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Original Research

Factors influencing the use of Complementary Alternative Methods (CAM) in patients attending an adult sickle cell clinic in Jackson, Mississippi.

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Abstract

Background: This study builds on a previous study that examined pediatric patients with sickle cell disease and use of complementary and alternative therapies. The results of the study revealed that the use of CAM therapies is common for children with SCD. Prayer, relaxation techniques, and spiritual healing were the most commonly reported CAM therapies. However, there is a paucity of research studies on CAM use among adult sickle cell patients and the associated factors that predict its use. This research sought to explain the frequency of CAM use and to examine the factors influencing the use of CAM as reported by patients attending an adult sickle cell clinic in Jackson, Mississippi.

Methods: Data for this study were derived from a survey administered during the months of July and September 2010 at an adult sickle cell clinic. All adults who were obtaining treatment for SCD at the clinic were invited to voluntarily complete a three page written questionnaire about CAM use and its benefits, while they awaited treatment. Selection criteria for this study included participants who had been diagnosed with SCD, were African American, were between ages 18 and 65, and had been experiencing pain within the last six months. Hinds County was chosen for this study because it has a high prevalence rate of SCD. Descriptive statistics was used to determine the frequency of CAM use. The various factors influencing the use of CAM were analyzed with binary logistic regression.

Results: The majority (65.1%) experienced pain which lasted 25+ months. Pain medications were taken on a daily basis during the past six months by 90%. Of the 227 respondents who completed the questionnaire regarding CAM use, 208 (91.6%) indicated that they have used CAM within the last six months to control pain. The frequency of CAMs used was higher amongst females (61%), singles (85%), older (69%), those with less education (77%), lower household income (67%), with Medicaid (51%) and those with HgbSS sickle cell type 32%). A higher proportion of females than males used CAM. Conclusions :CAM practitioners seem to give a more personal touch which makes people feel better with their treatment and medical condition. There is a sense of empowerment and the patient assumes a more active role in their health care which makes them feel in control of their health. Rates of complementary alternative methods are relatively high among adult sickle cell patients

INTRODUCTION

Sickle Cell Disease (SCD) remains a significant public health problem in the United States [1]. Despite the availability of tests to screen for compatibility of genotype [2, 3], and programs to increase individuals' awareness of the disease such as trait counseling and focus groups [4, 5], the prevalence rate of SCD has continued to rise in the past decade in some parts of the United States [6]. It is estimated that approximately 2 million Americans are genetic carriers of the sickle cell trait [7], and 70,000 people are estimated to be living with a history of SCD in the United States [8]. The incidence of SCD is particularly high among African

Americans [9]. The prevalence of this disease is greater than that of any other condition detected by newborn blood screening [7]. Research has suggested links between sickle cell disease and several acute pulmonary complications including asthma, thromboembolism, and acute chest syndrome [10, 11]. Other health complications that occur as a result of the disease include blindness, skin ulcers, gallstones, priapism, bacterial septicemia, splenic sequestration, stroke, and chronic organ damage [12-14]. These complications can be life-threatening and can affect the whole body [4].

One of the distinguishing marks of this disease is intermittent, unpredictable pain episodes of varying intensities [15]. Pain in sickle cell disease (SCD) presents unique challenges for patients, families, and health care professionals [16-18]. It is the most frequent problem experienced by people with SCD and has profound effects upon comfort and function in work, school, play and social relationships [19]. A study by Ballas and Lusardi, examined the frequency of painful episodes experienced by sickle cell patients and found that acute painful episodes were the most common cause of hospitalizations. The study also indicated that 50% of hospital admissions for acute painful episodes were readmitted within 1 month after discharge and the readmission was due to painful episodes that interrupted the flow of life. This was associated with pain, suffering, fear, anxiety, depression, the utilization of relatively high doses of opioids, and alienation from the realities of daily living [20]. The researchers suggested that improvement was needed in the management of pain during hospitalization and at home after discharge.

