
A Review of the Literature: Use of the Health Belief Model in Sickle Cell Research

Tilicia L. Mayo-Gamble

Abstract

Individuals with sickle cell disease experience a lifetime of morbidity as well as a decreased lifespan. Since African Americans are disproportionately affected by the disease, sickle cell contributes to growing health disparities within this population. Thus, addressing issues related to the disease presents an increased need for health education programming. A narrative literature review was conducted to assess the application of the health belief model in sickle cell trait screening research. Research articles were identified through an interdisciplinary search of peer-reviewed manuscripts. Articles including the following three criteria were selected for review: (1) use of the health belief model, (2) application to sickle cell disease/sickle cell trait, and (3) practical implementation in the field of public health education. Findings from this review indicate that the health belief model is not effective in all sickle cell trait screening interventions. Additional theories of health behavior should be considered when designing health education programs and interventions geared toward sickle cell screening.

Background

Sickle cell disease (SCD) is a recessive genetic disorder resulting in red blood cells forming into a sickled shape (Creary, Williamson, & Kulkarni, 2007; Long, Thomas, Grubs, Gettig, & Krishnamurti, 2010; Scott & Scott, 1999). The disease affects millions of people throughout the world and is particularly common among those whose ancestry comes from sub-Saharan Africa, Spanish-speaking regions in the Western Hemisphere (i.e., South America, the Caribbean, and Central America), Saudi Arabia, India, and Mediterranean countries such as Turkey, Greece, and Italy (CDC, 2014). It is estimated that at least 2 million people in the United States carry one sickle cell gene (U.S. Department of Health and Human Services, 2012).

Although there are several minority populations within the US affected by the disease, African Americans are particularly disproportionately affected. Approximately one in 12 African Americans has a sickle cell trait (SCT), while approximately one in 400 African American newborns are diagnosed with the disease each year. SCD is the most common genetically inherited disease affect-

ing African Americans (Acharya, Lang, & Ross, 2009). It is also the most commonly found genetic disease and has been recognized by the World Health Organization (WHO) as a major public health problem (Serjeant & Serjeant, 1992; WHO, 2011). As a result of SCD being identified as a public health problem, it is important to educate the at-risk community of the causes and implications of both being a carrier for the disease as well as having the disease (Acharya et al., 2009). It is also important for members of the African American community to know their SCT statuses so that they are aware of their risk of having a child with the disease.

One of the major complications of SCD is that sickled red blood cells become trapped within the blood vessels, thereby interfering normal blood flow and causing chronic pain (Scott & Scott, 1999). Identifying methods that have proven to be effective and ineffective in understanding attitudes and beliefs toward SCD and SCT will allow health educators to develop programs and interventions that more effectively build awareness and decrease the morbidity and mortality associated with SCD.

It is important to analyze the factors associated with low levels of knowledge and barriers in order to develop and implement interventions and education programs. To inform interventions that increase the number of individuals who know their SCT statuses, public health educators have applied behavioral theory interventions geared toward screening. One of these theories is the health belief model. This paper examines its application to sickle cell research as well as the population inherently afflicted by the disease. Identifying use of this model in research specifically geared toward a prominent health problem within the African American population would be valuable for practical use by public health educators. The primary purpose of this paper is to review the use and implications of applying the model in interventions that measure the knowledge, attitudes, and intentions of African Americans as it relates to screening for SCT. In addition, this paper discusses the use of the model as a tool that will allow health educators to increase both knowledge regarding SCD and SCT as well as increase the number of African Americans who know their SCT statuses.

Method

Theory

The health belief model (HBM) has been successfully used in the field of public health to inform interventions. The model posits that an individual will adopt a preventive health measure only if the person believes (1) the condition to be avoided is serious, (2) he or she is susceptible to the condition, (3) the intervention recommended will prevent the condition, and (4) there are no overwhelming barriers to adopting the intervention (Rosenstock, 1974; Rowley, Loader, Sutera, Walden, & Kozyra, 1991). The use of the HBM has been effective in assessing and motivating health behavior change among African Americans in regard to cancer screening, genetic information, and diabetic health care compliance (Gustafson, Gettig, Watt-Morse, & Krishnamurti, 2007).

Design

A narrative literature review was conducted to identify studies in which the HBM had been applied to sickle cell research. An interdisciplinary search of peer-reviewed manuscripts was conducted in social sciences, nursing, and educational databases. Examples of these databases include but were not limited to PubMed, JSTOR, ERIC, and Google Scholar. Key words used for the search included health belief model, sickle cell disease, sickle cell screening, and screening and African Americans. The titles and abstracts of articles identified in the search were checked for relevance based on the following criteria: (1) use of the HBM, (2) application to SCD/SCT, and (3) practical implementation in the field of public health education. After review, five studies were selected for further analysis. After screening these articles for the application of the HBM to sickle cell screening, all five were included in the final analysis. The studies in these articles will be summarized in chronological order.

