received at least in part and exercised agency in pursuing their reproductive desires in varying ways. Importantly, the agentic responses of women in this study were sometimes in opposition to the message and in other times their response was in agreement to the message. Hollander and Einwohner (2004) suggested that resistance takes a variety of forms ranging from overt to none at all. The everyday resistance behavior participants exhibited was intended to claim power over their reproductive lives (e.g. seeking medical expertise and becoming informed about their reproductive capabilities from alternative sources) and illustrates the agency women were able to exercise in their own reproductive decision-making (Hollander and Einwohner 2004). This chapter also illustrates that decisions regarding reproduction are not always definitive. While at one stage of life or health status, a woman may resist the message to have children but at another

stage she may be more amenable to the messages. Five participants were not discouraged from having biological children for any reason. While it is difficult to explain why family members, providers or others did not discourage them all women in this study, health status, cultural or religious background, and educational level could affect message transmission. For instance, Clem and Chloe had few symptoms and sickle cell disease may not have been a concern for their families. On the other hand, Dana was from Ghana, and perhaps discouraging women from reproducing is not culturally acceptable. Throughout her interview Aja also indicated that her family was not educated about sickle cell disease and she was not always comfortable talking about sexuality with her providers. Aja also noted that in her religious family, it was more important that childbearing occur within the sanctity of marriage than whether childbearing should be affected by sickle cell status.

This chapter specifically addressed participants' reports of discouraging reproductive messages and their agency in the face of these messages. In the next chapter I will describe how participants arrived at reproductive decisions based on their genetic identities and the internalization of these discouraging messages when confronting genetic testing.



**Table 6.** Participants' Responses to Discouraging Reproductive Messages

Participant	Did Not Receive A Discouraging Message N=5	Shouldn't Have Children Messages			Couldn't Have Children Message N=4
		Do Not Have Children, It's Too Dangerous N=14	Do Not Reproduce with a Partner with SCD or SCT N=7	Do Not Have a Child with SCD N=9	
Jada		X	X	X	
Joyce		X	X	X	
Nia		X	X	X	
Sophia		X	X		
Mya		X		X	
Gwen		X		X	
Ebony		X			
Faith		X			
Jewel		X			
Verlean		X			
Lynn		X			
Sydney		X			
Zora		X			
Tia		X			
Imani			X	X	
Yvonne			X	X	
Gabrielle			X		
Gina				X	
Raven				X	
Hope					X
Ivy					X
Katrina					X
Pearl					X
Aja	X				
Clem	X				
Chloe	X				
Dana	X				
Vivian	X				

## CHAPTER 6

### REPRODUCTIVE DECISIONS AND BEHAVIOR

*They wanted to do an amniocentesis on me to see if [her son] was going to have sickle cell disease or not and I'm like, "No. I'll wait until I have him to find out. It ain't that serious to me to know if he got sickle cell." ~Raven*

In the last chapter I indicated that nearly all of the women in the study exercised agency to pursue their reproductive desires. This chapter describes participants' perceptions and motivations regarding genetic-related reproductive decisions. Although reproduction is not a gendered experience, as the bearers of children, women are often considered the carriers of heredity, good or bad, placing more of the reproductive burden on them. Also, having a genetic illness placed an additional burden on participants not only to disclose their condition to potential reproductive partners but also to inquire about their genetic status as well.

Genetic testing is a technique used to identify a particular genotype. It may be offered to individuals on the basis of ethnicity, family history suggestive of a genetic disorder, presentation of symptoms suggestive of a genetic disorder, and existence of a disease with known genetic components (Natowicz and Alper 1991). Prenatal testing is performed to detect any abnormalities that are suspected because of (1) advanced maternal age, (2) previous pregnancy that resulted in the birth of a chromosomally abnormal child, (3) parent known to have or carry a chromosomal abnormality, (4) a family history of chromosomal abnormality, (5) history of three or more miscarriages, and (6) previous children (with multiple malformations on whom chromosomal analysis were not conducted) (Abram et al. 1983: p. 4). Thus genetic and prenatal testing are methods of gathering medical knowledge about reproductive partners and "unique" pregnancies and are presented as part of standard prenatal care alongside other measures

pregnant women take to protect their unborn child, such as seeing a health care provider, taking prenatal vitamins, and even stopping unhealthy behaviors.

In the following sections I describe participants' motivations for asking their partners to be tested, their own decisions whether or not to undergo prenatal testing, and how responsibility for genetic testing remains a gendered burden.

### **Why I Asked My Partner to Undergo Genetic Testing<sup>12</sup>**

As indicated in Chapter Two, women with sickle cell disease have a 50% probability of transmitting sickle cell disease to their children if their partner has sickle cell trait, and a 100% probability of transmitting the disease to a child if their partner has sickle cell disease (Platt and Sacerdote 2006). When one parent has the disease and the other parent has normal hemoglobin, all children born by that couple will have sickle cell trait (Platt and Sacerdote 2006). Given these facts, participants reported that determining whether partners were carriers of the sickle cell trait was an important element in their reproductive decision-making.

Twenty-two women in the study asked their partners to be tested; of these, nineteen partners agreed but three refused to be tested (See Table 7). Six participants had not been in a relationship serious enough to warrant a conversation about genetic testing. Participants described three key stages of reproduction in which they asked their partners to be tested: before intimacy, before pregnancy, and after pregnancy.

As discussed in Chapter Five, most women in this study had a clear understanding of the implications of reproducing with a partner with sickle cell trait, which strongly influenced their decisions to ask their partners to be tested. Nearly all of the women in the study (N=22) thought

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<sup>12</sup> In wider society, people often use the terms genetic counseling and genetic testing synonymously. However, this dissertation specifically refers to testing – in which an actual procedure is performed.

getting their partners tested was important enough to ask them to do so because of their embodied experience living with sickle cell disease (and the need to prevent children from living with the same experience), however not all participants identified the same sources of motivation for asking their partners to be tested. For instance, eight did not want their child to suffer the way they had. Another eight were motivated by their father's lack of awareness of his sickle cell trait status. Six were motivated due to a previous experience with an unplanned pregnancy with an untested partner. Most of the partners mentioned in this study had not been previously tested before being asked by a participant. In the few instances where partners said they had been tested already, women in the study (e.g., Aja and Nia) wanted them to be re-tested to confirm they were not carriers of the sickle cell trait.

### *I Don't Want My Child to Suffer Like Me*

Although pain is the hallmark of sickle cell disease, individuals with this condition are impacted socially, financially, and psychologically, greatly influencing their overall quality of life. Therefore over one-third (N=8) of the women I interviewed indicated that their motivation for asking partners to undergo genetic testing was to prevent having a child who would suffer from the disease as they had.

Zora, a 37 year-old mother of two, had experienced numerous health problems brought on by sickle cell disease including a coma, brain damage, temporary memory loss, and nine grand mal seizures. She admitted having moments in her life when she wanted to "give up."

He [her husband] was everything I had asked God for. I made sure Dr. [hematologist] met him and she got him tested, when we got engaged. She took his blood and he didn't have the trait. It was important that my husband was tested because I wouldn't want to see a child go through a lot of the suffering that I went through. You see, a lot of the suffering is not just physical, it's emotional, and it's spiritual because I had times I wanted to just give up. One thing I would

have done, if [her husband] would have had the trait, I would not have had a child by him and both of us had already discussed that actually. My mother and my father didn't even know they had the trait and when they found out I had the disease it really hurt them.

Zora was currently married and emphasized the importance of having her husband tested because she didn't want to bring a child into the world who would experience the same suffering. Not only did Zora ask her husband to be tested, but she also facilitated the testing with her hematologist. Additionally, Zora pointed to the hurt her parents felt for having a child with sickle cell disease and she did not want to experience that same feeling. So having her partner tested was a strategy for protecting her child from suffering as well as protecting herself from guilt. Both her parents lacked the embodied experience of sickle cell disease as asymptomatic carriers of the sickle cell trait. Zora also highlighted that the suffering is not limited to the physical symptoms and includes emotional as well as spiritual aspects. Having this disease was a burden she carried throughout her life and fueled her motivation for having her husband tested to discover his sickle cell trait status. This perspective influenced her reproductive decision-making so much so that she indicated her willingness to forgo having children if her husband would have had the trait.

Faith, a 19 year-old woman, described having sickle cell disease as being as "hard as ever" and was motivated to ask her boyfriend of two years to be tested specifically by her ongoing experience living with chronic pain.

I just asked him [her boyfriend] just straight up if he had sickle cell trait because I got it and I don't want no kids with it. I wouldn't want them to go through that. [PR: *Go through what?*] Just having pain like I have, constantly, every day, chronic. That's harsh right there. A child shouldn't go through that. [PR: *You went through it and you're surviving.*] Yeah, I have it, but it's not like I had a choice. If I had a choice, I wouldn't want to go through it. [PR: *How did testing come up?*] How does that come up? I just asked [her boyfriend] if he had the trait because I want kids later on and he said he didn't have it and I told him the next time you go to the doctor to make sure and he did and he doesn't have it.

She was very direct about asking her boyfriend to be tested and considered part of her role as a woman with sickle cell disease. Faith saw having a child with or without sickle cell disease as an outcome she could control and prevent. She reported being able to “handle” her own condition because she had no choice but to deal with it. However she vowed not to recreate the same suffering in her own child.

Aja, a 30 year-old single woman, also recounted a conversation with her current boyfriend about genetic testing. She informed him that she wanted him to be tested and provided additional contextual information to support her position.

I said, “I just want to let you know that if we were to ever have children that you would have to get tested first because we want to make sure that we aren’t going to pass this disease on to our children.” I said, “I won’t have that.” When you look into the future, you don’t want to pass this disease on. I feel like people don’t realize how bad it is. Talking about it can only tell you how bad it is, but until you live it... I would never want my child to live this disease and to live the life that I have lived. I know times are changing, but they’re not changing fast enough. I have been stereotyped. I have been looked at as a drug-seeking fool. I have sat in pain for hours waiting for treatment. I have been literally poked, prodded, had everything stuck in me, shoved up me, and shoved down me. I would not wish this on my children. If anything, I would adopt before I gave this [sickle cell disease] to a child. [PR: *Why do you think you’re stereotyped?*] It’s hard to say because sickle cell affects predominately Black people and it’s predominately seen in Black people in the United States. So, it’s hard to separate the two [being Black and having sickle cell disease].

For Aja, her future reproduction with her boyfriend was contingent on him getting tested. This was the first person she had asked to be tested because, prior to this relationship, she “never felt I was going to marry anyone or that I wanted to marry anyone.” Aja held firm beliefs that childbearing should only occur within marriage. She also indicated her motivation for asking him to be tested was not only to avoid passing the disease on, but also to avoid the social judgments, stereotyping, and poor medical treatment she had experienced from having this condition. Aja also emphasized the mental work that goes into having sickle cell disease, and stated that

“everything you do, every thought that goes into your day...goes into dealing with it.” For Aja, the sheer weight of sickle cell disease symptoms made having her partner tested very important to her.

Similar to Zora, Aja described her experience having sickle cell disease as an all-encompassing condition. Aja talked about not only having pain (i.e., the physical symptoms) but also the embodiment of sickle cell disease. That is, living with this disease meant that Aja was forced to deal with questionable care, poor medical interactions with providers, countless procedures, and drug stereotypes. Having to navigate all of the everyday experiences she suggests occur because she is living with a disease that is debilitating, life-threatening, invisible, not completely understood, and racially marked is not something she would wish on someone else. To both Faith and Aja, asking their partners to be tested was an agentic strategy to prevent having a child with sickle cell disease who would also have similar physical and social experiences.

### *Daddy Didn't Know He Had It*

Nearly one-third<sup>13</sup> (N=8) of the participants indicated that their motivation for determining their partner's sickle cell trait status was because while their mother was aware of her disease or trait status, “Daddy didn't know he had it.” For instance, Nia's mother knew she had sickle cell disease but her father did not know he had the sickle cell trait until her mother was five months pregnant with her.

I was so proactive about [partner testing] because my father told my mom that he didn't have it. She found out [my father had sickle cell trait] when she was five months with me that he did have it when he ended up getting surgery for his foot. She knew she had sickle cell disease, but all that time she thought that he didn't have it. That's why I was so proactive about [my boyfriend] getting tested. That

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<sup>13</sup> This includes women who favored genetic testing, yet had not had the opportunity to ask a partner to be tested.

was more secure for me to know considering that she believed what he said, but he had the trait. So that's why. Some people don't know until it's too late and you can't do nothing about it at that point. That's why I think it's so important for me. [PR: *How did that conversation go?*] Just one day we were talking about it and I said, "I would like for you to go get tested just to see if you have a trait." I had to explain to him why and since I have the full blown anemia, of course the kids are going to have the trait. He did get tested [and] it came back that he didn't have anything. Dr. [hematologist] actually wants to test him again just to make sure.

Nia made it clear that she was being proactive by asking her boyfriend to be tested, before it was "too late." She specifically attributed her request to her father's unawareness of his sickle cell carrier status. Nia also believed that testing was the only reliable way to make sure the pattern (and result) of her parents was not repeated with her and her boyfriend. She was determined to make sure that what happened to her mother did not happen to her. Her hematologist also wanted to re-test Nia's boyfriend to confirm his negative test result. Nia's story emphasizes the layered emotions that are experienced by a woman in this situation: empathy (toward her parents' situation years ago), hope (that the test results were accurate and that children free from sickle cell disease were possible), worry (not to pass on disease), and courage (to live with the disease and pain).

Joyce explained a similar situation, in which her mother was aware, but her father was unaware, of their status. Knowing of her parents' experiences and the consequences, Joyce was motivated to ask her sexual partners to be tested.

My mother knew that she had the trait and she asked my father, he didn't know he had the trait. Then when I came out with sickle cell disease, he found out [he had sickle cell trait] and that plays into him feeling really guilty about me. He feels terrible about it. My mother, my father, my doctors, we talk about how it happened. I'm not having a child with sickle cell anemia. So if you want to have sex with me there are things that you are going to have to do. That's why both people that I have had sexual relationships with have been tested because I don't go into that situation not knowing like my mother. I'm not like females who say, "Well, he said... Oh, he didn't want to wear a condom because it was uncomfortable." I say, "Oh, well, then you don't really want to have sex with



me.” That’s the same way that I feel about getting [my partners] tested. My mother went on “He said,” which I don’t blame her for. Because back then it really wasn’t as much knowledge. It’s 2012 and you can go get a blood test for anything that you would like to get a blood test for. They [her partners] weren’t jumping at the idea, but when I said, “If you really want to have sex, you’ll do what is necessary.” They need to have the blood test because I’m adamant about why bring a child into the world who is going to have health problems? I’m not just talking about a cold. I’m talking about strokes and serious things. It’s preventable.

Knowing that her father was unaware of his sickle cell trait status made Joyce very adamant about having her sexual partners tested for sickle cell trait prior to intercourse. Like Nia, Joyce was unwilling to go on “He said”—trusting their partners who said they were not carriers of sickle cell trait—without confirmation. Joyce’s narrative suggests that she did not feel as though her parents were behaving irresponsibly; rather, she attributed her father’s lack of testing to the scarcity of the necessary information and technology that would have aided their decision-making at that time. Joyce believed that with modern medical advancements there is no reason why her partners cannot get tested. She feared carrying the guilt of having a child with sickle cell disease, the way her father had for all these years, if she failed to confirm her partner’s trait status. According to Joyce, genetic testing is inherently linked to reproductive health. She compared her requirement that her sexual partners were tested to her stipulation that her sexual partners wear condoms, drawing clear connections between genetic testing and condom use in describing responsible sexual behavior.

Jada had also been told that her father was unaware of his trait status before she was born, yet her mother was aware of her status.

My mom knew she had the trait, but my dad didn’t know anything until I was born. Then it was too late. I tell my mom and dad this all the time and not just if I get mad to my breaking point I’m like, “You guys were just reckless. Like nobody knew nothing?” So I made sure my boyfriend got tested. To me it’s an easy cure to this, get your partner checked beforehand. That’s just the easiest way to me to stop sickle cell. Because in my mind that’s just disastrous and reckless.

Because you don't bring a child in the world [to] have to deal with the same thing you're going through already. That makes no sense to me. That makes no sense at all. It's perfectly fine with me if they have the trait. Now that leaves it up to me to educate them, like, "Don't go and be stupid and have sex with somebody that has the trait or sickle cell and risk getting pregnant, or getting someone pregnant, and now you're carrying a baby with sickle cell disease." I don't believe in abortion. I just don't, but I couldn't imagine bringing a child in this world to have this stupid disease.

For Jada, the importance of partner testing before conception was further reinforced via a game she described developed by the Director of the local Sickle Cell Disease Association of America (SCDAA) chapter, comparing reproduction without being tested as a roll of the dice.

Dr. [hematologist] made up this game with cubes with the different types of sickle cell on them and told the kids [at the SCDAA], "Go ahead take a pair of dice and roll them and see what you get." The majority of them got a baby with sickle cell disease because they didn't have their partner tested. That was very important to me because I get so sick and tired of seeing these little kids have strokes and heart attacks and this and that because of sickle cell. It's just like, "Let them have a normal life!"

Much of Jada's motivation for partner testing came from having the embodied experience of living with sickle cell disease symptoms as well. Like Joyce and Nia, Jada also attributed having sickle cell disease to her father's lack of knowledge of his carrier status. Knowing about their fathers' lack of awareness of trait status and their mothers' not insisting their fathers be tested served as a source of motivation for participants to be absolutely certain about their partners' sickle cell status. She also discussed the burden she had of educating her own children, who would have sickle cell trait, about inquiring about their own reproductive partner's status. Interestingly, similar to the participants whose fathers were unaware of their sickle cell trait status, an equal number of participants indicated *neither* of their parents knew they were carriers of sickle cell trait. In the latter scenario, participants did not express the same motivation for asking their partners to be tested. Also, in some cases (for example and Jada), both not wanting their children to experience the symptoms and their father's lack of awareness served as

motivation, thus these categories are not mutually exclusive. Blaming of their fathers for not knowing their sickle cell status and viewing their mothers not as proactive as they should have been is also a gendered perspective in that this suggests that women have a responsibility, more so than men to confirm their partner's status.

Joyce, Nia and Jada parents were all divorced and held their mothers in higher regard than their fathers. Also, they described very open and detailed conversations with family members and providers about how they came to have sickle cell disease. In Nia's narrative it is clear that she and her mother placed blame on her father for being unaware of his sickle cell status. As bearers of children, women experience a gendered burden in regards to reproduction. These women also expressed that the lived experience of sickle cell disease is also a burden. Thus these women experienced a third burden-to ensure their partners are tested. In carrying out the gendered responsibility of getting their partners tested, some women in my sample were also empowered to take control of their reproductive lives. Perhaps because sickle cell disease is such an unpredictable, uncontrollable, and difficult illness, these women were aware of the need to control the transmission of the disease many approached their partners in a very specific and direct manner. These women felt responsible not only for themselves, but also for their partners and potential children; some of these women took this responsibility very seriously.

In their attempt to understand their parents' lack of knowledge about genetic transmission, many participants referenced a lack of technology, awareness, or knowledge about sickle cell screenings within earlier generations and their parents' age groups. Some parents did not know or understand genetic testing, and believed access to testing was limited. In addition, during the time when participants' parents would have come of age—approximately 30-35 years ago—early genetic screening programs had just been launched, having begun in 1972 (Markel

1992). At the time when genetic screening programs were launched, tests unfortunately fueled racial prejudice and discrimination by simply reiterating that the largest prevalence of sickle cell trait resided among African-Americans (Markel 1992). This race-based context may have initially minimized parents' interests in or understanding of the value of genetic testing. It may be that women may be able to convince their partners to undergo genetic testing now that there is less stigma and more understanding attached to sickle cell trait.