Pharmacologic medications are a significant component of acute pain management in the adult sickle cell population and have been prescribed by physicians to assist sickle cell patients in dealing with, and managing their chronic pain [21-22]. However, recently, more and more patients have been turning to complementary and alternative medicines (CAM) to help manage their painful episodes [23]. SCD patients seeking to use CAM face a number of challenges such as additional treatments strategies, insufficient evidence-based interventions, lack of access to these methods and lack of policies in place to protect them as they utilize CAM methods [24, 25]. This study builds on the contributor study of Sibinga et al., who examined pediatric patients with sickle cell disease and use of complementary and alternative therapies. The results of the study revealed that the use of CAM therapies is common for children with SCD. Prayer, relaxation techniques, and spiritual healing were the most commonly reported CAM therapies. This study showed that these CAM therapies are being used commonly by SCD families. SCD patients seeking to use CAM face a number of challenges such as additional treatments strategies, insufficient evidence based interventions, lack of access to these methods and lack of policies in place to protect them as they utilize CAM methods.

There is a paucity of research studies on CAM use among adult sickle cell patients and the associated factors that predict its use. This research builds on earlier studies sought to explain the frequency of CAM use, as well as to examine the factors influencing the use of CAM as reported by patients attending an adult sickle cell clinic in Jackson, Mississippi.

METHODS

Data for this study were derived from a survey administered during the months of July and September 2010 at an adult sickle cell clinic. All adults who were obtaining treatment for SCD at the clinic were invited to voluntarily complete a three page written questionnaire about CAM use and its benefits, while they awaited treatment. Written informed consent forms were obtained from all participants. The study was approved by Institutional Review Board at Jackson State University and University of Mississippi Medical Center. Selection criteria for this study included participants who had been diagnosed with SCD, were African American, were between ages 18 and 65 years, and had been experiencing pain within the last six months. Hinds County was chosen for this study because it has a high prevalence rate of SCD [4].

The study sample consisted of a total of 227 individuals. The questionnaire was tested for reliability; Cronbach's alpha coefficient was greater than .80. The questionnaire was pilot-tested with individuals of similar demographic background to the study population, and was revised based on their comments. The questionnaire was assessed for content validity by experts in the field. The survey was written at an 8th-grade reading level and took approximately 20–25 minutes to complete. Respondents were informed that the principal investigator and a nurse were available onsite if they needed assistance with completing the questionnaire. Respondents handed all completed questionnaires to the principal investigator. The questionnaire consisted of nine structured items. Respondents were first asked about the length of pain experienced, number of painful episodes experienced within the past six months, level of pain when treated at home and the hospital, types of CAM used and its benefits and about their demographic characteristics. At the core of the questionnaire were a set of yes-no items on the types of CAM used and its effectiveness in controlling painful episodes in the last six months.

Respondents were asked: "Have you ever used the following for controlling pain during the past six months?" A total of 15 commonly used CAMs were provided on the list. In addition, there were separate questions on the effectiveness of CAMs. The data were analyzed using Statistical Package for Social Sciences (SPSS) version 19.0 [26]. Descriptive statistics was used to determine the frequency of CAM use. The various factors influencing the use of CAM were analyzed with binary logistic regression. Results are presented as percentages and odds ratios with 95% CI interval. A p-value of < 0.05 is considered significant.

RESULTS

The study was comprised of 96 (42%) men and 131(58%) women, a group with a mean age of 32 years. Over eighty percent (80.6%) identified themselves as single. Thirty-two percent were between the ages of 18-24 and 56% were older than 24 years. More than half of the participants had more than a high school or General Equivalency Diploma (GED), and almost a quarter (24%) of the respondents had less than a high school diploma or GED. Over fifty percent (62%) of the respondents had an annual household income of less than 15,000, and 64% of the respondents had Medicaid as a type of medical coverage and over half 55% of the respondents had Hemoglobin SS, which is the most severe form of SCD (Table 1).

