Predictors of Support for Genetic Sickle Cell Services in North Texas

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Abstract

The purpose of this research study was to identify determinants of Support for Genetic Sickle Cell Services (SSCS) in north Texas. Secondary data was used to generate a subset data file collected from 2004 to 2008, targeting a random stratified sampling *of n=400. Descriptive statistics and inferential analytical techniques were used to further explore the data set and allow for a better understanding of the study participants and their responses. The findings of the study indicated that Reproductive Age was the strongest predictor of SSCS. The identification of these predictors provides clear direction for the development and implementation of programs designed to increase awareness about sickle cell disease/trait and genetic inheritance patterns.*

Key words: Support, Genetics, Sickle Cell services, Reproductive Age.

1. Introduction

This study focuses on the determinants of attitudes toward Sickle Cell Services (SSCS) in north Texas, during the year of 2004 - 2008. A Multi-site study conducted by Anie and Telfair (2005) suggests that the identification of factors in support of Genetic Sickle Cell Services is necessary to inform the development of programs leading to decrease the incidence of sickle cell disease. According to Frenette and Atweh (2007), Sickle Cell Disease (SCD) is an inherited blood disorder caused by the presence of an abnormal form of hemoglobin, the oxygen-carrying pigment, often known as hemoglobin S. The predominance of hemoglobin S leads to a deficiency of oxygen in the blood as sickle-shaped red blood cells are formed and unable to squeeze through small blood vessels. This leads to the periodic episodes of severe pain and chronic health problems including stroke, pulmonary hypertension, renal failure, retinopathy and leg ulcers. SCD painful events often result in hospitalizations, time off required for treatment and recovery, and the psychosocial disruption these may produce (Dunlop & Bennett, 2007).

Although, bone marrow transplantation has been successful in a small number of patients, the scientific community still struggles to find a universal cure for this disease (Ballas, 2001; Bloom, 1995). Persons with sickle cell trait are carriers of the sickle cell disease and sickle cell trait. If one parent has Sickle Cell Disease and the other is normal, all of the children will have sickle cell trait. If one parent has Sickle Cell Disease and the other has Sickle Cell Trait, there is a 50% of having a baby with either sickle cell disease or sickle cell trait with each pregnancy. When both parents have Sickle Cell Trait, they have a 25% chance of having a baby with sickle cell disease with each pregnancy. Often without realizing, parents pass down the sickle cell trait or abnormal hemoglobin that causes sickle cell disease to their offspring's contributing to a self perpetuating cycle that adversely impacts health and wellness of generations (Loureiro and Rozenfeld, 2005; Quinn, Rogers, & Buchanan, 2004; Metha, Afenyi-Annan, Byrns & Lottenberg, 2006).

Individuals with SCD and their families are severely impacted psychologically and socially as they cope with the complications of the disease (Anie, & Green, 2006). Persons with SCD suffer from stigma, discrimination, and social isolation.

A larger proportion of persons with SCD are likely to die early and also experience disruptions in family activities, social function, academic performance and job retention (Assanasen, Quinton & Buchanan, 2003; Claster & Vichinsky, 2003; Dunlop & Bennett, 2007). According to Kauf, Thomas, Coates, Huazhi1 and Mody-Pate (2009), SCD impacts the physical health and wellness of about 70,000 to 100,000 people in the United States. In fact, Kauf et al. (2000) states that over $1.1 billion is spent every year to address the health care needs of people who suffer from sickle cell disease in the United States. Nevertheless, after considering the additional impact of sickle cell disease exacerbated by reduced quality of life, uncompensated care, lost productivity, and premature mortality, the full cost of sickle cell disease is likely to be quite higher than the figures reported.

Primarily, African Americans are the most impacted by the SCD with the condition occurring in about 1 in every 500 African American births. Although sickle cell trait is highly prevalent among African Americans, 70% of this population is unaware of this high risk (Assanasen, Quinton & Buchanan, 2003). Consequently, 1 child in every 350 African American babies is born in Dallas Metropolitan Area with SCD. In fact, 1 child is born with SCD every 2 weeks in Dallas County (Dzandu, 2002). According to trends reported by Texas Department of State Health Services (2006), 3 out of every 1000 newborn black babies in Texas are born with SCD. According to Quinn, Rogers and Buchanan (2004), the number of new children born with sickle cell disease and sickle cell trait in the DFW area is increasing very fast. Hispanic Americans also are affected; the condition occurs in 1 out of every 1,000 to 1,400 Hispanic American births. Prior studies suggest that the best approach to reduce the prevalence and incidence of sickle cell is through the development of data driven genetic programs. The lack of support for genetic services, however, often emerges as a major problem in providing genetic sickle cell services.