Asking their partners to be tested was a form of reproductive agency participants used to ensure their children would not have sickle cell disease. Women in the study recognized that their actions could be the difference between their children having the trait or having the disease. Among people with sickle cell disease, having the trait is considered as a far less serious condition and was reportedly acceptable for participants. For instance women in the study often referred to it as "just trait" rather than the "full blown" disease. Having a child with the disease was a much more serious issue and cause for concern in their minds. As women with the disease, they make reproductive decisions within the context of their experience living with the disease. This behavior illustrates the ways in which mothering begins even before conception, as participants looked at their behavior as a method of protecting their children, not only once conceived but even prior to conception.

### *Learning from Unplanned Pregnancies*

Six participants indicated becoming more proactive about asking partners to be tested after having an unplanned pregnancy in which the father of the baby had not been tested for sickle cell trait before conception. It was not until after Sophia became pregnant did she ask her fiancé about his sickle cell status and took him to the Sickle Cell Disease Association of America

(SCDAA) to be tested.

He [her fiancé] was tested. I took him to the detection center. I was like, “Come on, let's go.” I had known him since high school and he would go with me to the different events that the Sickle Cell Center would have. It was funny, because he was like, “I want to see. I asked my mother and she said she didn't know.” I'm like, “Really? Come on, I got to volunteer at the Sickle Cell Center anyway, you know, you can get tested.” His [test] came out that he had the trait. We both looked at each other, and he's like, “Wow,” and I'm like, “Oh, no.” [PR: *Oh no, what?*] The reason why I was saying “Oh, no” is if he has the trait and I have the disease, that brings a higher percentage of the child, you know, the probability of the child having it. That was my fear and after I lost the baby I had to break it off. He didn't understand that.

Sophia was pregnant at the time she asked her fiancé about his status and discovered he was a carrier. Because of her work at the SCDAA she was surprised that her fiancé and his mother were unaware of his status. Until this point, although she had known him since high school, she had not discussed the implications of carrier status with her fiancé. Nearly having a baby with sickle cell disease caused Sophia to give serious thought to the consequences. After she lost the baby she became adamant about not having children with this partner.

Pearl's first pregnancy ended in a miscarriage when she was 19 years old. Similar to Sophia, Pearl's first pregnancy was with a man whom she was unaware was a carrier of the sickle cell trait. She decided to dissolve the relationship once it was revealed he was a carrier of sickle cell trait.

Actually what he [father of the baby] didn't know, and never did find out, and is the reason why I let that [the relationship] die off, is I found out that he had the trait. [PR: *How did you find that out?*] His mother told it. I was in the hospital and she said, “You know, [the father of the baby] has the trait.” And I said, “Huh?!” She said, “Yeah, but he never had to go to the hospital. What's yours doing?” I said, “I don't have the trait, I have the full-blown disease.” We got into the explanation of what's going on with me, she said, “I remember when he was young and they told me he had the trait I didn't know what that was.” I was like, “Oh, okay.” I slowly pushed that guy away. [PR: *Why did you do that?*] I never wanted to get so serious, married, and have a kid that went through what I went through. You know what I mean? I know what it feels like to sit there and have to get poked over and over again by somebody who missed your veins.

In this case, her boyfriend was either unaware of his trait status or had not disclosed this information to Pearl. Upon learning of his status from his mother and based on the embodiment of the symptoms, she realized that she could not be responsible for someone else experiencing what she has been through. This story shows the additional burden that accompanies the lived experience with disease symptoms that her boyfriend did not possess as an asymptomatic carrier. This is another example of the gendered burden of relationship formation and dissolution in that Pearl's relationship formation was centered on her ability to identify a partner who did not have sickle cell disease or a carrier of the sickle cell trait and if he did to end that relationship. Taking what she learned from this experience, Pearl was proactive and made sure her future partners were tested to determine whether they were a carrier of the sickle cell trait.

Me and my dudes take two tests. We take the AIDS test when we're first getting to know each other and then as it's progressing you take another one before you get next to me and you also take a sickle cell test too. So in case something happens and I'm going to have kids or anything like that I didn't want the babies to be born with sickle cell. So he [her son] actually has C Trait, he doesn't really have S in him at all and it's because his father has nothing. I'm real careful about that. I don't think we have the luxury of an "Oops" because an oops is what caused me the trauma that I have.

Through her purposeful action, Pearl was successful in finding a partner without the trait. She was proud of her success in having her partner tested and ensuring her future children would be as healthy as possible.

Nearly twenty years later, Pearl was pregnant again and was questioned by her providers about her partner's sickle cell status during her initial prenatal visit.

That was the first thing they asked me and I let them know he [the father of the baby] didn't have it. [PR: *Who asked you?*] The specialist, OB/GYN said, "Did my partner have the trait?" and "When the baby comes out they're going to test him to see to see if he has sickle cell." I let them know that, no, he didn't. I let them know that I had him tested before then. They were like, "Oh, that's really smart." I'm like, "That's common sense."

Although her second pregnancy was unplanned, the father of the baby had already been tested and was not a carrier of sickle cell trait. Pearl's response indicated she was offended by the suggestion that she may not have realized that getting her partner tested was the "smart" thing to do. Pearl's interaction with her provider suggests an awareness of the reproductive burden women with sickle cell disease possess—having to ask their partners to undergo testing. However in this case, her provider appeared not to acknowledge that Pearl would have been responsible enough to already have asked her partner to be tested before becoming pregnant.

Pearl and Sophia illustrate the reproductive burden these women have in that they must make important reproductive decisions often independently based on what they feel is best for the future of their children. Both women experienced an initial pregnancy with a partner who had not been tested beforehand and they later realized the implications this could have on their children. These experiences provided the opportunity for them to give more thought into their future decision-making and did much to shape their reproductive and sexual lives. Additionally, both Sophia and Pearl give examples of a gendered burden in that their partners were carriers of the sickle cell trait and either did not share this information or had not been tested even though they were in intimate relationships with women with sickle cell disease. In Sophia's case she shouldered the entire burden by even physically taking her fiancé to be tested at the SCDA testing site.

Like the participants above, Jewel's first pregnancy was unplanned and she was unaware of the father of the baby's sickle cell trait status.

They [fathers of her children] had been tested. Now the first baby father, I didn't know if he had sickle cell or not. I didn't know. But [the second child's father], I asked him when we got really serious in the relationship. I asked him did he have sickle cell or sickle cell trait? Was he normal? He went and asked his mother and his mother said he didn't have anything, but I wanted him to get tested anyway

because she [his mother] had one kid with the trait and everybody else was normal. He didn't have it and I was like, "Oh, that's good."

From this experience, Jewel also became more proactive in ensuring her future partners were tested.

Two other women in the study also had unplanned pregnancies with partners who were never tested. In these two instances, both women were married and asked their partners to undergo testing instead of having to undergo prenatal testing themselves. Katrina, a 31 year-old woman was offered, yet declined to have, an amniocentesis.

[PR: *Where you offered prenatal testing?*] Yea, my doctor did because I have sickle cell. So they [her doctor] wanted me to do the amniocentesis, but there was a risk [with the test] or whatever. I just didn't want to take any risks and I was like I'm just going to trust God that he's going to be fine and he won't have anything. They said, "Well, do you want your husband to get tested?" So I made sure that my husband was tested and then when he was fine I said, "Well, he's fine." Because then what? You terminate the pregnancy? No. I wouldn't have done that.

Katrina had already been labeled a high risk pregnancy and was approached about having prenatal testing but did not want to add any more risk to her pregnancy. Instead she opted to ask her husband to be tested rather than "risking" her baby. Katrina had already decided to continue the pregnancy regardless of the test results and once genetic testing determined that her husband was not a carrier of sickle cell trait she did not feel compelled to undergo additional prenatal testing.

The father of Chloe's children also underwent genetic testing while she was pregnant with two of their three children, in lieu of having the amniocentesis that was offered to her.

[During the] first pregnancy they [her doctors] said, "Let's do genetic testing."  
[PR: *How did he feel about that?*] He was fine with it. He understood it. He knew it was to make sure that he was not a carrier. I mean, had I been older and it was a planned thing, we would have did that beforehand, but I was already pregnant. He did it twice—with the first and with the third one. Because it was two different hospitals, two different doctors. We just did it again so they could



have it on their record. He wasn't a carrier. Oh, I should mention this: my husband is the same father [of all three children]. So, once they found that he wasn't [a carrier], the talk about an amnio and all that kind of ceased. For what? That was my response [to doctors asking about the amniocentesis]. For what? I knew that without him being a carrier my kids would have the trait.

In the instances of unplanned pregnancies, both Chloe and Katrina illustrated how partner testing during pregnancy can be used in lieu of prenatal testing. Chloe and Katrina also illustrate that women do not always have their partners tested before pregnancy, even though they feel they should. Chloe also acknowledged that her testing came a bit too late and the optimal time would have been before conception. The participants highlighted above also show that regardless of having the belief that their partners should be tested before pregnancy, some partners still remain untested. Chloe's story shows that providers are very concerned about the transmission of sickle cell disease. Even though all three of Chloe's children had the same father, who had already been tested and found not to have sickle cell trait, testing was repeated when they encountered a different provider at a different health care system.

Of the 22 participants who were proactive about asking their partners to be tested, several were older (N=8), had experience with unplanned pregnancies (N=6), already had a child with sickle cell disease (N=1), or had extensive family experience in this regard (N=4). These stories show that participants did not necessarily begin their reproductive lives being proactive, but their agentic behavior developed over time in reaction to their initial experiences. Sometimes it took experience with and knowledge of the potential of having a child with sickle cell disease before women took a stand in ensuring their partners underwent genetic testing.

### *Unwilling Partners*

Three women in the study indicated asking their partners to undergo genetic testing, yet they refused. Hope, a 25 year-old mother who was currently pregnant with her second child, indicated that neither of her two sons' fathers were willing to be tested.

He wouldn't let them test him because [boyfriend] says the trait don't run on his side of the family. I'm going to still get him [her unborn baby] tested for sickle cell [disease] just to be on the safe side. Because nobody knows [for sure] because it skips generations. So I'll still get him [unborn baby] tested, just in case. [PR: *Did your first son's father get tested for the trait?*] No, he didn't. One thing I did was when [first son] was born was get him tested to see if he had it [sickle cell disease]. They said, "No, he don't have it," but automatically, "he do have the trait." I know this baby is going to have the trait too because [first son] has the trait.

Hope was unsuccessful in having either of her sons' fathers tested for sickle cell trait. She believed newborn screening was an effective method of determining whether her children had sickle cell disease. However, because her sons had different fathers her unborn child may in fact have the disease, not the trait. However. In the end, she accepted that her children would be carriers of the sickle cell trait. Hope did not describe being persistent in either explaining to either of her boyfriend's why they should be tested, although she was concerned enough to inquire about her sons' status after they were born. This may indicate that while she did not think having sickle cell disease was a tragic fate, she wanted to be prepared to care for her children should they have sickle cell disease.

Clem, a 32 year-old mother of three children, and Raven, a 39-year old mother of two, stated that the fathers of their children also refused to be tested.

They [her partner and his family] talked about it in their family and they don't have the sickle cell trait so...no choice but to go with that. He wasn't going [to get tested]. No, no, no, no. When we was having the genetic testing he didn't want to go. He doesn't like hospitals. [He said], "I will just tell you what you need to know." Well, I figure if he didn't know in his own family he would have went. But he said they had talked about it and nobody has it, so I pretty much took

his word for it. I have no idea [what it would take]. I've thought about that for a while and you see, you are repeating from generation to generation. (Clem)

Both of my sons have sickle cell anemia SS. Both of their fathers have sickle cell trait. And [son's] father, he swore to God he didn't have no sickle cell trait, nothing. He never went and got tested. He just told me that he didn't. [PR: *How about your other son's father? Did he ever get tested?*] He never got tested. I just knew [son had the trait] when I had him. I tried to get him to go to genetic counseling with me and he wouldn't go. (Raven)

While Clem recognized the information genetic testing could provide and how the lack of this information may perpetuate sickle cell disease for future generations, she was unable to convince her partner to get tested and was forced to take his word that he was not a carrier of the trait. Her partner relied on the absence of a family history with sickle cell disease as an indication that he was not a carrier. None of her three children with this father had the disease, thus Clem was inclined to believe he did not have sickle cell trait. Raven was also unable to convince either of her sons' fathers to get tested. Unlike Clem, however, both of Raven's sons had sickle cell disease. These stories show that regardless of the woman's desires, there is no guarantee that their partners will get tested just because they are asked. Women then have very hard decisions to make. They considered what was more important—the stability of their intimate relationship and respect for partners' wishes, the desire to have biological children, or the need to prevent having children with sickle cell disease.

### *Summary*

As shown in Chapter Five, over half of the participants were repeatedly told to ascertain their partner's sickle cell carrier status prior to having children and, in some cases, to refrain from dating and reproducing with men with either sickle cell disease or sickle cell trait. A few were simply told not to have children as well. This instruction framed participants'

understandings of the additional reproductive burdens and responsibilities they possessed because of their genetic condition. This knowledge also caused them to be particularly mindful of the impact of their behavior on future generations.

While women in the study were affected by the messages they heard from others, they also reported their own reasons for being motivated to have their partners tested, both to avoid having their children suffer as they did and their own mothers' experiences of being unaware of partners' sickle cell trait status. The majority described feeling a great sense of responsibility when making reproductive choices, because they wanted to ensure that they did not pass the disease on to their children.

With this sample, more participants whose partners underwent testing at their request were married or in long-term relationships, which may indicate both the intimate nature of a testing request and how important this testing is for relationships. More of the partners of the women in the study with children agreed to undergo testing than disagreed. Those who were less concerned about testing initially often became more interested after an unplanned pregnancy or pregnancy that concluded with the birth of a child with sickle cell disease. Thus, experiences with the realization of almost having or having a child with the same disease also eventually led women to have a different perspective on testing. Based on these data, then, it seems that relationship contexts, family contexts, and personal experiences with pregnancy and childbirth can impact women's views of the importance of genetic testing.

### **Decisions about Prenatal Genetic Testing**

Because of the genetic and health risks associated with pregnancy among women with sickle cell disease, they are typically offered prenatal testing and must make decisions about this

type of testing as well. While partner genetic testing can occur before, during or after pregnancy, prenatal genetic testing is a method of providing pregnant women with in utero information about the health of her fetus, including the presence of fetal abnormalities and disease.

Among the 17 participants who had ever been pregnant, 10 did not undergo testing: five declined, and five were not offered prenatal testing either because they miscarried or terminated early in the pregnancy, or their provider did not suggest the procedure (See Table 7). Seven participants did undergo prenatal testing: six to discover the sickle cell status of the fetus and one because she contracted Cytomegalovirus (CMV) while pregnant (See Table 7). Of the seven who underwent prenatal testing, only four participants did so even though their partners had already been tested for sickle cell trait—Zora and Gabrielle at the urging of providers, Vivian because she unexpectedly discovered her husband was a carrier while pregnant, and Sophia because her mother insisted.

#### *Prenatal Testing is an Unnecessary Test for Me*

Of the fifteen<sup>14</sup> participants offered testing, five participants were offered and decided not to undergo prenatal testing. Three of these women intended to continue the pregnancy regardless of any abnormal results and two had their partners tested instead (e.g., Chloe and Katrina). Pearl decided to forgo prenatal testing because she believed it was unsafe and unnecessary.

I let her [health care provider who offered the test] know that whatever was going to happen, it was going to happen and that's it. I didn't want them digging around. What if they break it? She explained the risks and I just declined, that was it. I still don't think that's a good idea. [PR: *Why not?*] It's like, you're looking at the answers to the questions on the test. You know what I mean? You're cheating a little bit here. Then people will decide, "Well, this one might have something wrong with it we can get rid of that one." That's awful to me. I guess some people would think that's more humane, but I didn't and I still don't.

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<sup>14</sup> Even after I explained the various testing procedures, two participants were unsure if they were offered prenatal testing.

In Pearl's opinion, information about an unborn child should not determine the fate of that child. Further, she saw little value in testing a fetus for abnormalities with the purpose of terminating the pregnancy. Pearl's mother also had sickle cell disease, which may have influenced her opinion about the value of those born with illness. Perhaps Pearl was able to assert her decision to forgo prenatal testing with certainty because her son's father had already been tested and was not a carrier of sickle cell trait.

Raven, a 39-year old mother, was offered but decided to forgo prenatal testing.

They just talked about ways of finding [out] if your child has sickle cell disease and stuff. They just wanted to do an amniocentesis and I was like uh huh [no]. They wanted to do an amniocentesis on me to see if [her 2<sup>nd</sup> son] going to have sickle cell disease or not. I'm like, "No, I'll wait until I have him to find out. It ain't that serious to me to know if he got sickle cell."

Raven resisted prenatal testing and was comfortable waiting until delivery to find out her son's sickle cell status. Raven had sickle cell beta-plus thalassemia Hb-Sβ<sup>+</sup>, which more closely resembles Hb-SC in terms of symptoms, and was not diagnosed until the age of 19 when her first son was born with sickle cell disease. Having unknowingly lived with sickle cell disease for a large portion of her life (without any foreseeable health consequences) Raven's disease status was not a major concern for her.

While Joyce did not have children, she expressed a very strong opinion against prenatal testing.

It doesn't matter at that point, it's [the baby] coming. We'll find out when it comes out. I'm just saying, to me it's an unnecessary procedure. Is there a way that you can go in there and correct it? Can you change that? Can you give me a shot and say, "Bam, your baby won't have that!" No. It doesn't work like that. It's going to come out like that. I would not give my baby up. That baby would be born because I don't believe in abortions because of religious purposes.

Joyce felt that prenatal testing was an “unnecessary procedure” because there was nothing that could be done to correct any abnormalities revealed. Her explanations support comments made by other participants highlighted above, implying that if the underlying purpose of prenatal testing is to determine whether or not to terminate the pregnancy, then there was no reason to undergo testing. Joyce, and most women in the study, firmly opposed termination. Furthermore, these three women and seven others suggested that if their already-conceived fetuses had abnormalities, then they (as parents) would learn how to deal with those abnormalities. Here again, participants were considering their motherhood roles as well as what was best for their unborn and “unconceived” children. What these women described was similar to their experience having sickle cell disease which required that they learn to manage their symptoms, medications, provider interactions, participants also indicated that they would learn to manage having children with sickle cell disease if that situation arose

#### *Just Wanted to Make Sure Everything Was OK*

Of the seven women in the study<sup>15</sup> who underwent prenatal genetic testing to determine the sickle cell status of their fetus, three participants agreed to undergo testing because of their mothers’ urgings, and two did so because of providers’ urgings (i.e., the latter group presented this testing as a form of safety for the fetus). Another participant underwent testing after discovering her husband was a carrier of the sickle cell trait well into her pregnancy. The decision of the last participant in this group was unrelated to sickle cell disease; instead she had contracted a serious virus while pregnant and her providers wanted to see if the fetus had any abnormalities other than sickle cell disease.

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<sup>15</sup> Participants with multiple pregnancies may have had undergone prenatal testing with one or more, but not all of their children.

Six of the seven women indicated the suggestion of prenatal testing arose solely because they had sickle cell disease, rather than age or previous miscarriage. Sydney, a 24 year-old mother of one, was urged by her mother to undergo prenatal testing. However, Sydney was unclear about the associating benefits or risks involved with the test.