Patients' length and number of painful episodes experienced

Ninety two percent of patients experienced some sort of pain lasting from 6 – 25+ months. However, the majority (65.1%) experienced pain which lasted 25+ months. Pain medications were taken on a daily basis during the past six months by 90% of the respondents to control pain. A majority of the respondents (40%) indicated that they had experienced between 1 to 5 painful episodes within the past six months when they were treated at home. On the other hand, when they were treated in the hospital, 48% of the respondents experienced between 1 to 5 painful episodes. The proportion of respondents experiencing between 1-5 painful episodes (which is the least number of painful episodes experienced) was higher when treated in the hospital. A higher percentage of the respondents experienced the least number of painful episodes when treated at the hospital. When asked to rank the level of pain they felt when treated at home with CAMs, 24.2% said that they had experienced mild pain, 42% experienced moderate pain and 34% indicated that they experienced severe pain. About 11 % of the respondents said that they experienced mild pain when treated in the hospital, 16% experienced moderate pain, with a larger proportion (73.0%) experiencing severe pain when treated in the hospital. An overwhelming number (73%) ranked their level of pain as severe when treated in the hospital compared to 34% who reported that they experienced severe pain when treated at home with CAMs. Similar observations were also noted amongst respondents who classified their level of pain as mild (24% vs 11%).

Table 1. Demographic Distribution of Participants Surveyed

Gender	Number	Percent
Male	96	42.3
Female	131	57.7
Marital Status		
Single	183	80.6
Married	37	16.3
Age		
18– 24	73	32.3
24 +	128	56.4
Education		
Less than high school	54	23.8
High school+	155	68.3
Household Annual Income (204)		
Less than $15,000	140	61.7
$15,000+	58	25.6
Medical Coverage (N=219)		
Private insurance	73	32.2
Medicaid	146	64.3
Types of Sickle Cell Disease (N=184)		
HgbSS	125	55.1
HgbSC	60	26.4

(Percents do not add up to 100% due to missing values)

Patients' Frequency and Perceived Benefit of Complimentary Alternative Methods

Of the 227 respondents who completed the questionnaire regarding CAM use, 208 (91.6%) indicated that they have used CAM within the last six months to control pain (p < 0. 002) [Table 2]. Seventy-four percent of the respondents who had used CAMs reported that it was beneficial in controlling painful sickle cell episodes. The frequency of CAMs used was higher amongst females (61%), singles (85%), older (69%), those with less education (77%), lower household income (67%), with Medicaid (51%) and those with HgbSS sickle cell type 32%) [Table 2]. A higher proportion of females than males used CAM (61% vs. 39% respectively). This difference was statistically significant, X^2 = (df =1) = p <.004. Over seventy five seven percent of the participants had an education of high school or above, X^2 = (df=1)= p<.002. Also, 67% of those who earned more than $15, 000 used CAMs while 34% of those whose annual income was less than $15, 000 used CAMs, X^2 = (df= 1) = p <.024) [Table 2].

Table 2. Mean frequency of Complementary Alternative Methods used by demographic characteristics

Socio-Demographic Characteristics	Users	Non-users	Effective	Not effective	Difference	
	(n=208) n (%)	(n= 19) n (%)	(n=48) n (%)	(n=2) n (%)	p- value	
Gender					0.004	0.514
Male	82 (39.4)	14 (73.7)	14(29.2)	1(50)		
Female	126 (60.6)	5 (26.3)	34(70.8)	1(50)		
Marital Status					0.076	0.703
Single	170 (84.6)	13 (68.4)	40(88.3)	2(100)		
Married	31 (15.4)	6 (31.6)	8(16.7)	0(00)		
Age					0.34	0.569
18– 24	65 (31.4)	8 (42.1)	16(33.3)	1(50)		
24 +	142 (68.6)	11(57.9)	32(66.7)	1(50)		
Education					0.002	0.327
Less than high school	123 (68.7)	13 (93.8)	9(19.6)	1(50)		
High school+	147 (77.4)	8 (42.1)	37(80.4)	1(50)		
Household Annual Income					0.024	0.583
Less than $15,000	123 (66.5)	15 (93.8)	1(50)	1(50)		
$15,000+	63 (33.5)	1 (6.3)	25(65.8)	13(34.2)		
Medical Coverage					0.608	0.808
Private insurance	99 (49.3)	10 (55.6)	5(20)	0(00)		
Medicaid	102 (50.7)	8 (44.4)	20(80)	1(100)		
Types of Sickle Cell Disease					0.262	0.524
HgbSS	119 (68.4%)	6 (54.5%)	24(70.6)	1(50)		
HgbSC	55 (31.5%)	5 (45.5%)	10(29.4)	1(50)		

Of the 208 respondents who used CAMs, 27% used prayer, 18% used relaxation techniques, 14% used massage, 11% used exercise, 11% used other, 5% used spiritual healing,

3% indicated that they had used herbal medicines, 2% used mega vitamin therapy, 2% used folk remedy, 2% used yoga, 1% used chiropractic, 1% used homeopathy, 0.5% used hypnosis, 0.2% used biofeedback, and 0.2% used acupuncture, to control pain during the past six months. [Table 3]. Respondents were more likely to use the three most commonly used CAMs if they were female, had a higher education, and had a household income of less than $15000.00 ($p< 0.05$).