Lin-Fu and Lloyd-Puryear (1999) suggest that the delivery of sickle cell genetic services targeting individuals of reproductive age often lack necessary support and utilization as most people believe they could not be at risk for genetic conditions if they do not have close relatives with the disease. Kalfoglou, Suthers, Scott, and Hudson (2004) conducted a research study employing a sample of 6,957 to assess Americans' awareness, knowledge, and attitudes about reproductive genetic services. They reported that 83 % of their participants had not heard of sickle cell genetic services. Furthermore, one third of their participants in the early reproductive age group (18-25 years old) believed that sickle cell genetic services such as screening and genetic counseling are unnecessary unless there is some family history of genetic disease. It is necessary to harness support for genetics services and bring about a clear understanding of the limitations and potential risks associated with genetic sickle cell services, to develop effective programs to combat SCD (Lin-Fu & Lloyd-Puryear, 1999). The purpose of this paper is to identify factors associated with support for sickle cell services delivery support for Genetic Sickle Cell Services (SSCS) in North Texas.

2. Review of Literature

Although the term ''sickle cell genetic services'' is easily found in the current literature, the cry for clarification regarding its implementation is defining. Davies & Oni (2001) suggests that sickle cell genetics explores the manner by which specific traits are passed from generation to generation and the way in which they are expressed. According Biesecker (2001) and Hegwer, Fairley, Charrow and Ormond (2006), modes of inheritance of the altered gene can be effectively controlled through the development of data driven sickle cell services. Nevertheless, the identification of predictors of support for sickle cell genetic services is still lacking in the current research study literature.

Upon an extensive review of the existing research literature, no salient studies emerged targeting the identification of factors associated with support for sickle cell services delivery. Most of the research conducted in the areas of SCD / SCT focused on understanding the disease process. This gap in the literature suggests the need for more research studies to test predictors of effective sickle cell services delivery. To all intents and purposes, Telfair and Nash (1996) strongly emphasized the importance of understanding main factors responsible for the effectiveness of sickle cell services delivery. According to Henneman, et al. (2001), the way in which sickle cell genetic services are offered, particularly as it regards to timing (i.e., preconceptional or prenatal) determine levels of support, participation and the reasons for decision making.

Lin-Fu and Lloyd-Puryear (1999) suggest that the delivery of sickle cell genetic services targeting individuals of reproductive age often lack necessary support and utilization as most people believe they could not be at risk for genetic conditions if they do not have close relatives with the disease.

Kalfoglou, Suthers, Scott, and Hudson (2004) conducted a research study employing a sample of 6,957 to assess Americans' awareness, knowledge, and attitudes about reproductive genetic services. Statistical findings indicated that 83 % of participants had not heard of sickle cell genetic services. Additionally, Kalfoglou et al. reported that one third of the participants in the early reproductive age group (18-25 years old) believed that sickle cell genetic services such as screening and genetic counseling are unnecessary unless there is some family history of genetic disease. It is note wordy that Texas Department of State Health Services (2010) reported a decrease in the number of individuals seeking genetic sickle cell services in the DFW area. Carrier status ignorance can result in future generations of chronically sick children with an additional burden of care exacerbated by emotional and financial cost to families and to the state. The identification of factors that influence support for genetic sickle cell services may prove to be effective in reducing the incidence of sickle cell disease in the DFW area.

According to Quinn, Rogers and Buchanan (2004), the number of new children born with sickle cell disease and sickle cell trait in the DFW area is increasing very fast. About 53,000 individuals are sickle cell trait carriers in Texas. The Texas Department of State Health Services (2006) showed the incidence of sickle cell trait among the main ethnic groups as follows:

- 1 in 12 (8%) or 47,848 African Americans,
- 1 in 200 (0.5%)or 3,624 Hispanics and
- 1 in 666 (0.15%) or 2,446 Whites

Although sickle cell trait is highly prevalent among African Americans, 70% of this population is unaware of this high risk (Assanasen, Quinton & Buchanan, 2003). Consequently, 1 child in every 350 African American babies is born in Dallas with SCD. In fact, 1 child is born with SCD every 2 weeks in Dallas County (Dzandu, 2002). According to trends reported by Texas Department of State Health Services (2006), 3 out of every 1000 newborn black babies in Texas are born with SCD. This tragic phenomenon is perpetuated by the faulty arrangements of health policies and laws in Texas. The Texas Department of State Health Services Newborn Screening (TDSHSNS) conducts follow-up only when there is a presence of the abnormal hemoglobin (SCD). When the newborn screen results identify only a presence of sickle cell trait instead of the disease, parental notification of test outcome is not required. Consequently, this practice perpetuates the sickle cell cycle.