[PR: *Let's go back to the amniocentesis. What did you understand the pros and cons of that test to be?*] To tell you the truth I don't even know. Back then I didn't do anything for myself. My mom was like my advocate. Up until I want to say last year my mom was there, she went to all my doctor's appointments. [She] pretty much handled all my stuff. I think it stopped because we were at the emergency room and the lady was just like, "Well, until you go get it in writing with a lawyer, she has to speak for herself." My mom talked to my doctors, filled out my papers, and just reported to me what was going on.

I asked Sydney why she decided to undergo prenatal testing and she replied, "Well, we [she and her family] did. I needed to know because I'm sick and ... you know, because they want you to get it to make sure they can know what to do." Sydney's comments suggest that she believed the test was being offered to allow providers the chance to adequately care for the baby upon delivery. Sydney's agreement to undergo testing appeared to be limited and mostly directed by her mother. With the childhood onset of her illness, Sydney's mother had been involved in her care since birth. She perceived her mother's involvement in her health care decisions very positively and saw her mother as an advocate. It was not until her mother's involvement was called into question by a health care provider that her mother stopped making decisions for Sydney. Sydney's mother still had a strong influence on her decision to undergo prenatal testing, however. Sydney deferred to both her mother and her healthcare providers in making the decision to accept prenatal testing.

Similarly, Sophia, a 35 year-old woman, also agreed to undergo prenatal testing at the urging of her mother.



I was scheduled for one. I just didn't make it. [PR: *Why did you decide to have the test?*] Like I said, we're [she and her mother] very close and we discuss everything. My mother, her thing was she wanted to make sure if it's sickle cell. She was like, "With you having sickle cell let's make sure there aren't things that could be a problem." I said, "Okay."

Sadly, Sophia's pregnancy caused her to fall into a coma and lose her baby before the testing occurred. However, she indicated agreeing to have prenatal testing to determine if the child would have sickle cell disease because her mother was concerned about making sure there were not "things" that could pose a problem. At the time of this incident, the father of the baby was overseas in the military and therefore had little involvement in these decisions. Her mother had previously expressed her concern about the pregnancy to Sophia because of her daughter's illness. Sophia's mother had also expressed guilt because Sophia had sickle cell disease and wanted to help prevent Sophia from having a child with sickle cell disease. Sophia told me about her discussion with her mother:

[My mother said,] "Well, because I felt bad that I had gave that to you," and I said, "Why did you feel bad?" She said, "I felt like you had this, you were hurting, because I had did this to you. I didn't want to do that to you."

Sophia's mother's concern for her daughter's health and the positive sickle cell trait result for the father of the baby led to her trepidation about a future baby's health.

Gabrielle, a 36 year-old mother of two, described her regretful experience with prenatal testing while pregnant with twins. With her first pregnancy, her ex-husband received a false-negative test result, and he was in fact a carrier of the trait and her oldest son was born with sickle cell disease. Because of this experience, she was adamant about having her next partner tested before becoming pregnant, and he did not have sickle cell trait or disease.

I had an amniocentesis and I'm totally against those now. They gave me an amino and they put something in [Nina] to shade her out so they could see [Tina]. Well when I went back a week later, [Nina] was dead and [Tina] was fine. But it was nothing wrong with her up until that point. They were growing fine. They

were the same size, nothing was wrong with her until after I had that amnio. I think whatever solution they put in my stomach to make her dark so they could focus on [Tina]. I think that's what killed her. They told me I had sickle cell and it's better to have an amnio to make sure the babies are safe. I said, "Well, I know they're safe and I'm keeping them anyway." You know, [I was] young; I was 23 [and they were] pressuring me so I just did it. Not knowing any better, just doing what the doctor was saying opposed to researching things for myself and saying, "No, I won't do this." But that's why they wanted to have it [the amniocentesis] because it was a twin pregnancy and I had sickle cell. That was their only reason.

During her second pregnancy, Gabrielle felt confident that her twins were developing appropriately and, because the twin's father had already been tested and found to not be a carrier of sickle cell trait, she was not concerned about genetic transmission. Yet she clearly states that her providers only wanted her to undergo testing because she had sickle cell disease, which they presented to her as concern for the safety of the twins and she succumbed to having prenatal testing upon their urging. Gabrielle attributed her acquiescence to testing to her provider's insistence and to her age. She became unwilling to follow her instincts. In this case, Gabrielle suggested that along with age and experience comes the ability to stand firm and advocate for what she felt to be the best decision for her and her children. Unfortunately it took the loss of one of the twins to get her to that point. Gabrielle also illustrates how through the pathologizing of pregnancy as a time of risk offers medical authorities additional control over pregnancy.

Vivian was the one participant who underwent prenatal testing because she unexpectedly discovered her husband had sickle cell trait five months into her pregnancy.

They took my blood, my families' blood, his blood and sent it to John Hopkins University so they could tell me what type of S she was going to have. It came back from John Hopkins University inconclusive. That was like... I don't understand that. After the [blood] test came back inconclusive, they had me do an amniocentesis. So I had that done and that's when they said it was a female. It was a girl. I was 5 months pregnant at the time. They said we really don't know, we know [there is] an S there, but we don't know what kind. They said do you want us to go into the umbilical cord. I was like, "No." It's another procedure where they can't tell through the amino and they will go into the umbilical cord to

get this type of blood. I guess it's more blood in the umbilical cord. But she could be retarded, etcetera, etcetera, etcetera. I was like forget it. I just have to have the baby.

Originally, she had been told her husband was not a carrier of sickle cell trait and their first child did not have sickle cell disease. However, after finding out suddenly her husband was a carrier of the sickle cell trait, she decided to undergo multiple tests to determine her baby's sickle cell status. The initial tests were inconclusive and when told that continued testing could cause harm, she stopped this pursuit. Of note, this information was revealed when Vivian was five months pregnant and not much could have been done at this point, hence Vivian resolved within herself that she "just [had] to have the baby." Her daughter, Nia, was born with sickle cell disease and, as mentioned in Chapter 5, Vivian felt guilty about this.

### *Summary*

The presence of risk during pregnancy opens the door for the medicalization—especially when matters of genetics are involved. Medicalization refers to the extension of medical jurisdiction or expansion medical experts influence over daily living about various forms of risks (Zola 1972). Participants' pregnancies were medicalized through attempts to compel them to conform to medical expertise and undergo testing. When presented with concerns for fetal risk, women can be placed in situations where they are viewed as either responsible or reckless as they make decisions to promote having a healthy baby and safe delivery.

The women in the study who agreed to undergo prenatal testing viewed testing as a positive form of pre-birth information or opted for testing because of others' urgings. The only other reason women noted when discussing why they agreed to testing was that it could be a source of knowing for themselves that their fetus was "Okay". Six of the seven participants who

agreed to have prenatal testing were also younger at first pregnancy and single at the time of their pregnancy and appeared to make this decision independently. The participants who decided to forgo prenatal testing tended to hold more negative views of testing as a potentially harmful procedure, or their *a priori* opposition to abortion made them interpret the purpose of testing as only providing information about whether to continue or terminate their pregnancy. The participants who declined prenatal testing were married and older at first pregnancy. Perhaps more importantly, their partners had already been tested for sickle cell trait or were tested in lieu of prenatal testing; therefore they already had some certainty of their child's sickle cell status. The uncertainty about whether their children would have sickle cell disease served as a strong motivator for women in the study to undergo prenatal testing if they did not have previous information about partners.

## **Conclusion**

In Chapter Five I discuss the agency participants' exercised to pursue their reproductive desires in the face of reproductive messages that they should not have children because of concerns about their own health and genetic transmission. This chapter builds on participants' responses to those messages by illustrating that thinking about genetic transmission is very much a part of living with sickle cell disease and reproduction and testing is an issue that they must confront. Participants were repeatedly placed in situations that required reproductive decision-making (e.g., whether to become pregnant, whether to ask their partner to undergo genetic testing, whether they themselves would undergo prenatal testing). The three motivating factors for women asking their partners to be tested were, not wanting their children to suffer how they had, their mother's lack of knowing her partner's status and having an unplanned pregnancy in

which they were unaware of their partner's sickle cell status.

Women entered all pregnancies and all opportunities for conception (including intimate relationships) with information about their own genetic characteristics. They also entered all pregnancies, opportunities for conceptions, and all relationships with some knowledge of their parents' own decision-making and knowledge of what it was like to live with sickle cell disease. Within this context, they encountered the burdens of deciding whether to require partners to be tested, whether to end relationships if partners carried the trait, whether to engage in prenatal testing in the case of both planned and unplanned pregnancies.

Many participants placed a self-imposed responsibility for not giving birth to a child with a serious illness that would cause children pain and suffering, through their decisions not to have children, asking their partners to be tested, or limiting their partners to men without sickle cell disease or trait. Participants expressed a deep conviction to protect their future children from the illness itself and from the stigma and labeling that come along with sickle cell disease. Participants who experienced numerous symptoms of sickle cell disease provided a unique perspective and sense of urgency for "not passing it on" or not wanting my child to "suffer like me" and "go through what I went through." Their experience of living with and embodying the disease, the inclusion of much more than just the pain and treatments, and the awareness of sickle cell disease as an all-encompassing, physical, social, emotional, sometimes stereotype-inducing, life-changing condition, dictated their attentions to genetic testing at least in part. Participants described not only the physical symptoms and accompanying hospitalizations but also the interactions and negotiations, worries and concerns, and strong medications that women with the disease have to manage. Providers and women's parents are actually concerned too, as

illustrated by participants such as Jada, Pearl, Sophia, and Nia but, for the most part, the participants themselves seemed the most concerned about not passing it on.

In addition to partner testing, women in this study were confronted with genetic risk during pregnancy and had to make decisions about this type of testing as well. Prenatal care has shifted from being a private concern to a social concern because of the fetus' role as a future family member and member of the population. This concern also gives rise to social norms devaluing of life those with illness.

For women in this study, prenatal testing was not used for fetal decision-making, but instead for information. In most cases, testing occurred as a means of uncovering sickle cell disease status. Therefore, these women tell a fairly consistent story—that providers, parents, and participants themselves view both prenatal and partner testing as testing against the potential for genetic transmission of sickle cell disease and nothing else.

Some participants whose partners were not tested before pregnancy opted to have their partners tested instead of undergoing prenatal testing as an alternative way of “knowing” their child's sickle cell status before birth. The uncertainty of whether their child would have sickle cell disease surfaced when the father of the baby varied (e.g., women with multiple children) or in the case of birth of their first child. When the father of the baby was the same and it was confirmed—through genetic testing—that he was not a carrier, this offered some certainty that sickle cell trait was a possibility for the child. For women in the study who already knew their partner's sickle cell trait status and that their child would not be born with sickle cell disease prenatal testing was less of an issue.

Participants gave more weight to partner testing than they did to prenatal testing. Half of the participants' partners were tested for the sickle cell gene and 40% participants' underwent

prenatal testing. These results may reflect participants' views toward partner testing as proactive and prenatal testing as a sign they would terminate their pregnancies.

In this study medicalization of the pregnancy experience emerged as more than just a matter of birth location or the gender of the provider, but the subjection to medical testing monitoring and surveillance during pregnancy. Susan Sherwin (2001) argues that the medicalization of pregnancy elevates the importance of medical interventions and distances women from their own pregnancies; this distance increases their anxiety and causes women to rely even more on medical expertise to assure them that everything is progressing normally, thus reinforcing the cycle of dependence (Sherwin 2001). The use of technology as a tool for routine care draws attention away from concern for the mother, and places more concern on the fetus as a future family member and member of society.

In the end, participants carried with them the reproductive burdens due to gender and illness to disclose their own sickle cell status, inquire about partner's sickle cell status, ask partners to be tested, sometimes even taking them to be tested. These activities were all part of their process for determining qualification for intimate relationships and eligibility for reproductive partners and their roles as bearers and carriers of children.

In the next chapter I will discuss how participants managed their reproductive health, specifically gynecological care, contraception and pregnancy.

**Table 7. Partners' and Participants' Uptake of Genetic Testing**

Participant	Partner Testing		Prenatal Testing	
	Partner Tested N=19	Partner Not Tested N=9	Prenatal Testing N=7	No Prenatal Testing N=10
<b>PARTICIPANTS WITH PREGNANCIES (N=17)</b>				
Chloe	X			X
Katrina	X			X
Pearl	X			X
Jada	X			X
Mya	X			X
Clem	X			X
Ivy	X			X
Zora	X		X	
Sophia	X		X	
Vivian	X		X	
Gabrielle	X		X	
Jewel	X		X	
Sydney	X		X	
Imani	X			X
Hope		X		X
Tia		X	X	
Raven		X		X
<b>PARTICIPANTS WITHOUT PREGNANCIES (N=11)</b>				
Aja	X			
Nia	X			
Verlean	X			
Joyce	X			
Faith	X			
Yvonne		X (N/A)		
Dana		X (N/A)		
Ebony		X (N/A)		
Lynn		X (N/A)		
Gina		X (N/A)		
Gwen		X (N/A)		

N/A – women who had not been in a relationship they felt warranted asking partners to be tested.



## CHAPTER 7

### EXPERIENCES WITH REPRODUCTIVE HEALTH CARE

*Reproductive health is very important because I want to have a normal life as a woman. I want to go through the normal cycles that women go through. Whether it is menopause or whether it is having a child. So it is important to keep all of that stuff intact. ~Faith*

In Chapter Five I described participants' responses to discouraging messages and to the strategies they used to pursue their reproductive desires in the face of these messages. In Chapter Six I discussed participants' perceptions of and decisions about genetic and prenatal testing within the context of sickle cell disease. Currently little is known about the reproductive health care experiences of women with sickle cell disease. Reproductive health reflects women's health over their lifetimes and lays the foundation for the next generation (Roberts 1990, Rutherford 1992). Reproductive health includes a wide range of processes including contraception, menstruation, conception, pregnancy, childbirth, abortion, menopause, etc.

This chapter describes how participants navigated their reproductive health care among providers with varying knowledge in caring for women with sickle cell disease. In particular participants described their attempts to: (1) maintain their gynecological health, (2) acquire appropriate contraception, and (3) garner quality care during pregnancy. This chapter illustrates important gaps in providers' knowledge about these normal reproductive events when dealing with patients with sickle cell disease. At the time of the interview, nearly all of the women in the study (N=23) reported seeking reproductive health care within the past 12 months. Of these, most went for an annual pap smear (N=15), some for contraception consultation (N=6), and others for prenatal care (N=2). Thus, most women in this sample had interacted with health care providers very recently about their reproductive health.

This chapter demonstrates that participants received reproductive health care from multiple providers, including: obstetrician/gynecologists, nurse practitioners, hematologists, emergency room physicians and primary care physicians. Participants frequently heard conflicting medical advice and receiving conflicting treatments and diagnoses from these different providers. Participants assumed these various providers held enough medical knowledge to recommend appropriate care and allowed these providers to influence their behavior and decisions. Through interactions with multiple providers, however, participants found the gaps in providers' knowledge. At times, participants' race, gender and illness locations influenced their encounters with providers.

### **Sickle Cell Disease & Gynecological Care**

#### *They Know Their Field, but They Don't Know Sickle Cell Disease*

Almost half of the women in the study (N=11) expressed their concerns about their health care provider's clinical acumen for understanding the reproductive health needs of women with sickle cell disease. Through their health care-seeking experiences, participants recognized that while providers may be adept in the field of reproductive medicine, not all are knowledgeable about providing reproductive health care to women with sickle cell disease. Nia, a 23 year-old woman, felt her obstetrician/gynecologist was unable to provide adequate advice on recent medical developments.

I do research and I found out that it's an HPV vaccine. I asked her [the OB/GYN], "Is it OK if I get that?" She said, "Oh, yea." I'm thinking, Well, why didn't you tell me about that? I said, "What do you think about it?" She said, "Well my daughter got it, so I would recommend it." I'm thinking, "Well if you would recommend it, why didn't you tell me about it?" I have to go in there being proactive and telling her what I'm going to do for her to react. I didn't think that was good. Honestly I want to find a better OB/GYN. With my OB/GYN, I think she's a good doctor, but I don't think she knows the

significance of sickle cell and the reproduction aspect of it. [PR: *What makes you think that?*] Just the care that she did. Because if she did I think she would have provided me with options. I told her when I first started there [that] I had sickle cell. I just feel like with sickle cell you have to be really careful. [PR: *Careful with what? What do you mean?*] With sickle cell you have to be cautious about everything, not just sickle cell, but even when you're having sexual activities. So, with me, with the certain vaccines out I want to be protected! With me having sickle cell that I have to be a lot more cautious than the average person. I think for an OB/GYN, I'm not going to say that every doctor should know what sickle cell is, but I feel that if you have a patient you need to make yourself more aware of sickle cell anemia, the causes, the outcomes, what could happen, what can coincide with it, different STDs. Offer support to that patient and let them know something that they may have not known with being sexually active. I feel that with sickle cell you need to become more aware of the whole package.

According to Nia, her obstetrician/gynecologist failed to do all she could to ensure she was protected from common viruses, so Nia took the initiative to investigate matters related to her reproductive health on her own. Nia was not doubtful of her provider's ability to care for her, but she doubted her doctor's awareness of how her illness might impact other aspects of her health. She believed health care providers' responsibilities were not limited to treating ailments, but included serving as a source of up-to-date medical information. Nia also believed she was proactive and honest with her provider by providing as much information as possible and used this strategy to motivate her physician to be more engaged and provide the same level of information. Nia's expectations for the type of care and attention her providers should offer her derived from her interactions with health care providers over time and her exposure to the health care field as a nursing student.

Like Nia, Joyce also felt that while her obstetrician/gynecologist was knowledgeable in her field, she did not possess sufficient knowledge of sickle cell disease.

I have an OB/GYN [but] I don't necessarily care for her. [PR: *Because?*] She's just not with it. She doesn't understand sickle cell. She understands her field, but sickle cell is not her thing. Anytime I'm having a cycle and I'm telling you my cycle is putting me in the hospital and you ask me when am I going to have a child and that will stop my cycle that's when I know you're crazy. Because if I

have a child I'm going to have all types of other health complications because of sickle cell. [PR: *What was her logic?*] To have a baby to cut my cycle off for nine months. I said, "How can I have a baby right now and I'm not married?" She's like, "Oh, well you're right." I'm like, "What?" I think that honestly they think any young, Black woman is automatically out here hoeing around. No, that's not going on. I don't plan on having kids until I'm at an appropriate stage in my life. She said that to me when I was like 19. So it resonated with me. It was crazy. She is the doctor over my case, but they have nurse practitioners who really handle everything and they're fine. [PR: *They know about sickle cell?*] They didn't know about sickle cell, but more than her they were willing to learn. They were willing to research and say, "Joyce, I was up all night looking for this, this, and this. I called this individual [and] this is what we are going to try."

Since menarche, Joyce experienced ongoing difficulties with her menstrual cycles causing frequent hospitalizations. She originally received reproductive health advice from her hematologist, and after becoming sexually active moved her reproductive health care to an obstetric/gynecological practice. In this practice, she had been seen by both the physician and nurse practitioners, and was able to make a clear comparison between these two points of care. Joyce preferred to be seen by the nurse practitioners, rather than the physician, because their approach was more patient-centered and they were willing to learn about sickle cell disease and make an effort to investigate potential solutions to her problem.