Results

Study 1

Rowley, Loader, Sutera, Walden, and Kozyra (1991) conducted a comprehensive prenatal hemoglobinopathy screening program in Rochester, NY. Their study provided insight into the process women go through when presented with an opportunity for genetic testing. According to the research, a woman who is identified as a carrier may face three decisions (Rowley et al., 1991). The first decision is whether to accept the offer of counseling. The second decision is whether to have her partner tested. If her partner also tests positive, then the third decision is whether to accept the offer of prenatal diagnosis. The study analyzed factors affecting a woman's decisions in this situation. These factors were assessed through the use of the HBM. Factors predicting that a patient who has

been identified as a carrier would come for counseling included the following: the patient had no prior knowledge that she is a carrier, a gestational age less than 18 weeks, and Caucasian race (Rowley et al., 1991).

As a component of the study, providers of prenatal care in Rochester, NY were offered free testing of all their prenatal patients for hemoglobinopathies and free genetic counseling for women found to be positive (Rowley et al., 1991). One of the questionnaires administered after counseling consisted of questions regarding health beliefs. Participants (N=416) were asked questions related to their knowledge of the disease, the severity of the disease, and the belief that their children would not only have the disease but would have certain symptoms of the disease (Rowley et al., 1991). Participants were also asked if they knew their sickle cell statuses and questions related to the burden of finding out the results of their tests.

Factors found to predict participants' intent to have their partners tested included greater postcounseling knowledge of the disease and a lesser perceived burden of intervention and belief that the partner is also a carrier (Rowley et al., 1991). Also for SCT counselees, factors predicting that the partner actually will be tested were the following: (1) living with the partner, (2) gestational age at identification less than or equal to 18 weeks, (3) a lesser perceived burden of intervention, and (4) a greater perceived seriousness of the disease (Rowley et al., 1991). Measuring intent prior to the intervention and actual response following the intervention was an efficient means of measuring whether the concepts of the HBM effectively explain a woman's intent to be tested and to have her partner tested. However, the number of women who wanted their partners tested was significantly greater than the number of women whose partners actually got tested. Unfortunately this is a limitation to both the study and the application of the HBM to the study. This study brings to light the responsibilities that researchers, health care workers, and health educators have when offering genetic testing. Even if it is important and valuable for parents to know the probability of having a child who is ill, it is just as important to understand the psychological and emotional ramifications that could follow a positive test. Responses and attitudes to the screening may vary based on minority group. This issue was further explored in the following study conducted by Hill (1994).

Study 2

Hill (1994) conducted a study in which attitudes and reproductive behaviors of low income African American mothers who have children with SCD were examined. The study included qualitative strategies, participation, observation, and in-depth interviews with women (N=29) ranging from 21-55 years of age (Hill, 1994). Hill ad-

dressed the lack of success of health education programs having an influence on women's reproductive behaviors. The findings of the study indicated that the HBM may be less applicable to low income African American women.

Despite receiving medical information regarding SCD prior to giving birth to a child with the disease, the women reported mistrust in the medical profession. For those who did trust the knowledge they had received regarding SCD, patterns among motherhood, lack of access to health care, and values placed on motherhood were all reported as being factors contributing to the transmission of SCD (Hill, 1994). In addition, the women reported that they had a lack of power in their relationship to persuade the potential fathers of their children to be screened for SCT.

Contrary to beliefs about screening for SCT, the women in this study had background knowledge, knew the severity of the disease, and in many cases, knew their carrier status (Hill, 1994). However, these were not factors in determining the reproductive decisions. Knowing the risks, many of the participants chose to have one or more children. This has public health implications in terms of educating mothers on the steps that need to be taken in the event that they have a child with the disease.

This study illustrates that while some women knew they had SCT, they did not know what this meant in terms of reproduction (Hill, 1994). This contributes to the idea that if screening services are provided, counseling services should follow. Lack of follow-up services introduces a new public health problem that would need to be addressed. Nearly all of the women in this study found out that they had SCT after giving birth to a child with the disease (Hill, 1994). The study concludes that in order for screening programs to be successful, the programs cannot contradict the values that exist within the African American female community. This includes acknowledging issues of inequality posed by race, class, and gender (Hill, 1994). Programs that disregard these notions are likely to fail. In the following study, Gustafson, Gettig, Watt-Morse, and Krishnamurti (2007), used the HBM to overcome some of the issues of uptake presented in Hill's study.

