SOJNR
Southern Online Journal of Nursing Research
Southern Nursing Research Society

Volume 8 – Number 3 www.snrs.org

Relationships among Types of Social Support and QOL in Adults with Sickle Cell Disease

Coretta M. Jenerette, PhD, RN, AOCN
Postdoctoral Fellow
School of Nursing
University of North Carolina at Chapel Hill
4008 Carrington Hall
Campus Box 7460
New Haven , CT 06536
coretta.jenerette@unc.edu

Relationships among Types of Social Support and QOL in Adults with Sickle Cell Disease

Background: Sickle cell disease (SCD) and its manifestations often result in a lifetime of pain and hospitalizations. Although social support has been supported as an important resource for individuals with chronic illnesses such as SCD, there has been little to no research about what type of social support adults with SCD need to improve health-related quality of life (QOL).

Purpose: To examine relationships among types of social support and health-related QOL in adults with SCD.

Conceptual Framework: Theory of Self-Care Management for Sickle Cell Disease

Design: Cross-sectional Descriptive

Sample and Setting: N=232 adults with SCD recruited from two southeastern SCD clinics.

Measures: Medical Outcomes Study Social Support Survey and the Chronic Illness Quality of Life Ladder.

Results: All four types of social support (affectionate, emotional/informational, positive social interaction, and tangible) and overall social support were positively and significantly correlated with all four time points (present, past, future, and without) and overall QOL. Of the four types of social support, affectionate support and tangible support were statically significant predictors of overall QOL in adults with SCD. There were no statistically significant differences between availability of types of social support between females and males with SCD.

Implications: The data suggests that adults with SCD benefit most from the availability of affectionate social support and tangible support. Self-care interventions for adults with SCD should include the family and friends. Additionally, it important to make sure that adults with SCD have access to the resources they need such as material aid in order to enhance health-related QOL. Further studies need to be done to develop appropriate interventions for adults with SCD that enhance their health-related QOL.

Key Words: sickle cell disease, social support, QOL

Relationships among Types of Social Support and QOL in Adults with Sickle Cell Disease

Introduction

Sickle cell disease (SCD), the most common genetic disorder of the blood, is an inherited, autosomal, recessive genetic disorder that is expressed as sickle cell anemia, sickle cell thalassemia disease, or sickle hemoglobin C disease.[1-3] SCD is a chronic blood disorder that, in the United States, most often affects African Americans occurring at the rate of 1 in every 500 African American births.[4] It is caused by a genetic mutation that produces defective hemoglobin.[5,6] This mutation leads to the possibility of damage to every system in the body.[7]

Advancements in the detection and treatment of SCD have led to increased life expectancy.[8,9] Thirty years ago, the median length of survival for SCD patients was 14 years.[10] Because of advances in medical management, those affected with SCD are living much longer.[11,12] The average lifespan of individuals with sickle cell anemia, the most severe form of SCD, is 42 to 48 years,[13] compared to healthy African Americans, who have an average lifespan of 67 to 75 years. Although adults with SCD are living longer, they may face barriers which include stigmatization of the care-seeking or self-care behaviors and a lack of social support.[14,15] Because people with SCD are living longer, it imperative for health care providers to make sure that those affected with SCD get the best possible comprehensive care.[16]

Comprehensive care includes addressing the psychosocial needs of adults with SCD. Research with adults with SCD support the significant role of psychosocial functioning in the trajectory and management of the disease. In particular,

research supports the role of social support as having a positive affect on the lives of adults with SCD.[17-19] In order to tailor comprehensive models of care, it is important to know more of about the types of social support that are most efficacious to adults with SCD in order to develop models of care to enhance health-related quality of life. The purpose of this research was to examine relationships among types of social support and health-related QOL in adults with SCD.