Joyce resisted the physician's recommendation that she have a baby out of wedlock as a resolution to her health problem and thus preferred to be seen by the nurse practitioners. Joyce took particular offense to this recommendation because she held traditional values toward the appropriate context within which to have children. Further, she felt this comment was suggestive of her being promiscuous, a longstanding racist and sexist stereotype of African American women. This stereotype has important implications for health care in that it justifies poor treatment from providers, jeopardizes health care, and exploits the reproductive behavior of African American women (Hill 2009). In the United States, the low position that African

American women occupy in society is related to the fact that they are in a position of being subjected to both racism and sexism.

Joyce and Nia both expressed their dissatisfaction with the care they received from their obstetrician/gynecologists. Both had providers who were more doctor-centered and approached their care with an assumption that they were the final decision-makers without including the patient in the process. Nia, as a nursing student, and Joyce, through her patient advocacy work, had clear expectations of quality health care. They felt they were not receiving the best care possible due to their physicians' lack of knowledge and interest to better understand sickle cell disease and the impact it could have on women's reproductive health. In response to their dissatisfaction, both women were compelled to consider finding another source for reproductive health care. In Joyce's situation, she opted to only see the nurse practitioners in the practice.

Yvonne, a 23 year-old woman, through the suggestion of her hematologist, identified a provider whom she felt confident would have knowledge of both sickle cell disease and reproductive health.

My periods were getting heavier; they were lasting longer. My cramps were getting worse and most of all my sickle cell pain was starting to get out of control when I was on my period. So that caused me to call up the gynecologist and say, "Hey, I need to figure out what's going on because this period is causing problems elsewhere. I have sickle cell." I figured that if I stop my period and completely get rid of it then maybe I wouldn't have to deal with these cramps that spark up my sickle cell crisis. [PR: *Is this a gynecologist you already had?*] No, it was the first time that I had been to a gynecologist. A friend, [name] [who also has sickle cell disease] talked to us about that [Depo-Provera] because she was having similar issues as well and told me that, "Hey, you know, you could try this [Depo-Provera]." The gynecologist was telling me that Depo-Provera would probably be my best option because I didn't want anything inserted in me, but I wanted to talk it through with Dr. [hematologist] and when he told me that he had a sickle cell gynecologist, I said, "Well, maybe it would be better to have her examine me and see what her options are." [PR: *Why is that?*] Considering that she knows more about sickle cell than the regular gynecologist would, I just wanted to talk with my sickle cell specialist to get his opinion. [PR: *Why is that?*] Just because he's my sickle cell specialist and he would know more about how

my period and the birth control would be and how it would benefit me as far as sickle cell. Because the other gynecologist, she doesn't know anything about sickle cell, all she knows is about female issues. But they know about female issues and sickle cell so I thought that would be better finding out what they would advise rather than her.

Yvonne was committed to maintain her virginity until marriage and therefore had not sought reproductive health care until now. Yvonne reported<sup>16</sup> having dysmenorrhea<sup>17</sup>—a painful gynecological condition that can interfere with daily activities—and concluded that her menstrual cycles were exacerbating sickle cell disease. In her initial experiences of seeking reproductive health care and using contraception, Yvonne was unfamiliar with determining the validity of the information she received from the obstetrician/gynecologist she was originally seen by. Yvonne's sources of information for her reproductive health not only included her obstetrician/gynecologist, but also included a friend with sickle cell disease and her hematologist. Ultimately she preferred to receive her reproductive health care from a provider knowledgeable of both sickle cell disease and “female issues.” Her decision to seek care from one provider rather than two separate providers would have reduced the burden of multiple visits to different locations, which may have increased the probability receiving comprehensive care. Nearly a year had elapsed between her deciding to seek care and then seeking care from the obstetrician/gynecologist in the sickle cell clinic which she attributed to “just me being sick and in the hospital like every month, so just it was me continuously being sick and not having the time to see another gynecologist.”

It is also important for women with sickle cell disease to have providers who are knowledgeable about their disease since it is common for individuals with sickle cell disease to

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<sup>16</sup> Yvonne did not indicate having received this diagnosis from a health care provider.

<sup>17</sup> There are two types of dysmenorrhea: primary and secondary. Primary dysmenorrhea is defined as recurrent, crampy pain occurring with menses in the absence of identifiable pelvic pathology. Secondary dysmenorrhea is menstrual pain associated with underlying pelvic pathology such as endometriosis.

receive pain medications that render them unable to be fully present amid moments of important reproductive decision-making. Aja passionately recounted a harrowing experience with a close friend whose reproductive capacity was jeopardized during a hospitalization.

She was in the hospital because she was bleeding [vaginally] and the doctor just said, “We’ll take out your uterus.” She was 27 at the time and I’m like whoa. I feel like a lot of that had to do with the fact that she was a Black woman, in a hospital that didn’t know anything about sickle cell. It was a majority White hospital and they were just jumping to it, let’s just do what has to get done instead of taking the time to talk to her and say what’s going on. I feel like a lot of that was just race-based because when I talked to her doctors, I was there being her advocate, I’m like, “Where’s this coming from? Do you do this for every sickle cell patient?” They were like, “No.” Then what is the problem? Is it because she’s extremely dark-skinned and she can’t talk to you right now? To me they were being racist against us. Because it [her bleeding] didn’t have anything to do with sickle cell. [PR: *Why do you think race had anything to do with them wanting to take out her uterus?*] I don’t know. It’s just the way that they... You know how patient interactions, how when a person looks at you [made a face as if she was throwing up]... It was partly because she couldn’t advocate for herself. I don’t get it, but to me it’s like with racism, you see it, it’s hard to explain it. But when you saw it, you were like immediately put off. Like, he was doing this because why? She had sickle cell? Because it would help her sickle cell? Do you see how that doesn’t make sense for somebody who is 27 and who has never had any children and has not been married? [PR: *What do you think they should have done?*] Do some background. Don’t just be like we’re taking her into surgery in five minutes to pull out her uterus. Talk to her! Wait until she can talk to you! [PR: *Your friend was unconscious when this decision was made?*] She was semi-unconscious. She was under heavy narcotics at the time. She couldn’t talk. She couldn’t relay what she needed to say. This was the on-call internist on the floor who was saying this is how we’re going to treat her sickle cell, by taking out this woman’s uterus.

Aja believed this doctor prioritized addressing her friend’s physical symptoms over preserving her reproductive capability. Specifically, she felt not enough consideration was given to the long-term consequences of this decision for a woman with these characteristics (age, marital status, and reproductive history). As an on-call internist, Aja felt this physician did not possess the medical expertise to make such a permanent decision nor was he aware of her friend’s desires about the best strategy to resolve the bleeding. With the numerous problems with this medical

encounter, perhaps most disturbing to Aja was her friend's lack of informed consent for allowing this procedure to be performed. Historically, women of color have been subjected to having hysterectomies performed on them for various reasons and frequently without their knowledge or consent (Roberts 1997; Nsiah-Jefferson 1989; Davis 1983). This situation lends importance to Aja's position as a patient advocate in times of her friend's health crises—to ensure health care providers adhere to established medical and ethical guidelines.

In addition to a lack of expertise and informed consent issues, Aja suggested that the provider's decision was racially motivated and continuously questioned the medical necessity of this procedure. Aja felt this particular situation was further fueled by the environment in which her friend was seeking care (e.g., a majority White hospital). Aja's perception of racial discrimination was not only based on the racial discordance between patient and provider but also on the non-verbal cues she detected during her own interactions with providers. Aja had also been semi-consciousness while hospitalized at times and also had a similar illness and social locations to her friend (e.g., similar race, gender, age, marital status, parity, and sickle cell identities). Aja was able to empathize and step in to advocate for her friend because of a common identity.

### *Summary*

Women in this study received care from multiple providers, which provided them with a unique perspective through which to gauge their providers' levels of knowledge of sickle cell disease. When participants described more negative interactions with their reproductive health care providers, they also described less confidence in their care. In these instances they were led to use purposeful strategies to ensure their health was maintained, mainly giving preference to, or



involving, providers with familiarity with sickle cell disease in their care or expressed confidence in the care they received. Participants also carefully considered the validity of medical information and recommendations they received with a degree of caution and, over time, became very proactive in pursuing optimal care despite challenges of insufficient clinical acumen.

Participants also emphasized that providers should have the knowledge and experience to know how best to incorporate sickle cell disease into their reproductive health care. They noted that many providers prioritize the problem or condition identified at that time, without giving consideration to their reproductive desires or the larger social contexts surrounding the current problem or condition, particularly in times of sickle cell crisis. Some participants felt that their care was influenced by their race, gender and illness locations, through providers' adherence to long-standing racial and sexist stereotypes of African American women and ideas about sickle cell disease representing women's primary concern. As a result, participants were distrustful of providers' recommendations.

### **Sickle Cell Disease & Contraception**

One of the most frequently reported purposes for seeking reproductive health care among women in the sample was for contraception. Nearly all participants in the study (N=25)<sup>18</sup> had used contraception during their lifetime. Of those, almost half (N=11) believed the contraception they were initially prescribed either exacerbated sickle cell disease symptoms (increased pain crises) or was a type not recommended for women with sickle cell disease.

Contraception is a special circumstance for women with sickle cell disease since many of the side effects of hormonally-based contraception parallel the co-morbidities of sickle cell disease (heart attack, blood clotting, stroke, etc.). Guidelines from the 2010 *United States*

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<sup>18</sup> Some women had used more than one type of contraception during their lifetime.

*Medical Eligibility Criteria (MEC) for Contraceptive Use* do not discourage the use of any contraceptive method for women with sickle cell disease (WHO 2010). These guidelines do not restrict the use of progestin-only contraceptives (pill, injectable, and implantable) and suggest the use of combined hormonal contraceptive methods (a combination of pill, ring, and patch) outweigh the risks for women with sickle cell disease making them acceptable methods of contraception for this population (WHO 2010). However, because the risks associated with combined hormonal contraceptive methods remain elusive, concerns and uncertainty regarding potential complications persist.

Both Ivy, a 27 year-old mother, and Pearl, a 37 year-old mother, believed the form of contraception they were prescribed interacted negatively with sickle cell disease. Participants drew these conclusions from their tracking of symptoms that coincided with contraceptive use.

I was on the pills but that interfered with the sickle cell. [PR: *When you say the pills interfered with the sickle cell, can you explain what you mean?*] I had more frequent sickle cell crises. [PR: *How did you decide to use the pills?*] From their recommendation. That's what they thought would be best so I just went along with it. I got the pills was after I had my first child. Before [that] I wasn't on birth control. I was on that for a few years and I would have a crisis every month. (Ivy)

They gave it [birth control] to me after that [miscarriage]. They said, "Well if you don't want kids, take this." [PR: *Who gave it to you?*] The people at [name] Hospital they assigned me an OB/GYN when I was in the hospital. The OB/GYN that they assigned me at the time put me on the birth control pill that was too strong. I ended up in the hospital for three weeks. I stopped taking the pill. They gave me another pill and I got real sick again. I stopped [taking contraception] a long time ago because I kept having issues. (Pearl)

Ivy gave birth and Pearl had a miscarriage, at the ages of 18 and 19 respectively. Prior to their pregnancies, neither had used contraception. Ivy had been told she could not have children and considered contraception unnecessary. Pearl had never been educated about using contraception by her family or health care providers. In both cases, the prescribing-provider was not someone with whom participants had an existing relationship and appeared unaware of the

unique circumstances of sickle cell disease and contraception. Also, as their first experience with contraception, Ivy and Pearl were also unaware of any limitations on contraception use and experienced a doctor-centered approach to being prescribed contraception, with minimal if any input from the patient as to what would be best. In addition to Ivy and Pearl, three other participants could have experienced potentially serious incidents due to their existing health issues and the side effects of contraception.

Aja, a 30 year-old woman, was told by her hematologist that she had been prescribed a form of birth control that would interact negatively with sickle cell disease and immediately “pulled her off” of it.

I went to Planned Parenthood when I was really young and thinking about having sex. I remember them saying, “Well you can take anything that you want.” Then actually I got up enough nerve to tell to my hematologist I was on the patch and him saying, “No, you can’t take anything you want because birth control will cause clotting. It’s known that birth control can cause clotting when you already have a clotting disorder that if you clot it’s not very good, you don’t want to promote that.” He’s like, “I don’t recommend this for you. This has been known to cause really bad clotting.” My hematologist told me “No” and he immediately pulled me off of that and told me I needed to go to the gynecologist.

Aja was raised in a religious family in which conversations regarding reproductive health or sexual behavior were taboo. Instead she was given a book about “where babies come from.” Feeling unable to talk to adults in her life about becoming sexually active, Aja took the initiative to visit Planned Parenthood without realizing the restrictions on the type of contraception she was able to use because of sickle cell disease. Being prescribed a potentially harmful contraceptive led Aja to question the knowledge some providers possess in relation to identifying reproductive problems among women with sickle cell disease.

I guess my biggest concern would be how much they [obstetrician/gynecologists] know about sickle cell disease when they’re looking at everything. Are they looking for the signs? Because I don’t know all of these. I don’t know what sickle cell can do to my reproductive health. I don’t know how this [sickle cell

disease] is affecting my reproductive organs. I know that it [sickle cell disease] wears on everything, but I'm not as educated in that area, so I want to make sure that they're educated. There isn't a specialist who specializes in sickle cell reproductive health so you're constantly hoping that they're asking you the right questions and that your doctors are communicating. You don't want everything to go awry down there. I want my hormones to be halfway decent. I may not want to go through menopause, but I want to be able to have those changes naturally.

Aja emphasized her desire to remain healthy and have reproductive bodily experiences naturally. She prided herself on her knowledge about sickle cell disease and recognizing the warning signs of potential pain crises and realized she did not possess the same knowledge when it came to how sickle cell disease may impact her current and future reproductive health. Thus, she looked to obstetrician/gynecologists to have this expertise, although she remained apprehensive about how much they actually knew.

Nia, a 23 year-old woman, actually experienced a negative reaction to the first form of contraception she had been prescribed.

I started [using contraception] when I was 20. I was on the patch, but I can't use the patch because I'm allergic to it. My OB/GYN prescribed the patch. They ask you, "Do you want to do the pill, the patch, or..." And I felt that I'm not good at taking pills consistently. I said, "Let me do something that I can remember at least once a week." I'm not taking anything right now because I just found out, less than a month ago that I'm allergic to it. I'm not sure if that coincides with the sickle cell or not.

Nia viewed using contraception as sexually responsible behavior and based her decision on the type to use on what she knew about herself and taking oral medication. From her description of the contraceptive consultation, she too was presented with various options without consideration of sickle cell disease. Similar to Aja, she was unaware of the potential for a negative reaction to the contraceptive patch. After three years of breaking out while using the patch and no guidance from her provider, Nia used her own trial and error process to deduce a relationship between this contraceptive method and her allergic reactions.

Jewel, a 41 year-old woman and Zora, a 37 year-old woman, used contraception before being told by a health care provider that it could potentially cause a health problem due to their medical history.

I took the Depo shot. Dr. [hematologist] told me that I should not have been on the shot. [PR: *Because?*] Because I had a stroke before and one of the side effects [of the shot] is a stroke. With taking birth control, the side effects are heart attacks, strokes, so he felt like I should not have been on birth control and I was getting the shot. I discontinued the shot. [PR: *Have you ever taken any other type of birth control, other than that?*] No, that was it. (Jewel)

I'm on Tegretol and Keppra [medications] and my neurologist had said that you can't take any birth control with the Tegretol and it could have killed my brain. They don't work together at all. It could have killed me. When I had found out—I was, “Oh, my goodness!” That's what I said and I couldn't just stop taking the Tegretol so I had to make a choice between the two. (Zora)

These participants spoke to the potential errors that could have occurred because their medical history was not given sufficient consideration at the time of contraception prescription. Again neither the prescribing provider nor the participants were aware of the potential harm hormonal contraception could cause. In these instances, participants benefited from being followed by a provider who knew their medical history well enough to warn them about the potential harm contraception could cause. Too often medical providers dispense medical advice in terms of a standardized model of care and when sickle cell disease is not brought into the equation, errors may occur.

*Summary*

Since sickle cell disease is a blood clotting disorder and some forms of contraception are known to cause blood clotting—even among women without a serious health condition—the type of contraception prescribed to women with sickle cell disease is critical.

Eleven participants indicated having been prescribed contraception that was potentially health harming. This occurred either due to provider's lack of knowledge of potential complications of sickle cell disease with some forms of contraception, or participants lack of introducing their disease during the conception consultation. Unlike the above section of results in which participants describe situations in which providers gave too much consideration to sickle cell disease, often prioritizing it over participants' reproductive desires, in these latter instances providers did not give sickle cell disease enough consideration, often leading to negative health experiences. For example, Nia above where she specifically mentions she told her obstetrician/gynecologist she had sickle cell disease when she was first seen at the practice. However, participants like Aja who sought care outside the traditional health care system or who sought care at a young age may not have known to bring sickle cell disease into a reproductive health discussion. In any case, participants looked to their providers to have the necessary expertise to prescribe the appropriate type of contraception. Of note, women in the study whose first experience with contraception was for the purpose of contraception (rather than to remedy problematic menstrual cycles) were more likely to experience a negative interaction with sickle cell. With these first experiences, participants may not have realized the importance of informing, or in some cases reemphasizing, that they have sickle cell disease with their provider, and this omission may have impacted the course of their reproductive health care.

## Sickle Cell Disease & Pregnancy Care

In addition to gynecological health and contraception, women in the study also emphasized pregnancy as another reproductive health event that required their providers' knowledge of sickle cell disease. Women with sickle cell disease face numerous pregnancy risks, complications and adverse outcomes (Barfield et al. 2010, Chase et al. 2008, Hassell 2005, Howard, Tuck and Pearson 1995, Smith et al. 1996).

### *Be Sure To Get a Doctor Who Knows Sickle Cell*

Of the seven women in the study who emphasized the importance of having prenatal health care providers who are knowledgeable about sickle cell disease, six had been pregnant before the time of the interview. Sophia, Katrina, and Chloe described varied levels of confidence in their prenatal care providers. Chloe, a 31 year-old mother, specifically sought providers with experience caring for patients with sickle cell disease.

They [providers] think I have the trait. They always say, "You have the trait?" and I have to tell them, "Here's the blood test." Then it's like, "Oh, okay, you do have sickle cell." It's not like that as much [now that] I started working in health care. I started picking doctors that came from [a medical center] that worked with the Black community and they are way more familiar with sickle cell. But I didn't learn that until I got into health care myself, to go with somebody that has dealt with patients that had sickle cell because they know a little bit more. [PR: *Did you have the same OB/GYN for all three children?*] For the first two [pregnancies] I did that, but for the third one I had a different one, she [obstetrician/gynecologist] wasn't as familiar, but one of her partners was *very* familiar so together they were fine. With the third pregnancy I did experience a lot of pain. I haven't had that pain in so long that I didn't know if I was having a crisis or not. [I said], "It's unbearable pain and I'm functioning, and I'm talking so I don't think I'm having a crisis." They didn't feel like I was having a crisis. He [the partner] did some blood work and he said I was not having a crisis, but I was just having a lot of pain. So they knew what to do.

Chloe experienced few pain crises or other sickle cell symptoms (e.g., fatigue, lower hemoglobin, and stroke) during her life. She had to constantly convince new providers that she

had sickle cell disease because they mistook her for having sickle cell trait. This frequent mistake, along with her professional experience as a nurse, caused her to be more diligent in selecting health care providers. She applied this same approach to selecting providers for her prenatal care because it was even more important that her providers have this knowledge. In her case, having providers who knew about sickle cell disease offered her peace of mind when she was worried she was having a crisis, because they knew how to care for her. Chloe preferred providers who were more patient-centered and took her knowledge and experience into consideration.

