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Spirituality, Self-Efficacy, and Quality of Life among Adults with Sickle Cell Disease

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Abstract

Spirituality and self-efficacy both have been identified as factors that contribute to management of chronic illnesses and quality of life (QOL). For individuals with sickle cell disease (SCD), the lifespan is increasing, but adults report low self-efficacy, ineffective coping skills and poor QOL. The care of adult patients with SCD requires a complex, multidisciplinary team approach with a focus not only on physiological, psychological, and social needs, but also on spiritual needs. However, spirituality, self-efficacy and QOL have been little studied in individuals with SCD.

This study explored the relationships among spirituality, self-efficacy, and QOL in adults with SCD. The study used a descriptive correlational design. Prospective participants, 18 years and older, were invited to participate in the study through a mail out and electronic survey.

Individuals who reported high levels of spirituality and self-efficacy reported high levels of QOL. Self-efficacy and spirituality accounted for more than 50%, of the variance in QOL.

This study provides information about the roles that spirituality, self-efficacy, and QOL play in the lives of adults with SCD and gives direction for developing holistic interventions.

Keywords: Spirituality, holistic, sickle cell disease, self-efficacy, quality of life, chronic illness

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Introduction

Sickle cell disease (SCD), an inherited, autosomal, recessive group of blood disorders affecting red blood cells, is characterized by the production of sickle hemoglobin, and affects approximately 72,000 individuals in the U.S.¹ This chronic, genetic condition affects individuals from the African Diaspora and includes those with heritage from the Caribbean, Mediterranean, European, Middle Eastern, Asian, African, and East Indian territories. The origin of the disease is unclear, but the mutation responsible for the disease has been traced to the African continent, specifically to central West Africa.²⁻⁴ While the early export of the sickle gene came largely through the forced migration of Africans to the Americas, twentieth century spread has occurred largely through migration of individuals from developing countries seeking better opportunities in more developed countries² and mass globalization.

Although individuals with SCD experience high mortality at young ages, better healthcare options and childhood antibiotic programs have contributed to longer life spans. In 1973, the average life span of an individual with SCD was 14 years. More than thirty years later, with the development of comprehensive care models, day hospitals, and ongoing clinical research, the life expectancy of persons with SCD has increased to 50 years.⁵

Though individuals with SCD are living longer, paradoxically they report decrements in some areas of health. Individuals with this chronic, genetic hemoglobinopathy report constant chronic pain that interrupts their lives,⁶⁻⁹ and poor quality of life (QOL),^{6,7,9-12 13-16} low self-efficacy,^{11,12,17,18} depression,^{10,11} a lack of effective coping skills,^{13,19-22} and at times they perceive life as hopeless.^{11,16} Thus, individuals suffer at home with their pain and seek healthcare only when the pain becomes unbearable,^{8,22} when they go to emergency departments.²² This major presenting symptom is complex and poorly understood, and it can be different for different individuals.²¹

Pain occurs constantly with most adults with SCD.⁸ Although patients with the same genotype are not homogeneous in disease severity,¹⁰ they tend to experience similarities in a prodromal stage, with a gradual increase of warning signs days and hours before a pain event that forces them to visit the emergency department.²² Patients often report that their pain is poorly managed when they are in the hospital,^{16,22,23} or staff are not responsive to patients' reports of pain. Staff perceptions of patients' dependence on pain medications affect pain management and place patients at risk for 'pseudo-addiction', defined by Weisman and Haddox²⁴ as an iatrogenic syndrome of abnormal behavior developing as a direct consequence of inadequate pain management. The individual develops feelings of anger and isolation that lead to acting-out behavior. The healthcare provider (HCP), who perceives the patient as having a behavioral problem, becomes frustrated at being unable to control the patient's pain and becomes fearful of inducing drug tolerance or dependence. Over time, the HCP avoids contact with the patient as a means to reduce conflict, the patient begins to distrust the HCP, and a vicious cycle stimulated by inadequate pain management results in 'pseudo-addiction' syndrome.^{24,25}