3. Method

The sample for this study was drawn from a population of clients served by the Sickle Cell Disease Association of Dallas (SCDAD) during 2004- 2008. The SCDAD is a community based not-for-profit organization that offers services focusing on improving the quality of life and empowerment of individuals, and families of those affected by sickle cell disease. All clients were requested to complete a demographic and attitudinal questionnaire at the time of intake. Each year formed a distinct, independent subgroup or stratum. From each of the four years of data, a sample of 100 clients was randomly drawn from all completed questionnaires. The Sample size was determined by power analysis using Lenth's (2009) computer software employing a small effect size of 0.3, and power of .80. By setting the alpha level at .05, it was ascertained that a sample size of 160 would result in a power of .80. This study utilizes a much larger sample size of 400 respondents than the recommended sample size obtained from power analysis. The attitudinal section of the questionnaire contained items from the Health Orientation Scale. The dependent variable *SSCS: is* a measure of attitudes towards SCT obtained by adding all the scores on the items related to attitudes toward SCD services. A coefficient alpha of 0.94 was obtained for all items addressing *Support for Sickle Cell Services*.

3.1. Statistical analysis

The data collected were entered and analyzed using the Statistical Package for Social Sciences 17.0. Descriptive statistics are tabled separately to describe the demographic characteristics of the participants of this study. The one-way ANOVA was conducted to examine whether *Support for Sickle Cell Services (SSCS*) scores differed by age groups (18-25 Early Reproductive Age, 26-34 Mid Reproductive Age, 35-44 Late Reproductive Age and 45-80 Post Reproductive Age), city of residence and ethnicity. Furthermore, independent *t* tests were used to examine whether *SSCS* scores differed by sickle cell status and gender.

4. Results

A description of the sample is provided in Table 1. Of the 400 participants, 54% (n = 216) were female and 17.8% were African-American (n = 287); 19.8% (n=79) of the participants classified themselves as Hispanics.

Fifty Nine percent (*n* = 237) of participants were single. The majority of the participants (n= 336; 84.0%) described themselves as having a minimum of high school education and 44.8% (*n* = 179) earned less than $30,000 per year. 40.5.0% of the study participants were married. Thirty eight percent (*n* = 158) of participants reported themselves as been residents of Dallas and twelve percent (*n* = 50) were residents of Arlington, followed by
Garland (*n*= 36; 9.0%), Grand Prairie (*n*= 28; 7.0%) and Cider Hill (*n*= 20; 5.0%).

The sample mean age was 40.1 years (18– 65). Most participants (n= 349; 87.3%) showed normal hemoglobin levels while 12% were carriers of sickle cell. It is noteworthy that n= 32; 11.9% of the study's participants identified with abnormal hemoglobin, which causes sickle cell disease and sickle cell trait were within the sample reproductive age (18 to 49 years of age). All the identified sickle cell carriers including those who were married did not know their sickle cell status.

Table 1: Distribution of participant's characteristics and levels of support in individuals screened for sickle cell disease and trait in the DFW area during the years of 2004-2008.