Sophia, a 34 year-old woman, emphasized how important it is for women with sickle cell disease to have a reproductive health care provider who understands their disease.

Besides having a hematologist that takes care of the blood disorder, sickle cell, you also need to have an OB/GYN that understands that you have sickle cell and your reproduction and things like that because then you also have somebody to tell them that they need to be more cautious about becoming pregnant and things like that. [PR: *What do you mean be more cautious?*] My physician told me that because for some sickle cell patients it's a certain time that is right for them to be pregnant and most of the time when they're young, our bodies are still progressing, hormones are still going all over the place, and it's just not good. Actually, when you're older and your body has become more settled, it's best. She's been my primary OB/GYN since I was 18. She's taken care of my whole family and she was really good. She was just one of those doctors, if she didn't know about it she would look it up. She was African American, she was very aware of African American care and sickle cell patients. She had also taken care of sickle cell patients who've been pregnant and she was along for my pregnancy ride too.

Sophia's confidence in her obstetrician/gynecologist originated from the longevity of their relationship, the provider's experience in caring for African Americans in general and women with sickle cell disease in particular, and her provider's willingness to investigate health issues with which she was unfamiliar. These qualifications gave Sophia confidence in her obstetrician/gynecologist's ability to offer her advice about family planning and prepare her body



for pregnancy and childbirth. Also, having a provider that she felt had an intimate experience with people like her (i.e., with the same race, gender, and illness locations) offered Sophia comfort and reassurance.

Since Sophia obviously expected this care not only for herself but also for other women with sickle cell disease, she passed her experience along to women she counseled at the Sickle Cell Disease Association of America.

I usually tell them [women she counseled] if they can just hold out and wait [*sic*]. But if you find somebody and you just can't wait, make sure that you're protecting yourself because it's a lot of other things out here, and [not] just you having to worry about sickle cell and a baby. But if you do find yourself pregnant make sure that you do see your OB/GYN and you stick close to them.

In contrast to Sophia and Chloe, Katrina, a 31 year-old mother, had an obstetrician/gynecologist who lacked knowledge of sickle cell disease and was unprepared to care for her during her pregnancy.

I would suggest that women, if they are pregnant, they see an OB/GYN that is knowledgeable in sickle cell. My OB/GYN gave me iron pills because [when] you're pregnant they think you need more iron and you need to take this prenatal vitamin. Well my body didn't take that. As a sickle cell patient you already have a lot of iron so I had too much iron ... iron overload. Once I saw my hematologist, he said, "Oh no!" Then my OB/GYN put me on something called Macrophone, but my hematologist felt like that was raising my bilirubin. She [OB/GYN] was putting me on this extra stuff not realizing what it was doing to the sickle cell. By me seeing my hematologist, he was like, "Oh no, your iron numbers are too high. Stop taking the iron. Don't take this Macrophone because it's raising your bilirubin." So I can't take any vitamins to help the baby but folic acid, which I had already taken anyway. The OB/GYN, she hadn't really dealt with women that have sickle cell before so she must have searched sickle cell or something and felt like well because you have sickle cell your iron is going to be low because your blood is low so I'm going to give you more iron. But she didn't do good research. She should have known that sickle cell patients have more iron, than less. We have low blood but more iron. The sickle cell got terrible. The doctors really didn't know what to do. Don't take anything unless your hematologist has recommended it, because they are knowledgeable about sickle cell and have a relationship with you and know your body better.

Unlike Chloe and Sophia's providers who had knowledge of sickle cell disease, Katrina felt her provider had limited experience caring for pregnant women with sickle cell disease. Her obstetrician/gynecologist's lack of knowledge led to two potentially health-harming recommendations and caused worsening sickle cell disease symptoms. This situation required the expertise of different providers to keep Katrina healthy during her pregnancy. Because Katrina continued to receive care from her hematologist throughout her pregnancy, she received advice on what was safe for her to take while pregnant that contradicted what her obstetrician/gynecologist recommended. Consequently, Katrina found herself between these two providers, each using their own specialty to advise her. The obstetrician/gynecologist focused on the pregnancy while the hematologist focused on the sickle cell disease. Katrina was in a unique position to compare the care she received from her providers and believed the care she received from her hematologist was superior due to his knowledge of sickle cell disease and his knowledge of her body. Therefore, she decided to follow his advice.

### *Summary*

The women highlighted illustrate two key strategies they used for ensuring optimal health care during pregnancy: (1) identifying providers knowledgeable of both sickle cell disease and reproductive health care and (2) involving providers knowledgeable in sickle cell disease in their reproductive health care. These strategies helped to ensure participants had providers with this knowledge during pregnancy as knowing how to manage their pain crises or other sickle cell-related symptoms. Again, not all participants' providers possessed the same level of knowledge of sickle cell disease. While Sophia and Chloe both had providers whom they felt were knowledgeable about their condition, Katrina did not share this experience. Sophia and Chloe

expressed their confidence in the care and advice they received. These participants felt that their providers gave special attention to understanding that sickle cell disease added a unique feature to their reproductive health care needs.

### *Responses to the “High Risk” Pregnancy Label*

In addition to concerns of the lack of knowledge during prenatal care, participants also encountered risk discourse during their pregnancy. To be without some element of risk is nearly impossible thus “individuals and populations are judged for degrees of risk—low, moderate, high—vis-à-vis different conditions and diseases, which determines what is prescribed to manage or reduce that risk” (Clarke et al. 2003: p. 172). Mary Douglas (1992) stated that “the word risk now means danger; high-risk means a lot of danger” (p. 24). High risk is a label providers use to classify women who are likely to experience maternal or fetal complications during pregnancy (Douglas 1992, Heaman 1998). As mentioned in Chapter Two, women with sickle cell disease face numerous pregnancy risks, complications, and adverse outcomes (Barfield et al. 2010, Chase et al. 2008, Hassell 2005, Howard, Tuck and Pearson 1995, Smith et al. 1996). Prior to 1972, maternal and perinatal rates averaged 4.1% and 52.7%, respectively, however these rates have declined and have been reported as averaging 1.7% to 22.7% (Powars et al. 2005). The decreases in maternal and perinatal mortality may be the result of advances in medical care: improvements in transfusion medicine and more frequent prenatal care. All thirteen women in the study who carried pregnancies to term indicated they were categorized by their reproductive health providers as “high risk” or were in the “high risk” category. The category of high risk suggests a deviation from the norm and an indication that medical expertise, surveillance or

regulation is warranted (Lupton 1999). In this section I explain the two disparate reactions women in this study reported after being categorized as high risk.

### Of Course I'm High Risk; I've Got Sickle Cell Disease

Less than half (N=6) of the women in the study who carried their pregnancies to term took being told they were a “high risk” pregnancy in stride. Katrina, a 31 year-old mother of one son with Hb-SS and Ivy, a 27 year-old mother of three children with Hb-SS, both felt being high risk was possible because they had sickle cell disease.

I was considered high risk because of the sickle cell. [PR: *When they told you that you were high risk, what did that mean to you?*] Nothing really. I have sickle cell. I have to be monitored a lot. (Katrina)

I am considered high risk for the sickle cell. They [her doctors] basically said, “You are high risk so some things are going to be a little different.” I kind of figured that I would be high risk because I do have sickle cell so that wasn't really anything new. They monitor the baby more closely with high risk mothers, I was getting an ultrasound at one month and I know with normal pregnancies they don't do that. (Ivy)

Both Katrina and Ivy easily accepted being categorized as high risk and perceived the additional prenatal monitoring as a consequence of having sickle cell disease. For Katrina, the label held no meaning. However, for Ivy the categorization did carry a meaning—additional medical attention and intervention—which she believed was different from the care other women having a “normal” pregnancy received. By creating a dichotomy, by labeling herself as abnormal and others as normal, Ivy recognized that her reproductive experiences might not be quite the same as others.

Hope, a 25 year-old mother of a two year-old son and currently pregnant with a second child and Hb-SS, described her experience with being categorized as high risk.

They [her doctors] put me as high risk because I have sickle cell. That's the only thing. I just figured that, "OK, I have sickle cell, I'm high risk, of course." I just left it at that. I don't know why I didn't ask more questions about it. I guess I was just like, "All right, I know I have sickle cell. I know there are risks [that] can be involved like losing a lot of blood or passing out" and I left it at that. I didn't get too much details into it because I probably in a way didn't want to know too much of the information because it would be in my head and I'd be panicking and I didn't want to know.

Hope was aware of the potential challenges she could encounter while pregnant and readily accepted being categorized as high risk as a consequence of having sickle cell disease. This label held the potential to bring these challenges to the forefront; therefore Hope did not question the categorization or request additional information because she was concerned that an explanation or further details may have provoked her to worry about having a safe pregnancy and delivery. To Hope, not knowing the details behind the categorization was a way of coping with the stress of potential complications she may face during pregnancy. Avoiding knowledge about the potential risks did not mitigate Hope's fear about her risks. Also, despite her concern about the associated risks, Hope still continued to pursue her reproductive desires and was currently pregnant with a second child.

Zora, a 37 year-old mother of two children with Hb-SS, easily accepted the high risk label.

Every last one of them [her doctors] came to me and told me they wished I had gotten my tubes tied. They said, "Do you know how scared we were for you?" They told me I was high risk. [PR: *When you heard that, what did that mean to you?*] You know what, I had been told I was high risk with everything since I was a little girl so words like that just rolled right off of me because that's just the way I am. If you tell me I am high risk, I will pray about it and leave it there.

For Zora, being labeled as high risk held little meaning because she had become accustomed to hearing such language throughout her life. Like Hope, Zora did not feel it was necessary to inquire about the specifics surrounding the categorization and accepted it a consequence of

having sickle cell disease. Each of the six women who accepted the “high risk” label in stride had the more severe form of sickle cell disease (Hb-SS) and they also had more frequent hospitalizations for sickle cell disease. For these women, the lived experiences of sickle cell disease and previous health warnings they had encountered caused the high risk label to be less alarming and almost expected.

### What Do You Mean I’m High Risk?

Conversely, several women in the study (N=7) were less accepting of the high risk label, because it did not parallel their past lived experience with sickle cell disease. Jewel, a 41 year-old mother of four, interpreted the high risk categorization as an indication of danger.

Everything about pregnancy with sickle cell is a precaution. I was high risk because I was sickle cell. Each time I went to the hospital for pregnancy, once the doctor found out that I had sickle cell they would take me off of their list and put me with the high risk doctors. [PR: *What did that mean to you when they said you were high risk?*] That meant to me, danger. Whereas these other people, like a person without sickle cell, they have a greater chance on having a smoother pregnancy and they didn’t have to see a specialist and the whole nine yards, whereas I did. I had to see a specialist for this, a specialist for that, every pregnancy it was the same. Being high risk just sounds so serious. Danger. You know, that’s when somebody says high risk to me. That’s what makes me think you’re in a dangerous situation to be categorized as high risk. [PR: *Did you feel like you were in a dangerous situation?*] Depending on what was going on, they would make you feel like you were in danger. From the littlest thing as having a headache or your blood pressure is a little elevated. Those are big alarms for them.

As a woman with sickle cell disease, Jewel was prepared to have a “different” pregnancy experience than women without sickle cell disease. However, she did not expect to be made to feel as if by being pregnant she placed herself in a dangerous situation. Her lived experience with sickle cell disease brought about much more serious health concerns than high blood pressure and headaches. For Jewel, who had a stroke during adolescence, these were minor

issues that did not warrant such a serious reaction. Further, outside of the stroke, Jewel did not have any other health issues, reproductive events, or frequent pain symptoms.

Similar to Jewel, being labeled as high risk made Tia feel uncertain about what was to come. She stated that for her high risk meant “anything could happen. You got to be extra cautious. Any little thing it was a problem. While I was pregnant, everything was normal, like regular pregnancies.” Tia took the label of high risk, with both pregnancies, as a sign of caution. She felt as though her pregnancy was “normal”, yet her providers labeled her as high risk.

Clem, a 32 year-old mother of three, suggested that hearing the high risk categorization with her first pregnancy “freaked her out”.

It was like, “Okay, you are high risk; you fall into high risk category.” [PR: *When they said that, what does that mean to you?*] I am like, “Oh my God! I have to be watched carefully.” It kind of freaked me out. I was like, “Okay, where do we go from here?” They [her doctors] said, “Okay, we are going to really watch you carefully when you come in for prenatal visits. We will constantly watch your levels—just really specific. You know, watching.” They watched me more than other people. Then as the pregnancy would get further along, they were giving me stress tests to make sure my stress levels were low and everything was going pretty normal. They were never really specific about why I was deemed high risk; it was just like that was the procedure [for women with sickle cell disease].

Clem’s surprise response originated from the fact that until the age of twenty-six she had been told she had sickle cell trait and had experienced very few sickle cell symptoms so to now hear she was high risk caused her to become uncertain about the future of her pregnancy. During this pregnancy, while her providers were very specific about the health care plan, she did not feel they provided similar details about why this care was necessary. She indicated that with each of her pregnancies “I didn’t really have too many complications” and “normal aches and pains” which may have caused her to not understand why she was being labeled high risk.

Like Clem, Chloe, a 31 year-old mother of three, also experienced minimal sickle cell related symptoms during her lifetime. She had Hb-SC, the milder form of sickle cell disease,

and had only had one pain crisis at the age of twelve, which led to her initial diagnosis. For Chloe, being told she was high risk caused her to feel scared.

I'm always a high risk pregnancy, because of the sickle cell, [but] I never did feel high risk. The first time [I was high risk] it was because they [her doctors] told me that I was high risk. They just said, "You have sickle cell, you're a high risk pregnancy because you're going to have a crisis." Well I don't have those and I tried to tell them that but they said, "Things get bad when you get pregnant. If you have something it tends to get more severe when you're pregnant." So I was scared. I just went along with whatever they said because I did not know, especially with the first pregnancy. But the third time around I was a little more informed and I was more comfortable with staying with my doctors because that wasn't a high risk clinic. So I was more comfortable because I felt like I knew a little bit more. The other two times I just kind of went along with whatever they said. By the time I got to the third one, I kind of told them like, "Oh, here's the deal."

It took having the knowledge and experience Chloe gained from two previous pregnancies before she spoke up about being referred to high risk obstetricians. Prior to this, Chloe felt her categorization of high risk from her provider was unwarranted because it did not accurately reflect her past health experiences, yet she did not feel empowered to speak up. This example illustrates how, in matters of pregnancy, health care providers are often considered the expert over the woman herself. Although Chloe informed her providers that she did not have "typical" sickle cell disease symptoms, her providers proceeded to label her without considering that her experience with sickle cell disease was unique. Initially, Chloe was unsure how her body would respond to pregnancy and therefore "went along" with the high risk label, even though she felt it was unwarranted. However, after two pregnancies and not experiencing any disease-triggered symptoms, in her third pregnancy she was much more comfortable rejecting the high risk categorization and exercising agency by intentionally seeking prenatal care from providers who did not specifically provide care to women who were high risk.

Gabrielle, a 36 year-old mother of two, also had the milder form of sickle cell disease.



In my case being pregnant actually helped me because my fetal hemoglobin mixed with the baby's hemoglobin I was never sick. I was high risk because they thought, "Oh she is going to be sick," but I wasn't. I didn't have one crisis, no pain, nothing. I was healthier pregnant—much.

Like Chloe, Gabrielle's providers predicted being pregnant would aggravate her symptoms. Yet, Gabrielle indicated feeling "healthier" when she was pregnant. From the beginning of the interview, Gabrielle continued to reinforce that she was "totally different than any other 'sickler.'<sup>19</sup> I'm tall, I'm fat and you don't see that in most 'sicklers.'" She also had not experienced frequent symptoms or hospitalizations. Different from the women who took being labeled as high risk in stride, Jewel, Chloe, Clem and Gabrielle were among the seven participants who were less accepting of the label, and both groups' attitudes were determined by their lived experiences of sickle cell disease.

### *Summary*

The concept of high risk is applied to women in this study because of the potential complications associated with pregnancy and childbirth among women with sickle cell disease and gives rise to medicalization. Pregnancy is an assumed time of risk and women should be motivated to avoid any type of risk and ensure they have a healthy pregnancy. Therefore women are considered able to minimize the pregnancy risk through testing, monitoring, and regulation. However, participants based the meaning of being high risk in their lived experiences, rather than the fact that they had sickle cell disease. Women with more symptoms and more sickle cell related reactions took the label in stride, while those with fewer symptoms and milder forms of the condition were less accepting of the label and suggested it did not reflect their experience. In many of the scenarios described above, health providers positioned all pregnancies, included

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<sup>19</sup> A "sickler" is a slang term for a person with sickle cell disease or sickle cell trait and in some cases is a negative word to describe this population

uncomplicated pregnancies, within the disease model and categorized them as abnormal. Under this guise, health providers, who have the skills and technology, gain authority to determine the type of pregnancy and undermine women's knowledge and experiences of pregnancy. Women who were less accepting of the high risk label indicated that having this categorization led them to fall under medical surveillance, receive additional and unwanted medical attention, and undergo increased interventions (e.g., frequent appointments, stress tests, prenatal testing, and ultrasounds). Participants with limited pre-pregnancy medical experience were less welcoming of the increased monitoring and additional prenatal care.

Participants' stories highlight the medicalization of their pregnancies because of the providers' disease orientations and expectations of increased illness-related symptoms. This heightened perception of risk is caused in part by pre-established notions of pregnancy is a time of risk and danger and therefore already subject to medical surveillance (Parry 2008). In this context the combination of the availability of medical technology (e.g., testing and monitoring) and women's pre-existing disease classification create opportunities for professional dominance and the diminished importance of participants' bodily experiences.

The two groups are also distinguished by genotype, with the former group having the more severe type of the disease (Hb-SS) and the latter having the less severe type of sickle cell disease (Hb-SC). Ultimately participants who experienced more sickle cell symptoms (e.g., pain crises requiring frequent hospitalization) accepted the high risk categorization in stride compared to participants who experienced fewer sickle cell symptoms who were less accepting of the high risk label. Even in this small sample, then, data indicate the variation in the sickle cell disease experience; not all women who have this disease have the same health trajectory. An implication of this variation is that providers need to assess more fully the exact nature of women's sickle

cell disease and how it might impact their reproductive life courses. Labeling all women “high risk” in pregnancy masks the severity of some women’s conditions and the more minor effect that sickle cell disease has on others. Additionally, women who were less accepting of this categorization had a different outlook on pregnancy and pregnancy risk when compared to their providers. How provider and patients differing outlooks on pregnancy might affect patients’ perceptions of risk should be explored further.

For women in this sample, sickle cell disease served as a context for providers to understand their pregnancy experiences. However, simply having sickle cell disease did not always determine how participants would think about pregnancy. Unlike in previous results sections in this chapter, here some participants did not understand the extra concerns their providers had that warranted high risk categorization. These data further highlight the variation in women with sickle cell disease and that reproductive health providers should consider this when providing care.