Like other chronic illnesses, SCD is best managed by promoting holistic health and comprehensive self-care strategies that decrease hospitalizations, increase psychosocial functioning,⁶ improve QOL^{11,13,26} and prevent premature deaths.¹⁰ Coping with the illness is best when the individual demonstrates self-efficacy, takes charge of life situations, and has a strong expectation of being successful with the outcome.^{10,17,18} Individuals with SCD who reflect high levels of self-efficacy also describe low levels of disease symptomatology.¹⁷

Quality of life (QOL), reflects a holistic balance of the biophysical, psychological, socio-cultural, and spiritual dimensions of life. However, Goddard^{27p808.28} noted that “Western society has tri-partitioned personhood into distinct biophysical, psychological and spiritual components and then banished the spiritual dimension to relative obscurity.” For persons with SCD, the role of spirituality in promoting holistic care appears to have been mostly overlooked, and individuals with SCD often lack the ability to cope spiritually with burdens of this chronic illness.²⁹ Improving QOL for individuals with SCD requires an understanding of factors that influence QOL and affect an individual’s coping.

Spirituality

Spirituality is a synthesis of personal beliefs about the essence of being that balances and connects other dimensions and domains of human traits and health.²⁹⁻³³ Studies of spirituality and religion among African Americans have concluded that African Americans tend to be highly spiritual by nature or culture,^{29.34.35} and thus they may benefit from culturally appropriate spiritual care.

Apart from psycho-social and physical issues in health, individuals with SCD experience spiritual issues such as hopelessness, negative self-talk, and fatalism. The fatalism that persons with SCD experience amounts to a feeling that there is little the individual can do to change the course of the disease, and actions for self-care are therefore minimal, because of despair.¹⁵

In studies that have examined spirituality and spirituality/religiosity among persons with SCD, the authors concluded that spirituality and religiosity contribute to an individual’s coping with SCD.^{9.29} Cooper-Effa et al.²⁹ for example, conducted a cross-sectional study to examine the influence of spirituality on pain experience, and concluded that existential well-being is supportive and can help individuals with SCD cope more effectively with the pain of the disease. Harrison and colleagues,³⁴ who examined the role that religiosity/spirituality plays in SCD patients’ pain experience, concluded that individuals who attended church once or more a week reported less pain. Spirituality and spiritual health are essential ingredients in remaining motivated and acting on the desire to maintain quality health outcomes, thus balancing life with a chronic disease.³⁷ Strickland and associates,¹⁵ summarizing the themes from their focus group, said that religion serves as a coping insulator. Participants in their study reported the use of religion, going to church, and frequent praying to cope with the pain, the stress of SCD, and the prospect of early death.¹⁵

Self-efficacy

Self-efficacy is the belief in one's ability to execute a course of action for a required task pertaining to day to day symptom and disease management.²⁵ Self-efficacy 1) can predict specific behaviors, 2) results in specific behaviors,^{37,38} and 3) is based on behavioral change and one's desire and motivation to achieve a set goal completely and effectively.^{38,39} According to Bandura³⁷ self-efficacy is the individual's belief in his/her ability to overcome specific challenges and can propel the individual to overcome obstacles. Perceived self-efficacy helps to foster coping and response to stress producing events.⁴⁰ For individuals with chronic diseases, self-efficacy is directly related to performance,⁴¹ confidence and beliefs of control over outcomes despite accompanying challenges.²⁵

Studies of self-efficacy among persons with SCD have been sparse,^{11,12,17,18} and in these studies individuals reported decreased self-efficacy. In Edwards et al.'s¹⁷ study, for example, adults with SCD who reported lower levels of self-efficacy had more physical and psychological SCD-related symptoms, more pain, and more frequent physician visits than individuals who reported higher levels of self-efficacy. Other researchers reported similar negative relationships between self-efficacy and healthcare services use.^{11,12} In addition, Lenoci et al.¹² reported a negative relationship between self-efficacy and pain severity.