Study 3

In the study conducted by Gustafson et al. (2007) the HBM was used to gain an understanding of low acceptance of disease prevention and screening related to SCD. The researchers chose this model as a lens for the study due to the fact that it has been successful in predicting intent amongst African Americans when applied to other diseases involving genetic testing. In using the HBM as a framework, the study posits that the pursuit of a health screening program will occur when an individual believes that the health concern is serious enough to warrant

screening, that he or she is at risk of the disorder and believes that there is a benefit to pursuing the screening, and that the barriers to pursuing screening are low (Gustafson et al., 2007).

The researchers collected data on the health beliefs of African American women to determine the causes of low acceptance of genetic testing and counseling despite the high prevalence of SCD and SCT carriers within the African American population (Gustafson et al., 2007). An assessment was conducted to determine factors motivating African Americans to participate in testing and counseling for SCD. The researchers argued that such an assessment would be beneficial in designing approaches to education and counseling. Participants in the study ranged from 18-45 years of age with the average age being 24 (Gustafson et al., 2007). The purpose of the assessment was to determine knowledge of SCD, perception of risk, severity, likelihood of benefit, and barriers to counseling (Gustafson et al., 2007).

It was found that high levels of knowledge were associated with high perception of severity and benefit to screening. The study concluded that African American women have a relatively high belief of the severity of SCD and benefits of genetic counseling (Gustafson et al., 2007). This finding is consistent with the literature regarding perception and intent for SCD screening. However, it was also found that African American women do not appear to believe that they are personally at risk of having a child with the disease. This is not consistent with the HBM. According to the hypothesis of this study, participants should have been motivated through a personal belief of their child's susceptibility. Similar to Hill (1994), while this study was successful in the aspect of increasing knowledge, it lacked in its ability to motivate participants to be tested for the sake of the child. Therefore, there must be other reasons to explain the lack of screening within the African American community. In the next study, Long, Thomas, Grubs, Gettig, and Krishnamurti (2010) applied the HBM to the concept of mistrust, which was not explored in the aforementioned studies.

Study 4

According to Long et al. (2010), research among African Americans indicates this population perceives SCD to be a serious disease and SCT screening an important intervention. However, studies have consistently demonstrated a lower than desired interest in SCD education, inadequate knowledge regarding personal and family trait status, and a low perceived susceptibility of giving birth to a child with the disease (Long et al., 2010). Consistent with the literature, Long et al. acknowledged that previous studies have reflected distrust toward genetic testing within the African American community. The researchers

examined general attitudes and beliefs regarding genetics and genetic testing including prenatal testing and newborn screening. This information was used as the foundation to more specifically assess attitudes and beliefs regarding SCD and perceived barriers to SCD education and awareness.

This study was conducted in two parts, a pre-discussion anonymous survey and focus groups. Thirty-five African American adult men and women participated in one of four focus groups. It was found that both prenatal testing and newborn screening are acceptable forms of genetic testing in the African American community (Long et al., 2010). Based largely on their personal experiences, participants possessed an understanding of the progression of SCD but had a limited understanding of inheriting the disease and the likelihood of giving birth to a child with the disease (Long et al., 2010). Barriers to education and greater awareness of SCD were classified as personal (fear of acknowledging the risk), familial (absence of discussion), and societal (mistrust from medical profession; Long et al., 2010). This study reported significant findings in identifying perceived barriers to SCD education in the African American community. The researchers proposed developing a community intervention based on the findings of this study.

Study 5

In another study to implement the HBM in sickle cell research, Treadwell, McClough, and Vichinsky (2006) identified knowledge and barriers to SCT screening in African American women. Knowledge, perceptions, and the effectiveness of different sources of information about SCT and SCD were evaluated. The purpose of the study was to determine individual knowledge of SCT status. According to Treadwell et al., while screening for SCD and SCT is imperative, it is also important to understand the ramifications of disclosing this information without offering education or means of dealing with psychological stressors associated with both the disease and the carrier trait. The study consisted of individuals who participated in one of three focus groups: healthcare providers, people affected by SCD or SCT, or community members (Treadwell et al., 2006). The focus groups were conducted with three goals in mind: identifying barriers to SCT follow-up, gathering perceptions of the general awareness of SCD, and generating potential solutions to the problem of low rate of trait follow-up (Treadwell et al., 2006).

Common themes across the focus groups included the limited general awareness of SCD and SCT, the emphasis on the nonthreatening nature of SCT rather than on future implications, and the need for public health education campaigns about SCD and SCT to involve media strategies (Treadwell et al., 2006). The majority of communi-

ty participants had correct general knowledge about the genetic basis and severity of SCD; however, participants were only aware of their own trait statuses (Treadwell et al., 2006).