#### *My Sickle Cell Disease Symptoms Don’t Stop Just Because I’m Pregnant*

Seven women in the study indicated they had experienced at least one pain crisis during their pregnancy, which required medical treatment from a health care provider. In addition to the lack of clinical knowledge non-sickle cell providers may have about sickle cell disease, this lack of knowledge may also impact their interpersonal interactions with patients causing judgment and racially fueled beliefs. Pain continues to be part of the pregnancy experience among women with sickle cell disease. Mou Sun and colleagues (2001) found that women with sickle cell disease (Hb-SS) are significantly more likely to need antepartum hospital admission (62%; often as a result of sickle pain crises, pyelonephritis, and anemia). Thus, as one of the primary

concerns among women with sickle cell disease, their reproductive health care providers should also be aware of this. Pearl, a 37 year-old mother, encountered disparaging remarks from a health care provider when she sought pain treatment while pregnant.

When you have it [SCD] and you're pregnant, that's a whole 'nother animal because people treat you like a dog. You deal with a lot of prejudice when you have sickle cell. I was like already stuck in this place and I will admit [hospital] is the nicest place to be stuck in because it's like a hotel. They have the refrigerator full of sodas and the TV, so that part was nice. It's just all the racism, [it's] really hard. They were really prejudiced. They talked to me like I was a crack-head. You know, some of the things they said to me were so hurtful, like I was a monster. [PR: *Like what?*] Because I had a couple of pain crises [when I was] in the hospital. [They asked me], "Why would you take Morphine? Your child knows what Morphine is. You're giving that to your baby now." Oh my God! I'm in here crying, screaming, biting a rag, that's how bad I'm hurting. If this was the Old West give me a shot of whiskey to pull the bullet out. You know what I mean? Anything! I'm dying in here! That was very difficult. I had a very difficult pregnancy. And then they're telling his dad, "Well they both might not make it. She's actually really bad." And I had to have to have two blood transfusions. This was the only time by the way I've actually had to have blood transfusions my entire life, when I was pregnant.

Pearl was hospitalized for four months prior to the birth of her son due to preeclampsia and high blood pressure. Having lived with sickle cell disease for over their years, this experience afforded Pearl the ability to contrast the treatment she received while pregnant to the care she received when she was not pregnant. Pearl's description of seeking treatment for pain while pregnant as "'nother animal" suggests that pregnancy caused a different response from providers regarding pain medication. She felt that these providers were judging her as a bad mother because she decided to receive pain medication. When the pain caused her to seek relief, providers responded with a lack of empathy. Pearl attributed some of this experience to the setting, a hospital in a very affluent location. While she benefited from the amenities in this location, she believed that she was treated poorly because of it as well.

One of the medications individuals with sickle cell disease take to mitigate pain crises is Hydroxyurea. As detailed in Chapter 2, Hydroxyurea is taken orally and stimulates fetal hemoglobin production, raises hemoglobin concentration, increases the size of the red blood cell, lowers white blood cell counts, and decreases red blood cell intracellular dehydration (Hankins et al. 2005, Steinberg et al. 2003). However, Hydroxyurea is discouraged during pregnancy as it may increase the risk of adverse effects and fetal abnormalities (Brawley et al. 2008, Hassell 2005, Lanzkron et al. 2010). Tia, a 29 year-old mother, had taken Hydroxyurea but stopped taking it during pregnancy, which caused her to experience chronic pain and frequent visits to the hospital.

I take Hydroxyurea, which is like a miracle drug for me. That actually keeps my fetal cell count high so it made my cells round instead of sickle-shaped and it kept me out of the hospital a whole lot. When I got pregnant, because it's a chemo drug, I had to get off of it. When I was pregnant and I came in [to the hospital] and I said, "I need Morphine." He's [unknown provider] like, "Well you've been coming in for morphine quite a bit. Before you weren't really hospitalized and now you come in a whole lot, why is that?" I said, "Because I've been more sick [*sic*]. I stopped my medicine. I don't understand why I have to explain this to you. If I say I'm in pain you should treat me." He said, "I'm just saying I don't want to be feeding your addiction." I said, "My addiction?" I said, "What do you mean my addiction? I'm not addicted to anything. The only thing I'm addicted to is living my life." The world just seems so ignorant of sickle cell and it makes it harder to live.

Similar to Pearl, Tia also felt judged by providers for requesting treatment for sickle cell pain. Tia's more frequent hospital visits and the fact that pain is an invisible and subjective symptom created doubts about the credibility of her repeated complaints of pain. Pearl attributed her providers' reactions to the setting. Tia attributed this judgment to the lack of public awareness about sickle cell disease and felt that if the public was better informed, stereotypes of patients with sickle cell could be lessened.

As health care providers themselves, two participants—Chloe was a nurse and Mya was a physician assistant—shared their insider experiences of witnessing negative encounters between providers and pregnant women with sickle cell who sought treatment for pain.

I've been on the floor with sickle cell patients that [are] pregnant and the nurses don't even want to give them their medicine. These girls be screaming and shouting. (Mya)

I've seen it [race] influence other people with sickle cell. Women, or anybody with sickle cell, people think they are just drug-seeking. I've seen that. I've seen it. And of course, I'm way more sensitive to that because I have it and I'm a woman. But I have seen it happen, numerous times. I have met women [when] I worked in labor and delivery that have a problem with their sickle cell during their pregnancy. They have crises and they're ill and they're bed-ridden. I didn't have that problem, but that's what I've seen. Some of the women got treated like they were drug-seeking when they were in fact in pain. That was the issue I had working at that hospital. You're on this [side of town] and they're racist and I just never could understand that. How are you racist and you work here? There it was pretty obvious. (Chloe)

For Chloe, the providers' reactions toward women in these instances were not due to a lack of knowledge or concern about the effects of pain medication on the fetus, but rather racist stereotypes and a belief these women with sickle cell disease were going to abuse pain medication. Chloe acknowledged how her own race and illness identities made her more sensitive to these negative encounters but she believed that, because the hospital where she worked served a predominantly African American population, the staff should have been more sensitive to patients with sickle cell disease. Chloe intentionally sought care from African American providers who served in an inner-city facility, believing she would receive better care with these circumstances.

Black Feminist Standpoint Theory highlights how African American women occupy a unique standpoint based on their subjection to both racism and sexism (Collins 2000b). Through Joyce's experiences as both a patient and a patient advocate, she gained insight into

how racial and illness identities intersect to influence the care patients with sickle cell disease receive.

It's much harder there [in the hospital]. Much harder because you're dealing with a lot of racism and it's hard in that aspect of it is hard for me. The racism is hard. [PR: *In your opinion is it race? Is it sickle cell?*] It's the combination. What you have is a predominantly African American disease. Having sickle cell is tough. I mean it is really tough. Being a predominately Black disease, it's tough because you're not treated fairly. There are a lot of times that I've had to deal with racism. I know where it comes from. America has had a very scattered history when it comes to race relations. I understand that, but it's difficult when you're at your lowest point or at your sickest, [and] you are at times on your deathbed and you throw in the United States of America and our issues with race and stereotypes and you have a problem on your hands.

### *Summary*

Maintaining their reproductive health is not something that can be accomplished independent of supportive family members, knowledgeable health care providers, and a non-judgmental society. Some participants expressed their perceptions regarding providers' judgments of drug-seeking due to racial and illness stereotypes during pregnancy. For Pearl and Tia, they resolved these racial remarks as ignorance of sickle cell disease in society. In the United States, sickle cell disease is closely associated with African Americans who are vulnerable to racial prejudice and stereotypical attitudes, causing the disease to be viewed through a negative racialized lens (Geller and O'Connor 2008, Nash and Telfair 1994). During pregnancy, these stereotypes did not diminish but were intensified due to the impact of their decisions on the fetus.

Participants discussed experiencing racialized situations with health care providers that they did not know or trust. These providers were often unfamiliar with participants' medical histories. Especially in certain locations within the hospital setting (e.g., Emergency Room or inpatient locations), care is often administered by providers who are unfamiliar with the patient

and their medical history, causing providers to be more likely to be suspicious and less empathetic to complaints (Ratanawongsa et al. 2009, Shapiro et al. 1997).

## **Conclusion**

This chapter illustrates the importance participants placed on identifying providers with knowledge about reproductive health care, particularly gynecological care, contraception and prenatal care. Women in the study also felt it was important for their providers to be aware of the potentially health-harming effects of specific types of contraception for women with sickle cell disease. Finally, participants wanted their providers to be able to provide care in times of pain crisis or other sickle cell-related symptoms and not pass judgment on them during pregnancy. Participants were not always savvy in determining quality and competent care upon their initial introduction to reproductive health care (e.g., first pregnancy, first contraception use, etc.). However, as participants aged and gained more exposure to health care providers, they adopted higher expectations for patient-centered and informed care that gives consideration to sickle cell disease. Of note, participants often lacked this knowledge themselves, so they were dependent on their providers to advise and offer them safe care.

Over time participants who described doctor-centered interactions about reproductive health care also eventually approached recommendations for contraception, prenatal testing, etc., with caution. The doctor-centered approach is characterized as paternalistic and is based on the assumption that the physician as the medical expert and dominates decision-making (Byrne and Long 1976). In doctor-centered interactions, little consideration was given to their status as women with sickle cell disease or to understanding how important sickle cell disease was as a context for reproductive health care (Mead and Bower 2000). Hematologists often helped



participants understand how much standard reproductive care might conflict with their sickle cell needs. Hayes-Bautista (1976) suggested that once a patient perceives the provider as providing inadequate treatment, the patient attempts to modify the situation (Hayes-Bautista 1976).

In these instances, participants developed strategies for mitigating medical errors and achieving optimal health outcomes, such as identifying and consulting with other providers they felt were more knowledgeable or doing their own research to ensure they remained healthy. For example, some women in this study included hematologists or nurse practitioners (i.e., providers who might possess additional knowledge about their reproductive health care and/or be willing to seek it out) or discontinued receiving care from a provider who seemed unwilling to learn more about sickle cell disease.

Participants whose reproductive health care was patient-centered described greater confidence in their provider's knowledge and experience caring for women with sickle cell disease by acknowledging the illness into their care and recommendations. The patient-centered approach to the medical encounter has been characterized as involving less provider-controlling behaviors and more sharing of power and responsibility between the patient and doctor. A patient-center approach also typically involves providers' acknowledgements of the meaning patients attach to their illnesses, and providers' attentions to both verbal and non-verbal communication from the patient (Byrne and Long 1976, Mead & Bower 2000). In some instances a nurse practitioner or hospital staff member provided this care, not the physician. This suggests that those most trained in a biomedical model may not be prepared to treat the "different" SCD case. Strict biomedical training may inhibit a patient-centered approach to reproductive health care.

Finally, this chapter highlighted the recommendations and advice participants received from numerous providers with different medical specialties and varied levels of experience with and knowledge of sickle cell disease. The number and variation of providers consulted speaks to whom and what can influence women's reproductive decision-making. Women in this study exist within a web of medical providers with varying levels of interest, knowledge and expertise about their reproductive health and disease status. Never quite knowing how much providers know about or have experience with sickle cell disease means that women receive reproductive health care in very complicated and piecemeal ways. There is considerable room for improvement of reproductive health care for women with sickle cell disease as a result.

## **CHAPTER 8**

### **CONCLUSION**

The specific aims of this study were to (1) explore and describe the reproductive health experience of women with sickle cell disease, (2) describe social, environmental, and cultural factors that influence their reproductive health experience, and (3) investigate the ways in which women with sickle cell disease manage their reproductive health. Using a qualitative, phenomenological methodology, this study captured the authentic voices of 28 adult women with sickle cell disease and their perceptions and experiences of reproductive health and reproductive health care. In the study I explored particular dimensions of reproductive health and health care: sexual health, intimate partner interactions, contraception, prenatal care, reproductive health screenings and genetic testing. In this dissertation, however, I limit the focus of the findings to only three themes: (1) participants' resistance to discouraging reproductive messages, (2) participants' perceptions of and decisions about genetic testing and prenatal testing, and (3) how participants navigate and secure reproductive health care. Findings on other aspects of reproductive health will be reported elsewhere.

Guided by the theories within literature on the Sociology of the Body this study explored the embodied reproductive health experiences of the women with sickle cell disease. Within literature on embodiment, bodies are considered to be socially constructed rather than restricted to their biological or physical features. Thus, participants' bodies are not only understood via their physical existence (e.g., illness and symptoms) but also given meaning through the process of social interaction with others (e.g., family members, health care providers) (Waskul and Vannini 2006).

I approached data collection using phenomenological and Black Feminist Thought approaches, by placing participants' experiences at the center of my analysis (Collins 2000b). These methodological approaches begin with the connected knowers, those who know from personal experience. During the initial telephone conversation and during the informed consent process I assured participants that they were experts on this topic and I was hoping to learn all I could from them. I wanted participants to know that I respected their vast knowledge of the topic up front, and was clear that I wanted to learn from them about reproductive health within the context of sickle cell disease. Knowing this often motivated women to share very personal stories with me.

This study investigated three specific research questions. The first research question, "How do women with sickle cell disease think about and experience reproductive health?" focused on gaining an understanding of the reproductive health care participants received and how they thought about this care. This question was answered by participants' discussions of being questioned about their desires to have biological children, acknowledging their responsibility to avoid having children with sickle cell disease, asking their partners to undergo testing, making decisions to be tested themselves, and approaching uninformed and semi-informed providers. Participants were quite mindful of how their behavior would impact future generations or future children. Participants also discussed approaching reproductive health care with trepidation and purposefulness to ensure they received safe and proper care. These findings are described in Chapters Five, Six and Seven.

The second research question, "How do race, gender, and genetic illness affect the reproductive lives of women with sickle cell disease?" focused on the ways in which participants' believed their social identities impacted their reproductive lives. This question was

only partially answered because the study was specifically designed for women with sickle cell disease, thus illness emerged as a as a primary social category as much as race or gender. This illness identity also intersected and overlapped with gender and race contexts to create specific situations (i.e., a burden to get genetic testing and encourage partners to get tested, women's suspicions of incomplete/discriminatory care, etc.). The intersecting categories of race, gender and illness influenced relationship formation and dissolution, decisions to have biological children and the types of reproductive conversations they had with potential intimate partners. These social identities also sometimes influenced their interactions with health care providers and the standard of care they received, particularly when they were in unfamiliar hospital environments or hospitals that served non-minority areas. In these instances, participants were less trustful of providers' recommendations and motives. Only a select few participants believed that race shaped their medical treatment or interactions with hospital staff. These findings are described in Chapters Six and Seven.

The final research question, "What social, environmental, and cultural factors influence the ability of women with sickle cell disease to either seek or receive reproductive health care?" sought to uncover how these factors may influence how women with sickle cell disease come to understand reproductive issues. This question was answered by data on participants' perceptions regarding who should be able to reproduce and others' willingness to provide reproductive health care to women with sickle cell disease or support women's reproductive health decisions. These beliefs emerged as a result of statements made by family members and providers discouraging them from having biological children. Participants were faced with judgments of cultural norms on who should reproduce. These findings are described in Chapter Five, Six and Seven.

*Summary of Major Findings*

The findings that emerged in the analysis are often about embodied risk. For participants in this study, risk of biological reproduction was established before pregnancy occurred (by family members, doctors, and women themselves) and reiterated during genetic testing situations, intimate partner selection and relationship dissolution, conception experiences, the initial prenatal visit, prenatal care, hospital stays, and throughout the duration of the pregnancy. These risks included risk to women's bodies and health status during pregnancy and risk of genetic transmission to the fetus. Thus, the notion of genetic risk interfaced with already established notions of maternal risk to creating a situation within which women received clear messages that embodying reproduction was risk-filled and (therefore) maybe not worth it (Katz-Rothman 1993).

Ulrich Beck (1992) argued that society is becoming increasingly vulnerable to scientific innovation. This study showed how participants' pregnancies were medicalized both through recommendations for prenatal testing and genetic testing, as a means of identifying the risk of fetal disease and potential harm to mother. The main assumption behind the medicalization of pregnancy is that pregnancy and childbirth is a time of risk and danger (Parry 2008, Sagrestano and Finerman 2012). By attaching the label of "high risk" to a pregnancy shifts pregnancy and childbirth from a natural and normal occurrence to one that requires scientific monitoring, testing and surveillance. From a feminist perspective, the medical involvement of pregnancy can be seen as a form of social control and an interruption to women's bodily autonomy that entitles medical professionals access to the body (Westfall 2006). For example, even when participants expressed their resistance to the high risk label—because they felt that their bodily experience did not warrant the label—health care providers continued to assume authority over the pregnancy

experience. Another example of medical surveillance is found in stories about participants being encouraged to undergo prenatal testing even after their partners had already been tested.

Risk also caused participants to be discouraged from having biological children at times. Women were discouraged because their bodies posed a risk to themselves and to any children they might have. Discouraging reproductive messages often came from close family members and health care providers. Participants believed that the messages arose out of health concerns. In other words, others (often family members but also providers) believed that they were too sick to bear children, or that they would become sicker when pregnant. However, participants often looked to their own embodied experiences of living with sickle cell disease to determine whether they were healthy enough for pregnancy and childbirth. Barbara Rothman (1986) introduced the concept of the “tentative pregnancy” to describe the context for prenatal testing. In my study pregnancies were considered tentative by participants’ parents and providers at times, due to concerns about maternal risk and genetic inheritance, but participants were less likely to think of their own pregnancies as tentative. Participants’ perceptions of their own risks were not static but, rather, changed over time however. For the most part, participants’ views of the appropriateness of pregnancy was based on the fluidity of their individual health statuses as well as their feelings about their intimate partners and embodied disease experience.

Faye Ginsburg and Rayna Rapp (1995) employed the term “stratified reproduction” to describe the conditions under which some categories of women are valued and supported in bearing and raising children while others are not. Stratified reproduction illustrates how reproduction is structured across social and cultural categories, empowering, encouraging and resourcing privileged women and disempowering other women. Some children are considered worthy of being born and efforts are made to ensure those births occur (e.g., assisted

reproductive technologies) (Ginsburg and Rapp 1995). Women in this study were discouraged from giving birth to children who would be born with sickle cell disease, however.

As Jada notes in Chapter 6, however, *“We’re still normal, regular women in my opinion.”* That participants often did not find themselves too sick to have children illustrates the importance of distinguishing between disease and illness and of recognizing that all women, regardless of what they specifically embody, may have reproductive desires. While others considered participants to be in a constant state of sickness, participants understood themselves as women with life-long (“lived-with”) illness. “Disease” is a biomedical concept based on empirical evidence of pathological abnormalities in the body, recognized by signs and symptoms which can be observed, measured, and analyzed using clinical standards (Eisenberg 1977, Idler 1979). “Illness” is a subjective phenomenon defined as a disturbance of social life preventing usual pursuits and activities within given social contexts (Conrad 1987, Idler 1979). Having a congenital, lived-with illness, participants did not view themselves as too sick to have children and, instead, allowed their own bodies to dictate their assessments of health status. Nonetheless, embodying sickle cell disease meant having to deal with others’ perceptions of the debilitating nature of the disease, even if it was something that one learned to live with and adapt to. This meant that women had to learn how to confront discouraging and often inconsiderate messages about reproduction and consistent suggestions about genetic testing while making their own decisions about whether and how to lead reproductive lives and navigate reproductive health care.

Throughout their lives, many participants described resisting discouraging reproductive messages and exercising agency in making their own decisions. Participants illustrated their abilities to negotiate their own reproductive desires with family and providers and respond to



external constructions about whether they should have children. Their behavior is best described as everyday acts of resistance in that their behavior may not be overt, but it is evidence of their ability and motivation to take control of their reproductive lives in small ways (Hollander and Einwohner 2004). For example, much of this agency was via enacting specific strategies including seeking additional information, soliciting medical expertise from multiple sources, exercising their right to reproduce, becoming informed about their reproductive capabilities, and drawing upon personal experiences to make decisions rather than letting doctors or family members make decisions for them.