Quality of life

Only a few studies of QOL among individuals with SCD have been conducted,^{7,8,13,14,16} and participants in these studies reported poor QOL. McClish and colleagues¹⁴ assessed whether SCD-specific variables, such as pain, genotype, and crisis, were predictive of the Short Form (36) Health Survey (SF-36) subscales, and concluded that individuals with SCD experience decreased QOL, which is inversely related to pain level. In qualitative studies,^{15,16} persons with SCD reported difficulty coping with physical pain that interfered with everyday task completion. Strickland and colleagues¹⁵ also reported that psychosocial burdens hampered emotional adjustment and pain control. Participants in Thomas and Taylor's¹⁶ study reported that pain affected their day-to-day activities, zapped their energy, and hampered physical aspects of QOL. Some individuals have reported coping with pain by using religion and spirituality.

No single study to date has examined the constructs of spirituality, self-efficacy and QOL in persons with SCD.²⁵ We examined the relationships among these concepts and the prediction of QOL based on spirituality and self-efficacy reports. The specific aim of the study was to examine the relationships among spirituality, self-efficacy, and perceived QOL in adults with sickle cell disease. We hypothesized that 1) there is a significant positive relationship between spirituality and QOL in adults with SCD, 2) there is a significant positive relationship between self-efficacy and QOL in

adults with SCD, 3) there is a significant positive relationship between self-efficacy and spirituality in adults with SCD, and 4) spirituality and self-efficacy predict QOL for adults with SCD.

Method

Research Design

The study used a descriptive correlational design to collect data from a convenience sample of 90 subjects.

Sample

Participants were diagnosed with SCD, were at least 18 years old, and were able to read and write English. After IRB approval from the university and the agencies involved, individuals with SCD were invited to participate in the study. Participants were recruited through various venues including local chapters of the Sickle Cell Disease Association (SCDA) and a personal e-mail list provided by a member of the national SCDA. Those who consented, anonymously completed mail out or electronically supplied surveys. The study was planned to initially use mail-out surveys but because of initial low response rate, the data collection package, without any content changes, was converted to an on-line web-based survey.

Measurement

Instruments

The instruments used to examine the constructs are listed in Table 1. All tools were used according to guidelines from the developers.

The *Functional Assessment of Chronic Illness Therapy* (FACIT) system includes the *Functional Assessment of Cancer Therapy-General* (FACT-G) and the *Functional Assessment of Chronic Illness Therapy-Spiritual* (FACIT-Sp). The FACIT-Sp^{42,43} is a 12-item spirituality measure that focuses on the existential aspect of spirituality and faith, assessing this meaning/peace and faith. The conceptual underpinnings, psychometrics and instrument use with chronic illness have been reported elsewhere.^{25,42-44}

The *Sickle Cell Self-Efficacy Scale* (SCSES) is a 9-item disease-specific instrument that measures the individual's self-efficacy, and ability to function on a day-to-day basis and to manage SCD symptomatology. Higher scores indicate greater self-efficacy for coping with SCD.¹⁷ The theoretical framework on which the SCSES is based is Bandura's³⁷ social learning theory which refers to an individual's judgment of his or her capacity to perform specified tasks.¹⁷

The conceptual framework for the FACT-G is based on Cella et al.'s^{42,45} views of QOL as a multidimensional concept that is subjective and only understood from the patient's perspective. Multidimensionality and Psychometrics for the FACT-G have been discussed elsewhere.^{25,44,46-48}

Results

Description of the Sample

Table 2 shows the response rate for each recruitment source, sample size, and the overall response rate of 36%. Demographic information for the sample is presented in Table 3. Most respondents were female, single, and relatively well-educated but they had quite low annual household income, less than \$20,000. This sample was similar to the persons with SCD reported in other studies^{11,12,19,49} in the areas of income, gender proportion, genotype, and level of educational attainment.

Findings

Table 4 represents descriptive statistics on study variables. The relationships among the primary outcome measures were assessed using Pearson correlation coefficients are represented in Figure 1. The scatterplot for the three variables indicates that as spirituality and self-efficacy reports increased, QOL reports increased. There were direct, positive, linear relationships.