Theoretical Perspective

The Theory of Self Care Management for Sickle Cell Disease (SCMSCD, Figure 1) proposes that (1) vulnerability factors (socio-demographic and health-need factors) have a negative impact on health outcomes (health status and quality of life) and (2) self-care management resources (assertiveness, self-efficacy, coping behaviors, social support, self-care ability, self-care actions, and communication skills) positively mediate the relationship between vulnerability factors and health outcomes (health status, QOL). The SCMSCD is based on the Theory of Self-Care Management for Vulnerable Populations (Figure 2), a middle range theory developed by the author to describe variables that influence self-care management, health status, and quality of life among populations who experience or are at risk for health disparities.[20] Model relationships have been supported in prior published research.[20,21] Although derived from the Theory of Self-Care Management for Vulnerable Populations, the SCMSCD is a disease-specific, testable model.

Research Questions

This study addresses three research questions:

- What types of social support (affectionate, emotional/informational, positive social interaction and tangible) are significantly positively correlated with health-related QOL in adults with SCD?
- What types of social support are significant predictors of overall health-related QOL in adults with SCD?
- Are there differences in the types of social support reported between females and males with SCD?

Review of the Literature

The review of the literature will be limited to concepts from SCMSCD, the conceptual model that guides this study. Therefore, the review of literature will focus on social support and QOL in adults with SCD. Because life expectancy for individuals with the most severe type of SCD was less than 30 years and SCD was described as a disease of childhood, there is a limited amount of research about intrapersonal resources, self-care management, and health outcomes in adults with SCD.[12,22]

Social Support

Social support is defined as one's internal perception that may influence interpersonal behaviors including expression of positive affect, affirmation of another's behaviors or views, or giving symbolic or material aid.[23] Sherbourne and Stewart (1991) describe five types of social support.[24] Emotional support is the expression of positive affect, empathetic understanding, and the encouragement of expressions of feelings from the recipient of the support. Informational support is the offering of advice, information, guidance, or feedback. Tangible support is the provision of material aid or behavioral assistance. Positive social interaction is the availability of other persons to do fun things. Affectionate support involves the expression of love and affection from the source of support. An example of emotional support could be Emotional support involves expression of support with words, listening, or facial expression while affectionate support involves Social support has the potential to mitigate some the developmental and condition-specific psychological and social issues associated with SCD.[25]

Self-esteem, social assertiveness, and use of social support were significant predictors of adaptation in adolescents with SCD.[26] Research about the role social support plays in the health of adults with SCD is limited. Nash (1994) presented a review of studies related to the psychosocial aspects of SCD.[27] The major theme that permeates the review is the continuous need for social support. Support is needed from family and health care providers. Support from family, noted in studies of other chronic illnesses, may increase compliance and decrease depression, while support from health care providers may increase satisfaction with the healthcare delivery system and decrease the discrimination felt by some patients with SCD. In adults with SCD, feelings of being isolated by their experience of a sickle cell pain crisis and a limited social support networks adversely affects pain management.[19]

In a review of empirically supported psychosocial interventions for pain and adherence outcomes in individuals with SCD, Chen, Cole, and Kato (2004) summarizes three social support intervention studies by Butler and Beltran (1993), Nash (1993), and Vichinsky (1982).[28-31] Chen and colleagues found that interventions that include family members and social networks have the potential advantage of being more cost-effective in the long-term. They also recommend that future social support intervention studies test whether improving social support or family relationships also help individuals with SCD to comply with recommended day-to day management of the disease.[31]

In adults with SCD, feelings of being isolated by their experience of a sickle cell pain crisis and limited social support networks adversely affect pain management.[14] With unpredictable pain crises, adults with SCD may have decreased work productivity, missed work, and school absences that significantly impair their social support network and quality of life.[32] Social isolation may lead

to limited peer interactions; therefore, some adults with SCD may lack experience with problem resolution skills, which can lead to social withdrawal and further exacerbation of poor peer relations.[1] Although previous studies make important contributions to the limited research about the role and importance of social support in individuals with SCD, specific types of social support have not been studied in the context of health-related QOL.