Much of participants' agency was possible because they believed that the outcomes of their child's sickle cell status was within their control and based on their behavior (Rowe et al. 2005, Wallston and Wallston 1978). Of all of the questions I asked during the interviews, the question that elicited the most response was, "What kinds of conversations have you had about genetic testing?" Nearly all women in this study acknowledged the risk of genetic transmission through their discussions of how to protect their future children from having sickle cell disease. Embodied risk establishes warnings about potential future illness for themselves and their children, susceptibility to the disease itself, and an awareness of the body as separate from the self (thus making desires for children separate from the reality of whether women can or should have children). However, In the face of this embodied risk, participants exhibited strong orientations toward an internal locus of control by asking their partners to undergo testing (Wallston and Wallston 1978). In regards to genetic risk that *is* constant, and particularly becomes more of an issue at times of reproduction, participants were more accepting of biomedical knowledge and knowingly carried the burden of trying to prevent the disease in their children. Asking partners to be tested was action they felt they could and should take to prevent

having a child with sickle cell disease. Additionally, several participants described having a spiritual locus of control, believing that whether they, or their children, would survive pregnancy and childbirth was in God's hands (Debnam et al. 2012). Through their own personal experience, participants were also committed to avoid "passing" sickle cell disease on to their children. One motivation participants expressed was to prevent their children from "suffering" the way they had, both from the physical symptoms and social judgment that accompanies sickle cell disease. Participants also viewed themselves as having the burden or responsibility of preventing this (as compared to someone who only carried the trait, for instance) because they knew the lived experience of having sickle cell disease. Participants illustrated this responsibility through their conversations about disclosure of having sickle cell disease to partners, about relationship formation and dissolution, and about using genetic testing to find out their partner's sickle cell trait status.

As I discussed in Chapter Six, this reproductive burden is gendered because, although both parents have a role in heredity, as the bearers of children, women are considered the carriers of sickle cell disease. As women in this study hinted, male partners did not always bear the brunt of decisions about testing or conceiving with partners who might have sickle cell as well. Male partners often took genetic testing less seriously or did not have as much information about testing as well. Thus, the responsibility for choosing to give birth to afflicted children (or, ultimately to confirm that this would not happen) falls on women alone (Caplan 1989, Ettore 2000).

Additionally, participants gave consideration to both their own assessment of their future as a mother as well as to social perceptions of themselves as mothers. In their considerations they speculated about whether they would carry parental guilt if they passed sickle cell disease to

their children and acknowledged that they would be blamed by society should their child be born with sickle cell disease. Parental guilt is a common response to a child's diagnosis with disease. For the most part guilt implies control over the situation and its occurrence (Kessler et al. 1984, Nixon and Singer 1993). According to Jackson and Mannix (2004), mother-blaming is a term that describes how mothers are blamed and held responsible for the actions, behavior and health of their children. Previous research supports these findings and indicates that mothers of children with sickle cell disease feel blamed for knowingly conceiving and giving birth to a child who suffers physically (Burnes et al. 2008, Hill 1994b). Society deems the decision of these women to have children as irresponsible—especially in light of knowledge of their genetic risk—and judges parents' who disregard genetic information as morally unacceptable. Thus, if women wish to have children in what are considered as less than ideal conditions, attempts are made by different sectors of society to dissuade and/or prevent them from doing so (Phoenix and Wollett 1991). Women can be viewed as both reckless and responsible in their responses to testing, because women who become mothers are viewed as bearing the burden of avoiding, reducing, or managing disability among her offspring (Lippman 1993).

#### *A Better Model for Reproductive Health Care*

The findings of this study demonstrate that a better reproductive health care model is warranted, one that includes individuals knowledgeable of sickle cell disease and one that provided an integrated system of primary and emergency care. Over time participants enacted their own strategies for ensuring they received adequate reproductive health care by involving multiple providers in their care and identifying providers with sufficient knowledge to care for them. Care for participants in the study appeared to be more thorough when it was delivered by

reproductive health providers (1) with existing knowledge of sickle cell disease (2) who are willing to learn more once they have a patient with the disease and/or (3) are in close contact with or in proximity to a hematologist who has specialized knowledge of sickle cell disease. Also, providers who acknowledge that, at times, sickle cell disease contexts are more important and that, at other moments, maybe those sickle cell disease contexts are less important to women. Both sickle cell disease and reproductive health can take precedence for women in different moments.

Participants emphasized that they needed their providers to offer reproductive health care options and attention to them just as to any “normal” woman, acknowledge the context of sickle cell disease as a context for care delivery but not use that context to limit care, and use as a starting point where individual women are within their reproductive experiences and sickle cell disease experiences, and treat both experiences as important. Also, the findings of this study suggest that closer attention should be paid to the offering of appropriate contraceptive methods, the meanings women give to genetic and prenatal testing, increased opportunities for patients to receive proper preconception counseling, and at base better understanding of the connections and overlaps between living with sickle cell disease and engaging in reproductive experiences.

Because the actual experiences of women with sickle cell disease have been excluded from most reproductive health literatures, policies and guidelines that affect them may have also emerged mainly from entities external to and uninformed by their experiences. Thus, an intended outcome of this study is to provide a better understanding of how women with sickle cell disease experience reproductive health care in order to inform clinical practice.

### *Study Contributions*

Results from this study make a contribution to the illness literature. Peter Conrad (1987) suggested the following types of chronic conditions: lived-with, mortal, at-risk, terminal, stigmatizing and disabling illnesses. Lived-with illnesses are non-life threatening conditions which a person is required to learn to live with, mortal illnesses are conditions that are life-threatening, and at-risk illnesses are conditions that are contracted through predisposing, exposure, or hereditary pathways. Sickle cell disease is a good example of overlapping categories as it has onset at birth, is genetic, life-long, and life-threatening. Within the context of congenital conditions, no comparison of a past self or reference to a pre-illness state exists. Therefore, congenital illness can become as much a part of participants' biographies as other social locations into which they were born (e.g., race or gender). Further, this study adds to the literatures on women's health and reproductive health in that research has only been completed on women's perspectives on reproductive health when they *develop* a disease (e.g. breast cancer, Huntington's Disease), rather than when they are *born* with a disease. Simon Williams (2000) suggested that genetic conditions should be investigated because, "phenomenologically and existentially speaking, it remains the case that these biographies have not, in any real or significant sense, shifted" (Williams 2000: p. 50).

Providers should also avail themselves of the nuances of this disease to be equipped to provide them with accurate and up-to-date information to maintain the gynecological and prenatal care. The idea of integrated care is supported by the American College of Obstetricians and Gynecologists (ACOG) recently issued a practice bulletin on hemoglobinopathies in pregnancy and, in summarizing much of the literature presented above, advocated for a multidisciplinary approach in the management of pregnancy for women with sickle cell disease.

Specifically, they encourage an ongoing discussion between the obstetrician, hematologist, and anesthesiologist involved in the patient's care during the perinatal period. Given the probability for painful crises during this period and adverse pregnancy outcomes, the Association stresses the need for coordinated care (ACOG 2007).

As discussed in Chapter Four, the fundamental tenet in Black Feminist Standpoint Theory suggests that alternative epistemologies are built upon lived experience, not upon an objectified position, and emphasizes the importance of giving voice to the lived experiences. This study gave that voice to African American women with sickle cell disease who have been silenced from bringing their reproductive health issues to the forefront in both medical and social milieus simply because researchers have not prioritized conversations with these women. Further, by placing these women at the center of this study, they were empowered through telling their own stories in their own word rather than victimized through the voices of others.

This study may also give attention to the need for health advocacy and activism for women's right to control their reproductive lives beyond the popular pro-life/pro-choice debates into other areas affecting sexual and reproductive health. There is indeed a need for advocacy related to women's equality and reproductive freedom focused primarily on women's right to control their reproductive lives. The findings of this study give attention to the reproductive discourse for women with illness and the ways in which illness can also influence women's rights to bear children, particularly under a medical model that has the power to dispense judgment and medicine (including reproduction limiting procedures). Particularly for this population, the autonomy for their own reproductive decision-making, the right to bear children, or forgo testing, regardless of concerns for health or genetic transmission, is especially relevant.

*Study Limitations*

There were several limitations to this study. First, the applicability of the study findings may be limited to those medically diagnosed with the sickle cell disease and not those with sickle cell trait. The findings of this study may also be limited by self-selection bias. Those who are talkative, critical or have a desire to share a particular life experience are more likely to volunteer than those who are private, quiet, or accepting of that experience (Rossi and Freeman 1989). It is also possible that those who had more severe symptoms did not volunteer for an interview due to their illness identities, symptoms, or low energy levels. It is also possible that those with more physical experiences with sickle cell disease symptoms may have given more thought and attention to the ways in which the illness impacted their lives. While I attempted to minimize any form of social distance between me and my participants due to education or economic status, social distance may have still been present because I do not have sickle cell disease. Snowball sampling may have increased trust levels between the participants and the researcher; however it may have also decreased the demographic variation (e.g., economic status, age, or education) within the sample. Because sickle cell disease was so closely connected to race for women in this study, it was difficult to determine the exact source of instances of discrimination or prejudice. Also, these findings are limited in that I did not ask specifically about care locations, race or gender of providers, or how long they had been seeing a particular provider, which may have also influenced participants' perceptions of the care they received. As previously mentioned in Chapter Four as well, the findings of this study may be limited to the sampling strategy from locations that either offer medical care or social support and education to women with sickle cell disease. Another limitation is that, as mentioned above, health status is not static and may influence perceptions and experiences which may also change at different stages of life.

Thus, the findings of this study may also be limited because it captured participants' perceptions of reproductive health at one time point rather than over their life course. Also, because I used illness as the starting point of this study, it is of no surprise that illness emerged as the dominant identity.

### *Policy Implications*

Two primary areas of policy are of importance for reproductive health for women with sickle cell disease. First, it is critical that genetic testing be accessible for those who desire to undergo testing. While prenatal and newborn screening have become commonplace in prenatal and postnatal care, genetic (partner) testing is not currently one of the services covered under The Patient Protection and Affordable Care Act (ACA). The Genetic Services Policy Project has reported low utilization of genetic counseling and carrier screening by at-risk individuals and couples, and limited provider awareness/attention to carrier screening, especially in non-prenatal settings (Genetic Services Policy Project 2013). Through the ACA, women can go directly to their OB/GYN without a referral, which may not only increase women's access to reproductive health care, but also allow them to receive other care (e.g., screenings for domestic violence, HIV, etc.) through preventative services offered without copays or deductibles. Due to the inherited nature of autosomal recessive genetic disorders, screening for these conditions is also frequently incorporated into routine obstetric care. It is essential that these physicians accurately assess and communicate the risk of genetic disorders. Also, continued support from the federal government (through legislation or research funding) for the Sickle Cell Disease Association of America will be important in future years. This organization has done much over the past 40



years to increase public awareness in hopes of both mitigating illness-related stigma and the social fear of contagion and advocating for improved health care services.

### *Directions for Future Research*

Since this research only collected the perspectives of women with sickle cell disease, this research could be expanded by investigating the perspectives of those delivering discouraging reproductive messages, such as health care providers and family members, in order to understand their rationale. Once understood, information and education could be developed and offered to providers and family members to give them the opportunity to be more supportive. Additionally, since males with sickle cell are also reaching reproductive age and experiencing urological problems (e.g., erectile dysfunction and priapism) that may influence their perceptions of reproduction, efforts should be made to incorporate their perspectives on reproductive health in order to capture uncover gender differences. Also, because I was unable to examine in depth how race affects women with sickle cell disease, perhaps a better method of exploring these identities would be to use a more quantitative approach with validated instruments that might be better able to disentangle social identities and the influences they have on health and health care. Finally, because this research suggests participants' decisions tended to be based on the embodied experiences of living with sickle cell disease, it would be helpful to compare attitudes of women with the disease to a sample of women with sickle cell trait who are asymptomatic. This would help us to comprehend the differences in women's perspectives toward reproductive health and decision-making.

The findings also support the concept of embodied knowledge in that participants used their own bodily experience (1) as a source of knowledge in reproductive decision-making and

(2) to define their own meaning of their reproductive risk. Hopefully, this study will begin a discourse that includes the voices of the women affected by this condition and will serve to raise awareness and bring these voices to the forefront to improve reproductive health care for these women. As Joyce put it, “*We **have** to have these conversations... Knowledge is power. Talking and communicating is the only way that you can bridge the gap.*”

**APPENDIX A**  
**PRE-SCREENING QUESTIONS/SCRIPT**

Thank you for contacting me regarding your participation in this study. The study is about the reproductive health experiences of African American women with sickle cell disease. If you are eligible and choose to participate, you will be interviewed, in-person, for about 1-2 hours and asked to fill out a short survey. I will also ask that I be able to contact you after the survey in case I have further questions or need to clarify anything that was discussed during the interview. During the interview I will ask you questions about your experiences as an African American women with sickle cell disease. I will also ask questions about contraception, pregnancy, motherhood and your interactions with family and health care providers.

Are you interested in seeing if you meet the criteria to participate in this study? Do you have any additional questions before I proceed?

Criteria #1 – Are you a female?

If yes, continue with next question.

If no, the person does not meet the study criteria.

Criteria #2 – Are over the age of 18?

If yes, continue with next question.

If no, the person does not meet the study criteria.

Criteria #3 – Are you African American?

If yes, continue with next question,

If no, the person does not meet the study criteria.

Criteria #4 – Do you have sickle cell disease (NOT TRAIT)?

If yes, continue with next question.

If no, the person does not meet the study criteria.

Criteria #5 – Are you willing to participate in a face-to-face interview?

If yes, continue with next question.

If no, the person does not meet the study criteria.

If all the answers to the above questions are yes, proceed. Great! You are eligible. Can we schedule the interview now? When is a good time for you to have the interview?

Day/date: \_\_\_\_\_ Time: \_\_\_\_\_ (am/pm)

Location \_\_\_\_\_

If it's OK, I will call you the day before just as a reminder. Is this the best number to reach you, or do you prefer another phone number? Preferred Phone Number: \_\_\_\_\_

What is the best time to call? Time(s): \_\_\_\_\_

Thank you and I will call you the day before the interview.

**APPENDIX B  
INTERVIEW GUIDE**

**STUDY CODE # \_\_\_\_\_**

**RECRUITMENT SITE/METHOD \_\_\_\_\_**

**INTERVIEW GUIDE**

Tell me about your life with sickle cell? (school experiences, family experiences, friends, relationships)

How did you first learn how to take care of yourself?

Is there anybody you can call on to help when you don't feel well?

How do you think you first came to understand what it meant for you to have sickle cell?

Are you open about having sickle cell? I'm interested in understanding how people make decisions about whether and when to share with others that they have sickle cell?

Are there any situations that you found it easier or harder to discuss?

What leads you to tell people in the first place? What causes you not to tell?

Thinking back, how do you think you learned about what it meant to be a woman? What do you know about these things? Where or who did you get this information?

What does it mean to you to be a woman with sickle cell disease? In what ways do you think you're the same or different as other women?

When you hear the term reproductive health, what things come to mind?

Thinking back, how did you first learn about reproductive issues (periods, how babies are born, birth control, etc.?)

What do you know about these things? Where or who did you get this information?

In what ways do you think having sickle cell may impact any of these reproductive issues?

If she says, her mother taught her...ask about the relationship with her mother? What is it like?

**PUBERTY**

When did you start puberty, developing? Start your menstrual cycle? How did you feel about that?

Had you already known what to expect before it happened?

In what ways do you think your menstrual cycles may be affected by having sickle cell?

Have you ever used **BIRTH CONTROL**

What type? How did you come to use birth control? How did you come to use this TYPE of birth control?

If no, why don't you use birth control?

**MOTHERHOOD**

Do you have any children?

Yes

1. Before you had children, what were your thoughts about becoming a mother?

2. Take me back to when you first found out you were pregnant, what was that like?
3. In ways might having sickle cell influenced your plans for becoming a mother?
4. Tell me a little bit about your interactions and conversations with your doctor.
5. In what ways do you think having sickle cell impacted your pregnancy?
6. Do you think you were able to make the choices you wanted to about becoming a mother?
7. What has it been like having children?
8. Do you think you'll have more children?

#### No Children

1. What are your thoughts about becoming a mother?
2. In ways might having sickle cell influence your thoughts about becoming a mother?
3. Do you think you are able to make the type of choices you want about becoming a mother?

Do think you may have any difficulties with getting pregnant? If so, would you consider infertility treatment or adoption?

#### SEXUALITY

Thinking back, how did you learn about sex? Who or where did you get information from? (are they sexually active?)

When you hear the term "safe sex" what comes to mind?

In what ways do you think having sickle cell may influence your intimate relationships (either hetro- or homosexual..having boyfriends, etc.)?

In what ways do you think having sickle cell may influence your sexual experiences (either hetro- or homosexual)?

#### OTHER

Do you see an **OB/GYN**? How old were you the first time you went to see an OB/GYN. What prompted the first visit? Have you continued to see this person?

#### Prenatal Testing

What kinds of conversations have you had about prenatal testing/amniocentesis?

Who? What was said? Did you understand it? What did you think some of the pros/cons were?

Do you think it is something you would consider doing?

#### Genetic/Partner Testing

What kinds of conversations have you had about genetic testing?

Who? What was said? Did you understand it? What did you think some of the pros/cons were?

Do you think it is something you would consider doing?

Would you feel comfortable asking your partner to get tested?

What types of things do you consider when you are making these types of decisions? Who do you look to for help when making these types of decisions?

#### Specific Issues

Have any of your providers ever asked you about **depression**?

Have any of your providers ever asked you about **domestic violence**?

Have you ever been tested for **HIV/STD**? If yes, what promoted the test?  
Would you say you feel more comfortable asking potential intimate partners about HIV/STDs or genetic testing?

Let's talk about your experienced with the health care system and providers.

How many health providers do you have?

What have your experiences been seeking health care?

In what ways do you think your experiences may have been influenced by your race?

In what ways do you think your experiences may have been influenced by having sickle cell?

In what ways do you think your experiences may have been influenced by being a woman?

What techniques do you use to make sure you get proper care?

What recommendations would you have to health care providers about taking care of women with sickle cell disease?

What does it mean to you to be a woman with sickle cell disease? In what ways do you think you're the same or different as other women?

What recommendations would you have to other women with sickle cell disease about any of the things we've talked about today?

Are there any issues that I did not address that you consider important as a woman with sickle cell disease?

Can I ask why you decided to participate in this research?

**APPENDIX C  
DEMOGRAPHIC QUESTIONNAIRE**

STUDY CODE # \_\_\_\_\_

RECRUITMENT SITE/METHOD \_\_\_\_\_

Thank you for your participation in an interview today. Please complete this short questionnaire. Answers to this questionnaire will also remain confidential and does not include a request for any identifying information.

Date: \_\_\_\_\_

**SOCIAL HISTORY**

What is your age? \_\_\_\_\_

In what year were you born? \_\_\_\_\_

What is your marital status? Please check one.

[1]  Single, never married

[5]  Married

[2]  Single, divorced

[6]  Other (please explain)

[3]  Widowed

[4]  Living with partner

How do you identify your sexual orientation? Please check one.

[1]  Straight/Heterosexual

[4]  Prefer not to state

[2]  Gay/Lesbian

[5]  Other

[3]  Bisexual

What is your highest educational attainment? Please check one.

[1]  No high school

[5]  College graduate (bachelor's degree)

[2]  Some high school

[6]  Advanced degree (master's or doctorate)

[3]  High school graduate or equivalent

[7]  Other

[4]  Some college or associate's degree

Have you ever been employed?