The correlational analyses, presented in Table 5, showed that all correlations were significant ($p < .05$), and in all but two cases the correlations were moderate to large. In general, individuals who reported high QOL in one area tended to report high QOL in all subset areas. The correlation between spirituality and QOL was positive and significant, $r(88) = .68$, $p < .05$. The Pearson product moment correlation between self-efficacy and QOL was also positive and significant, $r(88) = .67$, $p < .05$. The Pearson product moment correlation coefficient between self-efficacy and spirituality was positive and

significant, $r(88) = .63$, $p < .05$. The linear regression analysis revealed that spirituality and self-efficacy predicted reported QOL, with $R = .75$, $R^2 = .56$, and adjusted $R^2 = .55$. Spirituality and self-efficacy accounted for more than half of the variance in QOL reports in this sample.

Using the general linear model, spirituality accounted for 6.6% and self-efficacy accounted for 34.6% of the total variance in QOL. The relationships between spirituality, self-efficacy and QOL were significant, as demonstrated by high partial eta square (η^2). Spirituality and self-efficacy accounted for medium and large variations in QOL and predicted QOL for adults with SCD.

In summary, these results suggest that adults with SCD report strong, positive (direct) relationships between spirituality and QOL, self-efficacy and QOL, and self-efficacy and spirituality.

Discussion

This study supports the findings of previous isolated studies that spirituality was associated with QOL.^{29,50} Reports of self-efficacy and spirituality predicted QOL among these adults with SCD. This gives credence to including spirituality in evaluation of self-efficacy and QOL among adults with chronic illnesses such as SCD.

Brady and associates,⁵¹ who investigated QOL among individuals with cancer and HIV/AIDS, concluded that “Meaning/peace on the spirituality measure was the best predictor of contentment with QOL”.^{51p423} Likewise, in this study the meaning and peace subscale was a better predictor of QOL than was faith. In this study self-efficacy and QOL were positively related. Also, Edwards et al.¹⁸ reported that that self-efficacy was inversely related to changes in physical symptoms and there was a positive correlation between self-efficacy and QOL.

Also in this study, self-efficacy was positively related to spirituality. Reicks, Mills, and Henry⁵² found that spiritual practices such as prayer and reading scripture enhanced confidence to perform behaviors that enabled weight loss, and concluded that, for some, spirituality contributed to self-efficacy and attainment of goals. Self-efficacy has frequently been suggested as an important factor in successful management of chronic illness³⁸ and can give direction to relevant health promotion strategies.⁵³ Similarly, spirituality-based educational interventions have helped some individuals with prostate cancer cope with their illness.⁵⁴

Limitations

There were several limitations to this study that make it necessary to interpret the study findings with caution. The study used a convenience sample, however, the sample looked similar to other national samples of individuals with SCD. Further, self-report bias may have been introduced by participants in responding to sensitive personal information such as household income and educational level. Third, this cross-sectional study did not allow for measurement of variables over time, limiting cause and effect conclusions. Finally, there may have been an element of bias in recalling events over the past seven days. Individuals' reports may differ over time as they recalibrate feelings, perceptions, and responses.

Conclusions

Notwithstanding these limitations, this study identified strong correlations among these variables. This study was the first to examine the relationships. The results give support for including spirituality in health assessments and intervention, and incorporating a bio-psycho-socio-spiritual (BPSS) model in healthcare delivery.

Implications for Nursing

The findings provide further evidence that there are strong relationships among spirituality, self-efficacy and QOL in individuals with SCD. Nurses and clinicians caring for individuals with SCD can better plan interventions by intentionally incorporating spirituality and self-efficacy into self-care models for QOL. Nurses and other healthcare providers should intentionally include spirituality in care delivery. However, the inclusion of spirituality should be devoid of religiosity and include individuals of varying faiths. Individuals who may not subscribe to a particular religious faith must be encouraged to identify essence of their being and incorporate relevant practices into daily life activities.