Participants Characteristics	**Frequencies (%)**				
N= 400					
Sex	2004	2005	2006	2007	Total
Male	49 (49.5)	33(33.0)	51(51.0)	50(50.0)	183(45.8)
Female	50 (50.5)	67(67.0)	49(49.0)	50(50.0)	216(54.0)
Ethnicity					
Caucasian	4 (4.0)	10 (10.0)	2 (2.0)	2 (2.0)	18 (4.6)
Asian	1 (1.0)	3 (3.0)	2 (2.0)	1 (1.0)	7 (1.8)
Hispanic/Latino	8 1 (8.0)	19 (19.0)	24 (24.0)	28 (24.0)	79 (19.8)
African American	86 (86.0)	68 (68.0)	71 (71.0)	62 (62.0)	287 (71.8)
Education Background					
High school	95 (95.0)	87 (87.0)	77 (77.0)	77 (77.0)	336 (84.0)
College	4 (4.0)	12 (12.0)	17 (17.0)	17 (17.0)	50 (12.5)
Masters	1 (1.0)	1 (1.0)	4 (4.0)	5 (5.0)	11 (2.8)
Doctorate	0 (0.0)	0 (0.0)	2 (2.0)	1 (1.0)	3 (.8)
City of Residence (top five)					
Dallas	40 (40.0)	30 (30.0)	41 (41.0)	31 (31.0)	151 (37.8)
Arlington	21 (21.0)	4 (4.0)	13 (13.0)	12 (31.0)	50 (12.5)
Garland	5 (5.0)	14 (14.0)	7 (7.0)	10 (10.0)	36 (9.0)
Grand Prairie	6 (6.0)	6 (6.0)	4 (4.0)	12 (12.0)	28 (7.0)
Cedar Hill	9 (9.0)	5 (5.0)	3 (3.0)	3 (3.0)	20 (5.0)
Sickle Cell Status					
Normal (hemoglobin A)	87 (87.0)	88 (88.0)	83 (83.0)	91 (87.0)	349 (87.3)
Sickle Cell Trait	12 (12.0)	12 (12.0)	17 (17.0)	9 (9.0)	50 (12.5)
Marital Status					
Single	70 (70.0)	54 (54.0)	48 (48.0)	65 (65.0)	237 (59.3)
Married	30 (30.0)	46 (46.0)	52 (52.0)	34 (34.0)	162 (40.5)
Participants Reproductive Age					
18-49 years of age	71 (71.0)	64 (64.0)	77 (77.0)	58 (58.0)	270 (67.5)
All others	22.3 (23.3)	28. (28.0)	18 (18.0)	32.3	130 (32.5)
Family Income					
$31,000 and Lowest	34 (34.0)	31(31.0)	61(61.0)	53(53.0)	179 (44.8)
$32,000 tru $53,000	43 (43.0)	47(47.0)	28 (28.0)	39(39.0)	157 (39.3)
$54,000 tru Highest	23 (23.0)	22 (22.0)	11 (11.0)	8 (8.0)	64 (16.0)

Research question 1: What is the level of *Support for Sickle Cell Services* (*SSCS*) among residents of the DFW area?

SSCS scores in this study ranged from 8 (low *SSCS*) to 20 (high *SSCS*), with a group mean of 15.38 (SD = 2.704) and a median score of 16.00.

Approximately, 7.3% (n = 29) of participants' scores ranged from 8 to 11 (low *SSCS*); approximately 31.3% (n = 125) of participants' scores ranged from 12 to 16 (medium *SSCS*); and approximately 61.5% (n = 246) of participants' scores ranged from 17to 20 (high *SSCS*). Participants' mean score on individual *SSCS* items is provided in Table 2.

Table 2: Participants' responses to individual Support for Sickle Cell Services (*SSCS*) items

Item	*M*	SD	*N*
Do you support SCD carrier testing in young adults?	1.71	.535	400
Do you support SCD carrier testing in the African American community?	1.82	.593	400
If you were found to be a SCD carrier would you encourage your partner to get tested?	1.94	.669	400
Do you think that Sickle cell genetic counseling for young adults is..	2.04	.696	400
Do you think that more sickle cell genetic literacy in the African American Community is	2.04	.689	400
Do you think that SCD carrier testing in the African American community is	2.04	.657	400
Do you think that genetic services for children and families with sickle cell disorders is	1.99	.643	400
Do you think that support groups for children and families with sickle cell disorders is	1.87	.593	400

As these results show, participants scored highest (M = 2.04) on the items pertaining to genetic literacy, carrier testing and genetic counseling services followed by items pertaining to genetic services for children and families with sickle cell disorders (M = 1.99); and participants scored lowest (M = 1.71) on the item pertaining to support SCD carrier testing in young adults.

Research question 2: What are the differences in the level of Support for Sickle Cell Services (*SSCS*) based on demographic characteristics of residents of the DFW area?

One-way ANOVA was conducted to examine whether *Support for Sickle Cell Services* (*SSCS*) scores differed by age groups, city of residence and ethnicity. The variable age, was, recoded into four groups, 18 to 25 (early reproductive age) years and 26 to 34 (mid reproductive age), 35 to 44 (Post reproductive age). The *SSCS* scores were higher for the 26 – 34 age group (M=16.60, SD=1.518) and for the 35 – 44 age group (M=16.32, SD=1.502) than for the 18 – 25 age group (M=13.55, SD=2.951) and for the 45 and older age group (M=14.18, SD=2.517).
An analysis of variance showed that the effect of different age groups conditions was significant, F (3,395)=51.324, p=.000. Post hoc analyses using the Scheffé post hoc criterion for significance indicated that the average number of errors was significantly lower in the mid reproductive age and the late reproductive age groups (M = 12.4, SD = 2.26) than in the other two age groups (Early reproductive age and Post reproductive age groups) conditions.