Quality of Life

Quality of life (QOL) is defined as a subjective sense of well-being with physical, psychological, and social dimensions of one's life.[33] SCD is a condition that has profound consequences for the QOL of individuals with SCD and their family members.[34] Individuals with SCD experience health-related QOL worse than the general population.[35] This reduced QOL may be due to the chronicity of the illness combined with frequent hospitalizations for pain or other complications, which can contribute to impaired psychosocial functioning.[1] Although increasing life expectancy is an important accomplishment, QOL is also important.[36] Interventions in SCD should consider improvements in health-related QOL as an important outcome.[35,37] By discovering the influence of type of social support on health-related QOL, interventions can be better tailored to meet the needs of this vulnerable, minority population.

Methods

As a part of a larger cross-sectional descriptive study, a convenience sample of 232 adults with a diagnosis of SCD was recruited from two SCD clinics located within academic medical centers in the southeastern United States. Participant criteria included ability to read, write, or understand English, be at least 18 years old, and have a diagnosis of SCD. Institutional Review Board approval had been received from the two data collection sites and the principle investigator's academic institution. Participants were recruited and informed consent was obtained following the approved protocol. Data collection took place in a private area of each SCD clinic using paper and pencil. Participants completed the questionnaires during one clinic visit in an average of 30 to 60 minutes. Five participants requested assistance to complete the questionnaires. In these five cases, the investigator or nurse read the questions and recorded the responses. Upon completion of study instruments, each participant received $25 for the time required to participate in the study.

The questionnaire packet included a demographic data form and instruments that measured SCD knowledge, assertiveness, coping behaviors, SCD self-efficacy, social support, self-care, health status, and quality of life. All study instruments were developed or selected to encompass the range of variables relevant to the larger study in which the Theory of Self-Care Management for Vulnerable Populations was being tested.[20] The instruments relevant to examining

relationships among types of social support and health-related QOL in adults with SCD are described below.

Social Support: Perceived availability of support was measured with the Medical Outcomes Study Social Support Survey (MOS-SSS), a 19-item Likert-type scale containing four subscales (affectionate, emotional/informational, positive social interaction, and tangible). Total scale and subscale internal consistency reliabilities have been reported to be above 0.91. Construct validity is supported by both confirmatory and principal components factor analysis. Responses are summed, with higher scores indicating higher perceptions of available support.[24,38] Cronbach's alpha reliabilities for the social support subscales in the current study were 0.92, 0.81, 0.82, and 0.89, respectively and for the total scale 0.95.

Quality of Life: The Chronic Illness Quality of Life Ladder (CIQOLL) was used to measure health-related quality of life (HRQOL) in relation to living with SCD. The ten-step ladder measures QOL at four time points: present, life without SCD (i.e., if the individual no longer had SCD), one year ago (past), and one year from now (future), where ten indicates the best possible quality of life and one indicates the worst possible quality of life. These four points in time form the four subscales of the CIQOLL. Internal consistency reliability has been reported to be greater than 0.90 for each subscale. Principal components factor analysis resulted in four meaningful factors corresponding to the four time periods, accounting for 87% of the variance. The CIQOLL also has demonstrated convergent validity, by high significant correlations with the Life Purpose Scale (0.74) and divergent validity by high negative correlations with the CES-D -.65).[33,39] Subscale scores are obtained for each time period: present, without SCD, past, and future, with higher scores indicating higher QOL. Cronbach's alpha reliabilities for the quality of life subscales in the current study were 0.89, 0.88, 0.88, and 0.91, respectively, and 0.96 for the total scale.

Data Analysis

Descriptive statistics were calculated to describe the demographic characteristics of the sample of adults with SCD. Scale and subscale means, ranges, and standard deviations were calculated. Pearson's correlations were conducted to determine the relationships between types of social support and QOL in adults with SCD. Multiple regression was used to determine which type of social support is a statistically significant predictor of QOL in adults with SCD. T-tests were conducted to test for significant differences between availability of different types of social support in types of social support. T-tests were also used to examine equivalency of female and males with SCD on age, income, number of SCD crises per year, education, and number of SCD complications.