Narayanasamy⁵⁵ suggested that nurses incorporate individualized, holistic elements of spiritual care into practice and care delivery. Some of the practices included active listening, showing genuine, unconditional acceptance of patients' idiosyncrasies, use humor, and show humility. In addition, a spiritual assessment should be done on all patients. The nurse can ask the patient questions such as "*What gives you a sense of meaning or purpose in your life, what do you think is going to happen to you*"^{55p1143} and "*How do you cope with your illness and manage your day-to-day activities?*"

The use of the bio-psycho-socio-spiritual (BPSS) conceptual framework is appropriate for individuals with chronic illnesses such as SCD. Discussions of personhood include all human dimensions. However, in practice, attention has focused on biopsychosocial aspect with neglect of the spiritual dimension. This study helps to show the importance of being attentive to all dimensions and intentionally including the spiritual dimension in assessment, care and research. "Spirituality is important to health and individual expression of quality of life."^{44p44}

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Table 1

Description of variables, conceptual definition, operational definition and reliabilities

Variable	Conceptual Definition	Operational Definition and Measurement	Reliability
Spirituality	Spirituality is a synthesis of personal, self-expressed beliefs and activities of essence of being that balances and connects other dimensions and domains of human traits and health.	Using Functional Assessment of Chronic Illness Therapy-Spirituality (FACIT-Sp), ⁴³ participants were asked to rate feelings and thoughts about spirituality experienced within the last seven days.	Cronbach's alpha .87 ⁴³
Self-efficacy	Self-efficacy is the belief in one's capabilities to enable and execute a course of action for a required task by rating his/her ability to complete tasks pertaining to day to day symptom and disease management.	Using Sickle Cell Self-Efficacy Scale (SCSES), ¹⁸ participants were asked to rate their ability to complete tasks pertaining to day to day symptom and disease management.	Cronbach's alpha .89 ¹⁸
Quality of life	Quality of life is the individual's expressed interpretation of life events, and self-perception of well-being.	Using Functional Assessment of Cancer Therapy (FACT-G), ⁴⁵ 62 participants were	Cronbach's alpha for the overall scale is .89 ⁴⁵

asked to rate abilities or
 feelings about QOL
 experienced within the last
 seven days.

Table 2
Mailed Surveys, response rate, and electronic survey response

Mailed Source	Invitation Extended	Returned Number of Completed Surveys	Mailed Response Rate	Electronic Survey Completed	Total study Participants
SCDAD et al.	119	36*	29.4%		
SCDA (Alabama)	55	31	56.4%		
SCDA (North Carolina)	26	6	23.1%		
Electronic Survey				18	
Total	200	72	36%	18	90

* The data of one survey respondent with sickle cell trait were discarded

Table 3***Demographic Characteristics (N = 90)***

Characteristics	Total % N = 90	Female % N = 67	Male % N = 23
Marital status			
Single	51.6%	34 (50.7%)	14 (60.9%)
Married	23.7%	16 (23.9%)	6 (26.1%)
Divorced	16.1%	14 (20.9%)	1 (4.3%)
Separated	1.1%	1 (1.5%)	
Widowed	2.2%	1 (1.5%)	1 (4.3%)
Other	2.2%	1 (1.5%)	1 (4.3%)
Educational level			
Less than high school	6.5%	3 (4.5%)	3 (13%)
High school diploma/GED	15.1%	11 (16.4%)	3 (13%)
Some college	48.4%	36 (53.7%)	9 (39.1%)
Bachelor's degree	19.4%	12 (17.9%)	6 (26.1%)
Graduate degree	7.5%	1 (7.5%)	2 (8.7%)
Annual household income			
Less than \$10,000	32.3%	23 (34.3%)	7 (30.4%)