[1]  Yes

[2]  No

If yes, what is your current employment status? Please check one.

[1]  Unemployed

[4]  Retired

[2]  Employed part-time

[5]  Other \_\_\_\_\_

[3]  Employed full-time

Are you currently receiving Supplemental Security Income (SSI)?

[1]  Yes

[2]  No

What is your average household annual income? Please check one.

[1]  Less than \$25,000

[4]  Between \$75,000 and \$99,999

[2]  Between \$25,000 and \$49,999

[5]  Between \$100,000 and \$149,999

[3]  Between \$50,000 and \$74,999

[6]  More than \$150,000

In general, do you feel you have enough income to pay your basic expenses?

[1]  Yes                      [2]  No

### MEDICAL HISTORY

What type of sickle cell do you have?

[1]  Sickle cell anemia hemoglobin S (Hb-SS)

[2]  Sickle cell anemia hemoglobin C (Hb-SC)

[3]  Sickle beta-zero thalassemia (Hb-Sβ<sup>0</sup>)

[4]  Sickle beta-plus thalassemia (Hb-Sβ<sup>+</sup>)

[5]  Other \_\_\_\_\_

[6]  Don't know

How many pain crises, requiring hospitalization, have you had in the last 12 months?

[1]  None (0)

[2]  1-5

[3]  6-10

[4]  7-15

[5]  15-20

[6]  21 and up

List any other medical conditions (list any condition regardless of relationship to SCD):

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What type of health insurance do you have? Please check all that apply.

[1]  No insurance

[2]  Medicaid

[3]  Medicare

[4]  HMO insurance

[5]  Other private insurance

[6]  Other (please explain)

\_\_\_\_\_

### REPRODUCTIVE HISTORY

Do you have an obstetrics/gynecology (OB/GYN) physician?

[1]  Yes                      [2]  No

If no, why not? \_\_\_\_\_

---

How many times within the last 12 months have you seen him or her?

[1]  None (0)

[2]  1-5

[3]  6-10

[4]  7-15

[5]  15-20

What was the reason for your most recent visit to see your OB/GYN?

[1]  Annual pap smear

[2]  Pregnancy care and delivery

[3]  Miscarriage/abortion care services

[4]  Family planning services

[5]  Contraception consultation (to get  
contraception)

[6]  Sexually transmitted infection  
treatment and counseling

[7]  Other (please explain)

\_\_\_\_\_



How old were you when you got your first period? \_\_\_\_\_

Do you have regular monthly periods?

[1]  Yes                      [2]  No

Have you experienced menopause or early menopause?

[1]  Yes                      [2]  No

What type of birth control method have you ever used/currently using? Choose all that apply.

- [1]  Birth control pills
- [2]  IUD (Intrauterine Devise)
- [3]  Condom
- [4]  Contraceptive Patch
- [5]  Contraceptive Ring
- [6]  Depo-Provera (the shot)
- [7]  Rhythm Method
- [8]  Norplant
- [9]  None

How often do you use condoms during sexual intercourse?

- [1]  Never
- [2]  Sometimes
- [3]  Always

When was the last time you used contraception during sexual intercourse

- [1]  Never
- [2]  0-3 months ago
- [3]  4-6 months ago
- [4]  7-9 months ago
- [5]  10- 1 year

If never, why have you not used contraception?

- [1]  I am not sexually active
- [2]  I want to have a child/get pregnant
- [3]  I don't believe I am able to conceive
- [4]  I don't like contraceptives

Have you ever been pregnant?

[1]  Yes                      [2]  No

If yes, how many times have you been pregnant? \_\_\_\_\_

If yes, have these been planned pregnancies?

[1]  Yes                      [2]  No

Do you have any children?

[1]  Yes                      [2]  No

If yes, how many children do you have? \_\_\_\_\_ Ages: \_\_\_\_\_

What types of births have you had?

[1]  Vaginal birth

[2]  Cesarean section

[3]  Natural birth

[4]  Medicated birth (received pain medications during labor/delivery)

[5]  Other (please explain) \_\_\_\_\_

Did you breastfeed any of your children?

[1]  Yes                      [2]  No

If no, why not \_\_\_\_\_

Have you ever had an abortion/terminated a pregnancy?

[1]  Yes                      [2]  No

If yes, how many have you had? \_\_\_\_\_

Have you ever had reproductive difficulties or other reproductive events? Check all that apply.

[1]  Dysmenorrhea (pain during menstruation that interferes with daily activities)

[2]  Vaso-occlusive pain associated with menstrual cycles

[3]  Miscarriage                      If so, how many? \_\_\_\_\_

[4]  Ectopic pregnancy

[5]  Infertility

[6]  Hysterectomy

[7]  Unplanned tubal ligation (tubes tied)

[8]  Endometriosis

[9]  Cancer (ovarian/uterine/cervical/breast)[please circle all that apply]

[10]  Uterine fibroids

[11]  Ovarian cysts

[12]  Fibrocystic disease of the breast

[13]  Other reproductive difficulties (please explain) \_\_\_\_\_

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**Thank you for participating in this study**



## APPENDIX E PARTICIPANT INFORMATION SHEET

TITLE: Exploring How Women With Sickle Cell Disease Experience Reproductive Health

### Research Information Sheet

**Title of Study:**

Exploring How Women With Sickle Cell Disease Experience Reproductive Health

Principle Investigator (PI): Paula Thompson Ross  
 Department: Sociology, Wayne State University  
 Phone: 734-945-8929

**Purpose:**

You are being asked to participate in a research study to explore how women with sickle cell disease feel about their reproductive health and how they approach this aspect of their lives. This research is being conducted as part of the investigator's requirements in the PhD program in the Department of Sociology at Wayne State University. This study will recruit between 25-30 participants.

In this research study you will be asked to share your beliefs, attitudes and experiences about your reproductive health, which includes contraception, sexual activity, pregnancy, intimate relationships, genetic testing, and interactions with health care providers.

**Study Procedures:**

If you decide to participate in this study you will be asked to complete an initial 1.5-2-hour interview with the principle investigator. At the end of the interview you will be asked to complete a 5-minute questionnaire asking questions about your social background, medical and reproductive health history. The initial interview will be audio-recorded and will be transcribed and these transcripts will serve as the data for this study. The audio file and questionnaire will be kept in a locked file until transcribed after which they will be deleted. Once the dissertation has been completed the audio files will be erased and destroyed, however the non-identifiable transcripts will be kept.

**Benefits:**

As a participant in this research study, there may be no direct benefit for you; however, information from this study may benefit other people now or in the future.

**Study Costs:**

Participation in this study will be of no cost to you.

**Compensation:**

You will receive a \$10 Visa Gift Card for completing the in-person interview and survey.

**Risks:**

You may experience some psychological risk in thinking and talking about your illness and related reproductive health choices.

**Confidentiality**

Submission/Revision Date: [10/20/11]  
 Protocol Version #: [#1]

Page 1 of 2

### TITLE: Exploring How Women With Sickle Cell Disease Experience Reproductive Health

All information collected about you during the course of this study will be kept confidential to the extent permitted by law. You will be identified in the research records by a code name or number. Information that identifies you personally will not be released without your written permission. However, the study sponsor, the Human Investigation Committee (HIC) at Wayne State University, or federal agencies with appropriate regulatory oversight (e.g., Food and Drug Administration (FDA), Office for Human Research Protections (OHRP), Office of Civil Rights (OCR), etc.) may review your records.

You will be identified in the research records by a code name and number. When the results of this research are published or discussed in conferences, no information will be included that would reveal your identity. All audio files and written information will be kept in a locked file and only accessible by the investigator.

The investigator may stop your participation in this study without your consent. The PI will make the decision and let you know if it is not possible for you to continue. The decision that is made is to protect your health and safety, or because you did not follow the instructions to take part in the study.

#### **Voluntary Participation/Withdrawal:**

Taking part in this study is completely voluntary. If you decide to take part in the study you can later change your mind and withdraw from the study at any time. You are free to answer only the questions that you want to answer. Your decisions will not change any present or future relationship with Wayne State University or its affiliates, or other services you are entitled to receive.

#### **Questions:**

If you have any questions about this study now or in the future, you may the Principal Investigator, Paula Thompson Ross at (734) 945-8929 or [ptw2372@wayne.edu](mailto:ptw2372@wayne.edu) or Dr. Heather Millaway at (313) 577-3276. If you have questions or concerns about your rights as a research participant, the Chair of the Human Investigation Committee can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call (313) 577-1628 to ask questions or voice concerns or complaints.

#### **Participation:**

By completing the interview and survey you are agreeing to participate in this study.

## APPROVAL PERIOD

OCT 25 '11

OCT 24 '12

WAYNE STATE UNIVERSITY  
INSTITUTIONAL REVIEW BOARD

Submission/Revision Date: [10/20/11]  
Protocol Version #: [#1]

Page 2 of 2

IIR Date: 5/1/11

## APPENDIX F PARTICIPANT RESOURCE SHEET

### PARTICIPANT RESOURCES

#### SICKLE CELL

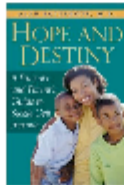
**National Heart Lung and Blood Institute**  
[www.nhlbi.nih.gov/health/health-topics/topics/sca/](http://www.nhlbi.nih.gov/health/health-topics/topics/sca/)

**Sickle Cell Disease Association of America**  
231 East Baltimore Street, Suite 800  
Baltimore, Maryland 21202  
Phone: 800-421-8453 | Fax: (410) 528-1495  
sclaa@sicklecelldisease.org  
<http://www.sicklecelldisease.org>

**American Sickle Cell Anemia Association**  
DD Building at the Cleveland Clinic, Suite DD1-201  
10900 Carnegie Avenue  
Cleveland, Ohio 44106  
Phone: (216) 229-8600 | Fax: (216) 229-4500  
<http://www.ascaa.org/>

Sickle Cell Information Center  
[www.scinfo.org](http://www.scinfo.org)

Book: *Hope and Destiny: A Patient's and Parent's Guide to Sickle Cell Anemia*  
by Alan Sacerdote, MD



**Sickle Cell Support Group**  
St. Joseph Mercy Oakland  
Room G on 4 Pavilion at St. Joseph Mercy Oakland  
44405 Woodward Ave.,  
Pontiac, MI 48341  
Phone: (248) 858-3399

**Sickle Cell Warriors (Information and Support)**  
[www.sicklecellwarriors.com](http://www.sicklecellwarriors.com)



## APPENDIX G HIC NOTICE OF APPROVAL

**WAYNE STATE  
UNIVERSITY**

IRB Administration Office  
87 East Canfield, Second Floor  
Detroit, Michigan 48201  
Phone: (313) 577-1628  
FAX: (313) 993-7122  
<http://irb.wayne.edu>

### NOTICE OF EXPEDITED APPROVAL

**To:** Paula Roca  
Sociology  
Faculty/Administration - 2226

**From:** Dr. Scott Millis *S. Millis*  
Chairperson, Behavioral Institutional Review Board (B3)

**Date:** October 25, 2011

**RE: IRB #:** 104811B3E  
**Protocol Title:** Exploring How Women with Sickle Cell Disease Experience Reproductive Health  
**Funding Source:**  
**Protocol #:** 1110010216

**Expiration Date:** October 24, 2012

**Risk Level / Category:** Research not involving greater than minimal risk

The above-referenced protocol and items listed below (if applicable) were **APPROVED** following *Expedited Review Category (#7)* by the Chairperson/designee for the Wayne State University Institutional Review Board (B3) for the period of 10/25/2011 through 10/24/2012. This approval does not replace any departmental or other approvals that may be required.

- Revised Protocol Summary Form (received in the IRB Office 10/21/2011)
- Protocol (received in the IRB Office 10/21/2011)
- The request for a waiver of the requirement for written documentation of informed consent has been granted according to 45 CFR 46.117(1)(2). Justification for this request has been provided by the PI in the Protocol Summary Form. The waiver satisfies the following criteria: (i) the research involves no more than minimal risk to participants as this is a 1.5 to 2 hour interview and the topic is not sensitive, no greater risk than would be encountered in daily life, (ii) the research involves no procedures for which written consent is normally required outside of the research context, (iii) the consent process is appropriate as it is minimal risk and there is no need for identifiers, and (iv) an information sheet disclosing the required and appropriate additional elements of consent disclosure will be provided to participants.
- Research Information Sheet (dated 10/20/2011)
- Tear-off Flyer
- Flyer
- Recruitment Letter from Andrew Campbell
- Recruitment Letter from PI
- Data collection tools: Pre-Screening Questions, Interview Guide, and Demographic Questionnaire.
- Participant Resources

- Federal regulations require that all research be reviewed at least annually. You may receive a "Continuation Renewal Review" approximately two months prior to the expiration date; however, it is the Principal Investigator's responsibility to obtain review and continued approval before the expiration date. Data collected during a period of lapsed approval is unapproved research and can never be reported or published as research data.
- All changes or amendments to the above-referenced protocol require review and approval by the IRB **BEFORE** implementation.
- Adverse Reactions/Unexplained Events (AR/UE) must be submitted on the appropriate form within the timeframe specified in the IRB Administration Office Policy (<http://www.irb.wayne.edu/policies-human-research.php>).


**APPENDIX H  
HIC AMENDMENT APPROVAL**

**WAYNE STATE  
UNIVERSITY**

IRB Administration Office  
87 East Canfield, Second Floor  
Detroit, Michigan 48201  
Phone: (313) 577-1628  
FAX: (313) 993-7122  
<http://irb.wayne.edu>

**NOTICE OF EXPEDITED AMENDMENT APPROVAL**

**To:** Paula Ross  
Sociology  
Faculty/Administration - 2228

**From:** Dr. Scott Millie   
Chairperson, Behavioral Institutional Review Board (B3)

**Date:** March 07, 2012

**RE:** IRB #: 104611B3E  
Protocol Title: Exploring How Women with Sickle Cell Disease Experience Reproductive Health  
Funding Source:  
Protocol #: 111001021E

**Expiration Date:** October 24, 2012

**Risk Level / Category:** Research not involving greater than minimal risk

The above-referenced protocol amendment, as itemized below, was reviewed by the Chairperson/designee of the Wayne State University Institutional Review Board (B3) and is APPROVED effective immediately.

- Protocol – Other changes which include the addition of the Sickle Cell Disease Association of America – Detroit Chapter as a recruitment location (letter of support dated 02/17/2012). This change does not affect risk to participants.



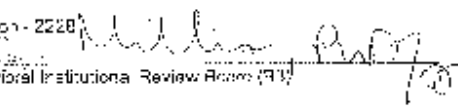
## APPENDIX I HIC AMENDMENT CONTINUATION



IRB Administration Office  
37 East Canfield, Second Floor  
Detroit, Michigan 48201  
Phone: (313) 577-1628  
FAX: (313) 993-7122  
<http://irb.wayne.edu>

### NOTICE OF EXPEDITED CONTINUATION APPROVAL

**To:** Paula Karr  
Sociology  
Faculty/Administration - 2228

**From:** Dr. Scott Willis   
Chairperson, Behavioral Institutional Review Board (B3)

**Date:** October 12, 2012

**RE:** R3 # 10401/B2E  
Protocol Title: Exploring How Women with Sickle Cell Disease Experience Reproductive Health  
Funding Source:  
Protocol #: 11107/0210

**Expiration Date:** October 31, 2013

**Risk Level / Category:** Research not involving greater than minimal risk

Continuation for the already approved protocols and items listed below (if applicable) were APPROVED following Expedited Review by the Chairperson/Designee of the Wayne State University Institutional Review Board (B3) for the period of 10/12/2012 through 10/31/2013. This approval does not replace any departmental or other approvals that may be required.

- Closed to accrual and active intervention completed 5/1/12

- Federal regulations require that all research be reviewed at least annually. You may receive a Continuation extension certificate approximately two months prior to the expiration date; however, all the Principal Investigator's responsibility to obtain notice and continue approval before the expiration date. Data collected during a period of expedited approval is unapproved research and can never be made or published as research data.
- All changes or amendments to the approved protocol must be reviewed and approved by the IRB BEFORE implementation.
- Advance Renewal of Expedited Awards (ARAE) must be submitted on the appropriate form within the timeframe specified in the IRB Administration Office Policy (Review of Wayne State policies for human research.php)

**NOTE:**

1. Upon notification of an impending regulatory revision, notification, and/or external audit the IRB Administration Office must be contacted immediately.
2. For updates for download from the IRB website to each unit.

\*Based on the expedited Review Certificate Number 1438

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**ABSTRACT****RISKING REPRODUCTION:  
REPRODUCTIVE HEALTH AMONG WOMEN WITH SICKLE CELL DISEASE**

by

**PAULA THOMPSON ROSS****August 2013****Advisor:** Dr. Heather Dillaway**Major:** Sociology**Degree:** Doctor of Philosophy

Reproductive health among women with sickle cell disease remains a critical gap in the literatures on sickle cell disease, reproductive health, and women's health. Sickle cell disease (SCD) is a condition with a complicated clinical sequelae, accompanied by a myriad of health complications, unremitting, extreme pain, and frequent hospitalizations. The purpose of this study was to explore the meaning and lived experiences of reproductive health and health care among women with sickle cell disease. Using a qualitative, phenomenological methodology, this study captured the authentic voices of 28 adult women with sickle cell disease and their perceptions and experiences of reproductive health and health care. Nearly all women in this study were advised to avoid having biological children because of the concerns for their health or that they would have a child with sickle cell disease. Despite this recommendation, participants exercised agency and looked to their embodied experience living with sickle cell disease when determining whether they were healthy enough for pregnancy and childbirth. Participants also described carrying a reproductive burden due to their genetic characteristics to ensure they did not "pass" sickle cell disease on to their children. Their motivations were derived from their desire to prevent their children from "suffering" the way they had, both from the physical

symptoms and social judgment that accompanies sickle cell disease. These findings illustrate the need for women with sickle cell disease to receive reproductive health care that takes into consideration their particular health characteristics in regards to gynecological care, contraception and prenatal care to avoid potentially health-harming recommendations that may exacerbate sickle cell disease symptoms.

This study extends existing ideas concerning the embodied risk and reproductive health from women who develop or contract risk, to those who were born with it. This information may also encourage more appropriate reproductive health care, and improve the understanding regarding the significance of reproductive health in general and within the context of illness among health care providers.

**AUTOBIOGRAPHICAL STATEMENT**  
PAULA THOMPSON ROSS

I earned a Bachelor's degree in African American Studies and Political Science in 2003 from Eastern Michigan University. In 2007, I earned a Master's degree in Sociology and African American Studies, also from Eastern Michigan University. In 2008, my thesis, *African American perspectives on Racial Solidarity* was published as a monograph. During these years I also worked at the University of Michigan Medical School where I believe I developed an interest for applying sociological concepts to the field of medicine and health. In 2007, I began the pursuit of a doctoral degree in medical sociology at Wayne State University. In 2008, I received a King/Chavez/Parks Fellowship and in 2010 was offered a Robert Thumble fellowship in recognition of her academic excellence. In 2012 I was the recipient of the Chow-Green Women of Color Scholarship and an award from the Blue Cross Blue Shield Foundation of Michigan. My research interests include reproductive health, sickle cell disease, stigma and illness, and health care disparities. I have also spent the last several years involved in medical education research exploring ways to improve perspectives of diversity within health care delivery and minimize health care disparities. Prior to pursuing my education, I served in the U.S. Army and am a proud Operation Desert Storm veteran.