Results

The sample (Tables 1 and 2) consisted of 143 (61.60%) women and 89 (31.40%) men. The average participant was 35 years old with a high school education. The respondents had an average of three SCD crises per year. Almost 62% of the sample had never been married and three-quarters (75%) lived with their families. The majority of participants were either not employed (27.60%) or were unemployed due to disability (41%). Using zip codes provided by participants, the average median household income was determined to be approximately $36,000.[40] This is below the average median household income for the US which was $47,584 at the time of data collection.[41]

Research question 1: What types of social support (affectionate, emotional/informational, positive social interaction, and tangible) are significantly positively correlated with health-related QOL in adults with SCD? All four types of social support and overall social support were positively and significantly correlated with each time point of health-related QOL and overall health-related QOL in this sample of adults with SCD (Table 4).

Research question 2: What types of social support are significant predictors of overall health-related QOL in adults with SCD? The regression analysis revealed that both affectionate social support and tangible social support are statistically significant predictors of overall health-related QOL in adults with SCD (Table 5).

Research question 3: Are there differences in the reported availability of types of social support reported between females and males with SCD? Females and males with SCD were more alike than difference. Females were significantly older than males (36 years versus 33 years, $p < .05$), otherwise there were no significant differences in income, the number of SCD crises per year, education, or SCD complications. There were no statistically significant differences in reports of availability of types of social support between females and males with SCD.

Limitations

There are several limitations that need to be acknowledged. The self-selected convenience sample was recruited from two different clinic sites. In the original data analysis, there were significant differences in age, onset of first SCD crisis, and median household income) between the two data collection sites. However, overall, the sites were more alike than different and were combined to achieve the required sample size required for structural equation modeling, the data analysis technique used in the larger study.

Furthermore, there were missing data. Several factors may have resulted in missing data, including the multiple task responsibilities of the data collectors, which led to less than consistent follow-up for complete data from each participant. Also, the longest scale, 54 items, contained the most missing data. T-

tests confirmed that that there were no significant differences in respondents with complete data and those with incomplete data.

Respondents were not asked to identify their specific type of SCD (e.g., Sickle Cell Anemia [SS], Sickle-Hemoglobin C Disease [SC], or Sickle Thalassemia). Because the types of SCD have differing levels of severity, it will be important to obtain this information in future studies.

Conclusions

The data suggest that all four types of social support (affectionate, emotional/informational, positive social interaction, and tangible) have a positive impact on health-related QOL in adults with SCD. Moreover, affectionate and tangible social support are predictors of overall health-related QOL. For individuals with chronic illnesses such as SCD, interventions that enhance both affectionate and tangible social supports may improve health outcomes.

Study findings support previous research that indicates the importance of involving friends and family of adults with SCD in interventions.[31] Friends and family members may be able to provide the affectionate support that will decrease feelings of isolation and improve social networks and social support.[19] These provisions may decrease maladaptive coping strategies and therefore improve health-related QOL.

Tangible support, the provision of material aid or behavioral assistance, are often harder for adults with SCD to obtain due to the barriers they face upon entering a healthcare system. Barriers include seeking treatment for pain which is poorly understood and 'invisible' in nature to clinicians, lack of understanding by non-specialist clinicians, and feeling mistrusted by medical staff.[19] Additionally, many adults with SCD have poor socio-economic status due to their chronic illness and its effect on educational and employment opportunities. System and socio-economic barriers may result in adults with SCD making the choice to actively avoid using available, although inadequate, services. Adults with SCD need assistance in overcoming barriers in order to access and use the tangible supports that are available.

Due to advances in medical care, adults with SCD are living much longer. Unfortunately, there has been little research on In order to tailor comprehensive models of care, it is important to know more of about the types of social support that are most efficacious to adults with SCD in order to develop models of care to enhance health-related quality of life. Self-care management resources such as social support positively affect health-related QOL. This study is an important step in developing tailored interventions to meet the needs of adults with SCD. Future studies should be done to further explore the specific needs of adults with SCD in order to develop and test interventions that will improve health-related quality of life.