There was little variation between the scores of those in the mid reproductive age and the late reproductive age groups. Furthermore, one-way ANOVA was conducted to examine whether *SSCS* scores differed by ethnicity and city of residence. The results were not significant for any of these variables. Independent t tests were used to examine whether *SSCS* scores differed by sickle cell status and gender. The results were not statistically significant when comparing *SSCS* among participants with Normal Hemoglobin (M=15.5, SD=2.435) and those with Abnormal Hemoglobin (M=15.24, SD=2.544) conditions; t (397) = .598, p = .550. Additionally, independent-samples t-test was conducted to compare the scores of *SSCS* among Males and Females. There was no statistically significant difference in the scores for Males (M=15.58, SD=2.389) and Females (M=15.31, SD=2.493); t (397) =.1.136, p = .257.

5. Discussion

As seen in Table 2, participants scored highest (M = 2.04) on the items pertaining to Sickle Cell Genetic Counseling (M = 2.04), sickle cell genetic literacy and SCD carrier testing (M = 2.04), which suggest that participants are willing to support *SCD/SCT genetic* services as a viable mean of disease identification and treatment purposes. In this study, a one-way ANOVA revealed *Reproductive Age* as the strongest predictor of *SSCS* with a statistically significant difference (p = .00) found between the groups. Participants within the prime and late reproductive ages (25 to 44) expressed the strongest support for SCD/SCT community education. Overall, the participants indicated low levels of awareness regarding SCD inheritance patterns.

Nevertheless, the majority of the participants expressed a desire to learn more about SCD and SCT and indicated that health education campaigns about SCD/SCT must be increased. This conclusion is supported by findings of studies recently conducted by (Boyd etal., 2005; Treadwell et al., 2006).

It is noteworthy; that out of 35 cities *(where data were collected)*, the Dallas and Arlington areas emerged as centers with the highest concentrations of African Americans and Hispanics within the reproductive ages of 25 to 44. These participants fit the criteria of inclusion of at risk population as suggested by many researchers (Boyd et al., 2005; Poss, 2001; Treadwell et al., 2006; James, Campbell, & Hudson, 2002). Although there was no significant relationship between participants' *SSCS* scores and ethnicity, and city of residence, these results could be attributed to limitations in the variance in the study sample. Most participants were from African American Ethnicity (71.8), residents of Dallas (37.8) and Arlington (12.5). A sample with broader variance among the demographic variables may reveal different relationships between *SSCS* and ethnicity as well as city of residence.

6. Limitations

The main limitations of the present study are linked to measurement. In terms of measurements, a broader variety of constructs could had been used to measure the latent variable *SSCS*. Another limitation of this study comes from the fact that a secondary data set was used, which was collected with a different purpose or agenda. Concern for specification error constitutes another limitation, as it is possible for the present study to reach dissimilar results if additional variables are included or excluded as predictors in the present model. Since *Support for Sickle Cell Services* is broad enough to include several pathways and factors, future research needs to include more indicator variables.

Each of the limitations discussed above, can be viewed as a methodological gap challenging future studies to bridge it as opportunities to strength both research rigor and generalizability of the findings. Taking into consideration the proposed limitations, this study attempted to contribute to the Sickle Cell genetic services literature, which to date remains underdeveloped.

7. Implication for Practice

The finding of the present research has implications for future program planning for Sickle Cell Services. This study assessed the prevalence rates for sickle cell trait carriers in the DFW area. Practitioners caring for individuals with SCD can better plan interventions by incorporating long-term solutions to monitor changes in the rates of trait and disease in the population. Increased awareness of sickle cell inheritance patterns among African Americans and

Hispanics of child bearing age could have profound effects on family relations, sexual relationships, marriage, and reproduction driven by the desire to know trait status will have a significant impact in the incidence of sickle cell trait and disease. The study of Ogamdi (1994) for example, found that by increasing education, as it is related to SCD, could reduce the incidence of SCD or prevent it. Ogamdi stated that "one aspect of this education may stress reduction in crisis triggering situations, such as dehydration, hypoxia, bacterial infection, excessive stress at home, work or school, overexertion, and sudden temperature variations" (p. 234) .

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