\$10,000-\$19,000	23.7%	15 (22.4%)	7 (30.4%)
\$20,000-\$34,000	9.7%	7 (10.4%)	2 (8.7%)
\$35,000- \$49,000	9.7%	6 (9%)	3 (13%)
\$50,000- \$60,000	7.5%	6 (9%)	1 (4.3%)
More than \$60,000	14%	10 (14.9%)	3 (13%)
Sickle cell disease genotype			
HbSS	47.3%	32 (42.9%)	12 (52.2%)
HbSC	31.2%	20 (30.8%)	9 (42.9%)
Sickle Beta Thalassemia	14%	13 (20%)	
Other	1.1%	1 (1.1%)	
Missing			2
Hospitalization in previous year			
0	20.4%	15 (22.4%)	4 (17.4%)
1	21.5%	14 (20.9%)	6 (26.1%)
2	21.5%	16 (23.9%)	4 (17.4%)
3	8.6%	3 (4.5%)	5 (21.7%)
4	6.5%	6 (9%)	
5	5.4%	3 (4.5%)	2 (8.7%)
6	4.3%	3 (4.5%)	1 (4.3%)

7	1.1%	1 (1.5%)	
8	1.1%	1 (1.5%)	
9			
10	6.5%		1 (4.3%)
Hospitalization based on genotype			
HbSS	51.2%	32 (49.2%)	12 (57.1%)
HbSC	33.7%	20 (30.8%)	9 (42.3%)
Sickle Beta Thalassemia	15.1%	13 (20%)	

Table 4

Descriptive statistics for Quality of life, spirituality and self-efficacy (N=90)

Test (Measurement)	Possible (Test) Range	Sample Range	Median	<i>M</i>	<i>SD</i>	Cronbach's Alpha
Quality of life (FACT-G) total	0-108	19-107	75	72.3	20.1	.93
Physical well-being	0-28	0-28	16	16.2	7.0	.88
Social/family well-being	0-28	2-28	21	20.6	6.5	.84
Emotional well-being	0-24	4-24	19	17.8	5.0	.82
Functional well-being	0-28	2-28	18	17.7	7.1	.89
Spirituality	0-48	5-48	40	38	9.2	.91

(FACIT-Sp)

Total

Meaning/Peace	0-32	2-32	24	24.1	6.8	.88
Faith	0-16	3-16	16	13.8	3.3	.86
Sickle cell self-efficacy (SCSES)	9-45	10-45	31	30.3	8.2	.87

** Correlation is significant at the 0.01 level (2-tailed)

Blank spaces indicate data not applicable

Table 5

Pearson correlations among study variables (N = 90)

	Self-efficacy	Spirituality	QOL total
FACT-G (total)	.67**	.68**	-
Physical well-being	.49**	.37**	.77**
Social/Family well-being	.27*	.64**	.66**
Emotional well-being	.70**	.53**	.81**
Functional well-being	.66**	.66**	.86**
FACIT-Sp (total)	.63**	-	.68**
Meaning/Peace	.64**	.96**	.68**
Faith	.42**	.80**	.48**
Sickle Cell Self-Efficacy Scale (SCSES)	-	.63**	.67**

** Correlation is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed)

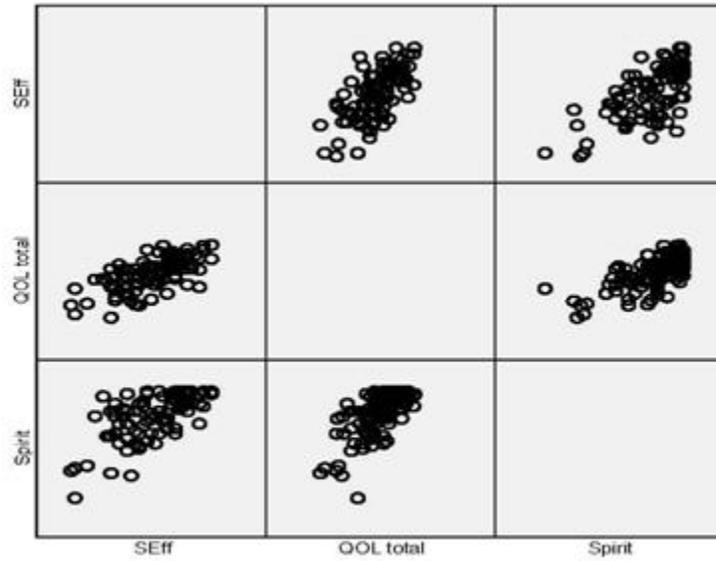


Figure 1. Scatterplot matrix of study variables