Table 1

Demographic Description of the Sample (means, standard deviation, range)

	N*	x (SD)	Range
Age (Years)	231	34.91 (12.42)	18-73
Education (Years)	232	12.36 (1.99)	5-21
Average SCD crises per year (Number)	219	2.65 (3.08)	0-25
Median household income	221	$36,039 ($10,125)	$17843-$65,375
*Note: The sample size varies due to missing data			

Table 2

Demographic Descriptors of the Sample (frequencies) (N=232)

Variable	Categories	N (%)
Gender	Female	143 (61.60)
	Male	89 (31.40)
Employment	Full-time	48 (20.70)
	Part-time	24 (10.30)
	Not-employed	64 (27.60)
	Disabled	96 (41.40)
Marital Status	Never Married	143 (61.60)
	Married	47 (20.30)
	Divorced	18 (7.80)
	Widowed	12 (5.20)
	Separated	12 (5.20)
Living Situation	Alone	42 (18.10)
	With Family	174 (75.00)
	With Friends	14 (6.00)
Environment	Rural	75 (32.30)

	Urban	153 (65.90)

Table 3

Summary of Social Support and Quality of Life Data

Scale	Subscale	N*	Range	X(SD)	Cronbach's Alpha
Social Support (MOS-SSS)	Total Scale	198	22-95	75.64 (15.12)	0.95
	Emotional/ Informational subscale	212	9-40	31.00 (7.01)	0.92
	Affectionate subscale	222	3-15	12.27 (2.82)	0.82
	Tangible subscale	226	5-20	15.82 (3.58)	0.80
	Positive Social Interaction subscale	221	4-20	15.37 (3.64)	0.87
Quality of Life (CIQOLL)	Total Scale	188	51-280	223.07 (33.72)	0.95
	Present Subscale	216	7-70	51.77 (10.90)	0.87
	Without SCD Subscale	214	7-70	61.13 (8.98)	0.87
	Past Subscale	202	13-70	49.67 (10.88)	0.86
	Future Subscale	200	14-70	58.37 (10.14)	0.90
MOS-SSS= Medical Outcomes Study Social Support Survey CIQOLL= Chronic Illness Quality of Life Ladder *Note: The sample size varies due to missing data					

Table 4

Correlations among Types of Social Support and Health-Related QOL

Social Support					
Quality of Life	Affectionate Subscale	Emotional/ Informational	Positive Social	Tangible Subscale	Total Social

		Subscale	Interaction Subscale		Support Scale
Present Subscale	.41**	.41**	.41**	.25**	.43**
Without SCD Subscale	.41**	.37**	.31**	.24**	.37**
Past Subscale	.36**	.39**	.38**	.23**	.40**
Future Subscale	.32**	.34**	.30**	.18*	.32**
Total QOL Scale	.45**	.45**	.43**	.28**	.46**
* = p < 0.01 ** = p < 0.05					

Table 5

Summary of Simultaneous Regression Analysis for Types of Social Support Predicting Total Health-Related Quality of Life in Adults with SCD

Variable	*B*	*SE B*	*ß*
Affectionate	4.34	1.45	.36**
Emotional/Informational	.75	.60	.16
Positive Social Interaction	1.59	1.22	.18
Tangible	-2.0	.90	-.21*
R 2			.28
F			15.31**
* = p < 0.01 ** = p < 0.05			

References

1. Edwards, C. L., Scales, M. T., Loughlin, C., Bennett, G. G., Harris-Peterson, S., Castro, L. M., et al. (2005). A brief review of the pathophysiology, associated pain, and psychosocial issues in sickle cell disease. *International Journal of Behavioral Medicine, 12*(3), 171-179.
2. Godeau, B., Noel, V., Habibi, A., Schaeffer, A., Bachir, D., & Galacteros, F. (2001). Sickle cell disease in adults: Which emergency care by the internists? *La Revue de Medecine Interne, 22*(5), 440-451.