Factors Influencing the Use of Complimentary Alternative Methods

Factors associated with the frequency of CAMs used are presented in Table 4. The association of frequency of CAMs used by gender, marital status, age, educational level, household income, medical coverage and type of sickle was examined. Respondents were more likely to use CAMs to control painful sickle episodes if they were female (OR, 0.12; $p<0.02$) and their educational level was less than a high school diploma or GED (OR, 0.39; $p < 0.05$) [Table 4]. Marital status, age, level of education, medical coverage and type of sickle cell disease had no impact on the frequency of CAMs used among the respondents surveyed. Females were .1 times more likely to use CAMs to control sickle pain than men. CAM use was more prevalent among females, singles, older people, those with less education, lower household income, with private insurance and those with HgbSS sickle cell type.

Table 3. Complementary Alternative Methods Use and Benefit among Sickle Cell Patients

	Reporting use (%)	**Reporting Benefit (%)**
	n = 208)	(n = 208)
Use of prayer	27.10%	11.70%
Use of relaxation technique	17.90%	20.00%
Use of massage	14.40%	8.30%
Use of exercise	11.20%	16.70%
Use of other	11.20%	1.70%
Use of spiritual healing	5.10%	6.70%
Use of herbal medicine	3.00%	8.30%
Use of folk remedy	2.40%	1.70%
Use of mega vitamin therapy	2.20%	3.30%
Use of yoga	2.20%	8.30%
Use of Homeopathy	1.10%	6.70%
Use of chiropractic	1.10%	1.70%
Use of hypnosis	0.50%	3.30%
Use of acupuncture	0.20%	-
Use of biofeedback	0.20%	1.70%

Table 4. Adjusted odds ratios (95% CIs) for predictors of CAM use

	CAM use (OR)
Gender*	0.1 (0.2 - 0.7)
Marital status	1.7 (0.5 -6.5)
Age*	0.8 (0.3 -2.2)
Education*	0.4 (0.1 -1.0)
Household	0.8(0.3-1.7)
Medical coverage	0.9 (0.6 -1.4)
Types of Sickle Cell Disease	1.7(0.6-4.6)

DISCUSSION

The current study comprises one of the largest surveys to date on the factors influencing CAM use in adult sickle cell patients. As such, it provides initial evidence of the extent of the use of CAM and perceived benefits. These results suggest that the majority of the respondents who completed the questionnaire had previous exposure to the use of CAMs. The use of CAMs was particularly high with 208 (91.6%). Several studies have looked at the benefits for using CAM instead of conventional medicine. Greene, Walsh, Sirois, and McCaffrey, shared the following reasons: CAM is more cost effective, has fewer side effects, more holistic approach, and treats the "whole person" taking into consideration lifestyle, background, habits, and physical health [27]. It provides a more complete health picture and more effective way to treating the disease. CAM practitioners seem to give a more personal touch which makes people feel better with their treatment and medical condition. There is a sense of empowerment, meaning that the patient assumes a more active role in their health care. This makes them feel in control of their health [28]. Because rates of complementary alternative methods are relatively high among adult sickle cell patients, a study such as this, elucidating patterns of use of these therapies among these patients, is of importance for health professionals concerned with issues related to pain management and use of CAM.