One of the most significant results of this study, both statistically and theoretically, was the fact that when respondents had received information about SCD from friends and acquaintances, they were three times more likely to know their SCT status, compared with respondents who had not received information from a personal source. According to Treadwell et al., SCD management and detection can be a model for the empowerment of communities in making informed decisions about their own futures and that of their families, given the growing amount of information on genetic diseases specifically related to the African American community.

Discussion/Conclusions

Genetic research in general is an important discipline as it relates to the future of a community's health. While the HBM has proven to be effective in some interventions, the findings of this review indicate that educational techniques which implement the HBM are not always successful with SCT screening. One problem stemming from applying the HBM to screening for SCT is the issue of screening for a condition that is not preventable (Janz & Becker, 1984; Rosenstock, 1974). The concept behind the HBM is that by participating in a health related action, in this case screening, the individual will be able to prevent or avoid the health condition. Because SCT is genetic, individuals are not able to avoid or prevent their carrier statuses. In addition, if individuals test positive for SCT, they cannot avoid having a 25% chance of passing the trait on to their offspring.

Practical Implications

Initially, this analysis began with the goal of understanding the role of the HBM in motivating African Americans to be screened for SCT. However, these studies have revealed that this process extends beyond the boundaries of the HBM. In situations where the model is found to be effective, health educators must be prepared to offer follow-up services to individuals who are found to be carriers. If individuals are not provided with follow-up services in the form of counseling, education, and case management, the result is the establishment of a new problem within this community. In order for interventions geared toward identifying sickle cell carriers through screening to be effective, they must take a holistic approach to the problem rather than approaching the problem from one viewpoint. Future health education programs should also apply the HBM to further explore additional minority populations within the US in more strategies to increase screening and knowledge for the disease and trait.

Limitations

The limitations of this review should be considered. This review focuses on the use of one theory. There may be other theories within the field of health behavior that could be appropriate for the subject of interest. Also, data within the reviewed articles contain self-reported information which may be inaccurate due to recall bias, respondent bias, or interview bias. In addition, participants within the reviewed studies were residents of various states; therefore, the results may not be generalizable to states not included within the studies. I believe these limitations do not outweigh the relative contribution of this review.

References

- Acharya, K., Lang, C. W., & Ross, L. F. (2009). A pilot study to explore knowledge, attitudes, and beliefs about sickle cell trait and disease. *Journal of the National Medical Association, 101*, 1163-1172.
- Centers for Disease Control and Prevention. (2014). *Sickle cell disease (SCD)*. Retrieved April 1, 2014, from <http://www.cdc.gov/ncbddd/sickle-cell/facts.html>
- Creary, M., Williamson, D., & Kulkarni, R. (2007). Sickle cell disease: Current activities, public health implications, and future directions. *Journal of Women :S Health, 16*, 575-582.
- Gustafson, S. L., Gettig, E. A., Watt-Morse, M., & Krishnamurti, L. (2007). Health beliefs among African American women regarding genetic testing and counseling for sickle cell disease. *Genetics in Medicine, 9*, 303-310.
- Hill, S. (1994). Motherhood and the obfuscation of medical knowledge: The case of sickle cell disease. *Gender & Society, 8*, 29-47.
- Janz, N. K., & Becker, M. H. (1984). The health belief model: A decade later. *Health Education & Behavior, 11*, 1-47.
- Long, K. A., Thomas, S. B., Grubs, R. E., Gettig, E. A., & Krishnamurti, L. (2010). Attitudes and beliefs of African-Americans toward genetics, genetic testing, and sickle cell disease education and awareness. *Journal of Genetic Counseling, 1-21*.
- Rosenstock, I. (1974). The health belief model and preventive behavior. *Health Education & Behavior, 2*, 354-386.
- Rowley, P. T., Loader, S., Sutera, C. J., Walden, M., & Kozyra, A. (1991). Prenatal screening for hemoglobinopathies III: Applicability of the health belief model. *American Journal of Human Genetics, 48*, 452-459.
- Scott, A. A., & Scott, K. D. (1999). Cultural therapeutic awareness and sickle cell anemia. *Journal of Black Psychology, 3*, 316-335.
- Serjeant, G. R. & Serjeant, B. E. (1992). *Sickle cell disease*. New York, NY: Oxford University Press.
- Treadwell, M. J., McClough, L., & Vichinsky, E. (2006). Using qualitative and quantitative strategies to evaluate knowledge and perceptions about sickle cell disease and sickle cell trait. *Journal of the National Medical Association, 98*, 4-10.
- U.S. Department of Health and Human Services. (2012). *Blood disorders and blood safety*. Retrieved from <http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=4>
- World Health Organization. (2011). *Sickle-cell disease and other haemoglobin disorders*. Retrieved from <http://www.who.int/mediacentre/factsheets/fs308/en/>