3. Andrews, M. M., & Mooney, K. H. (1994). Alterations in hematologic function in children. In K. L. McCance, & S. E. Huether (Eds.), *Pathophysiology: The biologic basis for disease in children* (pp. 908-939). St. Louis: Mosby-Yearbook.
4. National, Heart, Lung & Blood Institute. (2007). *Chapter 12. Minority activities*. *NHLBI FY 2006 Fact Book* (pp. 152-153).
5. Reed, W., & Vichinsky, E. P. (1998). New considerations in the treatment of sickle cell disease. *Annual Review of Medicine, 49*, 461-474.
6. Yang, Y. M., Shah, A. K., Watson, M., & Mankad, V. N. (1995). Comparison of costs to the health sector of comprehensive and episodic health care for sickle cell disease patients. *Public health reports (Washington, D.C. : 1974), 110*(1), 80-86.
7. Smith, W. R., Bovbjerg, V. E., Penberthy, L. T., McClish, D. K., Levenson, J. L., Roberts, J. D., et al. (2005). Understanding pain and improving management of sickle cell disease: The PiSCES study. *Journal of the National Medical Association, 97*(2), 183-193.
8. Mayfield, E. (1996). New hope for people with sickle cell anemia. *Federal Drug Administration Consumer, 30*(4), 4.
9. McKerrell, T. D., Cohen, H. W., & Billett, H. H. (2004). The older sickle cell patient. *American Journal of Hematology, 76*(2), 101-106.
10. Diggs, L. M. (1973). Anatomic lesions in sickle cell disease. In H. Abramson, J. F. Bertles & D. L. Wethers (Eds.), *Sickle cell disease: Diagnosis, management, education, and research* (pp. 189-229). St. Louis: C.V. Mosby.
11. Wojciechowski, E. A., Hurtig, A., & Dorn, L. (2002). A natural history study of adolescents and young adults with sickle cell disease as they transfer to adult care: A need for case management services. *Journal of Pediatric Nursing, 17*(1), 18-27.
12. Lenoci, J. M., Telfair, J., Cecil, H., & Edwards, R. F. (2002). Self-care in adults with sickle cell disease. *Western Journal of Nursing Research, 24*(3), 228-245.
13. Platt, O. S. (1994). Easing the suffering caused by sickle cell disease. *The New England Journal of Medicine, 330*(11), 783-784.
14. McClish, D. K., Penberthy, L. T., Bovbjerg, V. E., Roberts, J. D., Aisiku, I. P., Levenson, J. L., et al. (2005). Health related quality of life in sickle cell patients: The PiSCES project. *Health & Quality of Life Outcomes, 3* , 50.
15. Jenerette, C., Funk, M., & Murdaugh, C. (2005). Sickle cell disease: A stigmatizing condition that may lead to depression. *Issues in Mental Health Nursing, 26*(10), 1081-1101.
16. Davies, S. C., & Gilmore, A. (2003). The role of hydroxyurea in the management of sickle cell disease. *Blood Reviews, 17*(2), 99-109.
17. Edwards, C. L., Scales, M. T., Loughlin, C., Bennett, G. G., Harris-Peterson, S., DeCastro, L. M., et al. (2005). A brief review of the pathophysiology, associated pain, and psychosocial issues in sickle cell disease. *International Journal of Behavioral Medicine, 12*(3), 171-179.