Findings revealed that the length of pain experienced by these patients increased the knowledge and use of CAMs to control painful episodes. One possible explanation could be those who had longer periods of pain had less success in treating their episodes so that their continued suffering may have prompted them to seek alternative methods. Prayer was the highest and most commonly used CAM therapy that respondents used to manage their painful episodes. Prayer was also used to relieve stress and to cope with the issues of daily life [29]. This can be accounted for since Mississippi is considered the "Bible Belt" of the South, and prayer in particular connects to the spiritual roots of the African American community together. Pain, fatigue, and sleep disruptions can cause a considerable amount of distress in one's life, and the high prevalence of prayer is not surprising in this context. This finding is consistent with prior studies that have documented the high use of prayer to cope with pain among people with chronic pain, especially sickle cell pain [30]. There was also a high perceived benefit among the study population that CAMs use was effective in controlling pain. The high frequency of perceived benefits among CAM modalities with relaxation, prayer and exercise, confirms the respondents' perception about its effectiveness.

Generally, females were more apt to use CAMs in this study which was also consistent with other studies that were conducted on CAM use. Possible reasons for using CAM can include personal beliefs, women may just believe that using CAM will decrease their pain and in fact it has worked for them. Other women may just be disappointed with conventional medicine, especially when they have been taking these medications for a long period of time to relieve their pain and did not receive the desired results.

Over half of the respondents surveyed indicated that they had experienced sickle cell related pain for 25+ months. When specifically asked how many painful episodes they had within the last six months when treated in the hospital, the majority said that they had between 1 to 5 painful episodes. Interestingly, even after being treated in the hospital, respondents were still experiencing frequent episodes of pain. The benefit of CAMs was associated with type of SCD ($p< 0.021$), meaning that people with HgbSS, which is the worse form of SCD, found CAM to be an effective method in pain crisis.

The prevalence of CAM use in our study was 37% higher than previously reported in other studies on CAM among sickle cell patients in the United States [31]. This can likely be accounted for by using adults in our study instead of children. Children must have adult consent before using many alternative therapies. However, in our study adults were able to give consent and make their own decisions, thus likely raising the use and reporting rates of CAM use. Another possible reason for the higher percentage of CAM use may be because there were more adults with HgbSS which is the worse form of SCD and people experiencing chronic pain are, according to research, more likely to use CAM therapies to manage pain [32].

Those with lower incomes were more likely to use CAMs to control sickle cell pain than those with a higher income. This finding may be due to the lack of insurance that poverty stricken minority adult patients face in rural areas like Mississippi. Other reasons can be related to less trust of the medical community and greater difficulty in accessing a hematologist due to access to care with transportation being one of them. However, this is not abnormal, as previous research has shown that lower income is one of the predicators of CAM use [33-35].

Older people were also more likely to be involved in CAMs use [36]. Our study showed that individuals between the ages of 24 years and older were more knowledgeable than younger individuals (aged 18 to 24 years) about CAMs, and were also more likely to use CAMs to control sickle cell pain. Generally, the

respondents suggested some perceived benefits attributed to its use such as; improved life control, fewer hospital visits, fewer school absences and less disruption in household activities.

While respondents are knowledgeable and receptive to the idea of CAMs use, many physicians are less knowledgeable of the benefits of CAMs modalities and as a result are urged by medical leaders to increase their understanding of these approaches so that they can advise their patients appropriately [37]. Physicians can partner with CAM providers in the community to offer patients a wider range of holistic options. Research has shown that better knowledge of CAMs by physicians will enable patients and physicians to work together in developing a more holistic treatment plan for their condition.

This study has a number of limitations. The study although having the largest sample size for this particular study, was relatively small and restricted to this geographic state, because patients were identified through having had specialty care at this institution. In addition, the population sampled was African Americans and as a result the study cannot be generalized to other ethnic groups.

CONCLUSION

In conclusion, findings from the study suggest that there is substantial CAM use in the adult SCD population. A variety of CAM therapies are used, with the most common being prayer. Recent clinical studies suggest benefits of these CAM therapies for adult SCD patients; however, the need to increase the evidence base of CAM therapies cannot be over emphasized. This is important from an economic point of view as the use of CAM is a multibillion dollar industry in the United States and more so worldwide [38]. Health care providers should investigate patients' CAM availability and promote collaborative public health care. They should value the choice of consumer groups in order to improve the quality of health care and the patient-provider relationship. Hematologist, local doctors, and other health care providers can play an integral role in assisting patients with knowledge on CAM modalities, giving them the opportunity to explore other treatment options. This can be used in combination with their prescribed medications to reduce painful episodes as it relates to SCD crises.

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