18. Burlew, K., Telfair, J., Colangelo, L., & Wright, E. C. (2000). Factors that influence adolescent adaptation to sickle cell disease. *Journal of Pediatric Psychology, 25*(5), 287-299.
19. Booker, M. J., Blethyn, K. L., Wright, C. J., & Greenfield, S. M. (2006). Pain management in sickle cell disease. *Chronic Illness, 2*(1), 39-50.
20. Dorsey, C. J., & Murdaugh, C. L. (2003). The theory of self-care management for vulnerable populations. *The Journal of Theory Construction and Testing, 7*(2), 43-49.
21. Jenerette, C. M., & Phillips, R. C. S. (2006). An examination of differences in intra-personal resources, self-care management, and health outcomes in older and younger adults with sickle cell disease. *Southern Online Journal of Nursing Research, 7*(3), 1-24.
22. Onitilo, A. A., Lazarchick, J., Brunson, C. Y., Frei-Lahr, D., & Stuart, R. K. (2003). Autologous bone marrow transplant in a patient with sickle cell disease and diffuse large B-cell lymphoma. *Transplantation Proceedings, 35*(8), 3089-3092.
23. Kahn, R. L. (1979). Aging and social support. In M. W. Riley (Ed.), *Aging from birth to death: Interdisciplinary perspectives* (). Boulder, CO: Westview Press for American Association for the Advancement of Science.
24. Sherbourne, C. S., & Stewart, A. L. (1991). The MOS social support survey. *Social Science and Medicine, 32*(6), 705-714.
25. Telfair, J., & Gardner, M. M. (2000). Adolescents with sickle cell disease: Determinants of support group attendance and satisfaction. *Health & Ssocial work, 25*(1), 43-50.
26. Burlew, K., Telfair, J., Colangelo, L., & Wright, E. C. (2000). Factors that influence adolescent adaptation to sickle cell disease. *Journal of Pediatric Psychology, 25*(5), 287-299.
27. Nash, K. B. (1994). *Psychological aspects of sickle cell disease: Past, present, and future directions of research*. New York: Haworth.
28. Nash, K., & Kramer, K. (1993). Self-help for sickle cell disease in african american communities. *Journal of Applied Behavioral Science, 29*(2), 202-215.
29. Butler, D. J., & Beltran, L. R. (1993). Functions of an adult sickle cell group: Education, task orientation, and support. *Health & Social Work, 18*(1), 49-56.
30. Vichinsky, E. P., Johnson, R., & Lubin, B. H. (1982). Multidisciplinary approach to pain management in sickle cell disease. *The American Journal of Pediatric Hematology/Oncology, 4*(3), 328-333.
31. Chen, E., Cole, S. W., & Kato, P. M. (2004). A review of empirically supported psychosocial interventions for pain and adherence outcomes in sickle cell disease. *Journal of Pediatric Psychology, 29*(3), 197-209.
32. Todd, K. H., Green, C., Bonham, V. L., Jr, Haywood, C., Jr, & Ivy, E. (2006). Sickle cell disease related pain: Crisis and conflict. *Journal of Pain, 7*(7), 453-458.

33. Murdaugh, C. (1997). Health-related quality of life as an outcome in organizational research. *Medical care, 35*(11), NS41-NS48.
34. Strickland, O., Jackson, G., Gilead, M., McGuire, D. B., & Quarles, S. (2001). Use of focus groups for pain and quality of life assessment in adults with sickle cell disease. *Journal of the National Black Nurses Association, 12*(2), 36-43.
35. McClish, D. K., Penberthy, L. T., Bovbjerg, V. E., Roberts, J. D., Aisiku, I. P., Levenson, J. L., et al. (2005). Health related quality of life in sickle cell patients: The PiSCES project. *Health & Quality of Life Outcomes, 3* , 50.
36. Dorman, K. (2005). Sickle cell crisis! managing the pain. *RN, 68*(12), 33-6; quiz 37.
37. Anie, K. A. (2005). Psychological complications in sickle cell disease. *British Journal of Haematology, 129*(6), 723-729.
38. Padilla, G. V., Frank-Stromberg, M., & Koresawa, S. (2004). Single instruments for measuring quality of life. In M. Frank-Stromborg, & S. Olsen (Eds.), *Instruments for clinical health-care research* (3rd ed., pp. 128-149). Boston: Jones & Bartlett.
39. Murdaugh, C., Moneyham, L., Jackson, K., Phillips, K., & Tavakoli, A. (2006). Predictors of quality of life in HIV-infected rural women: Psychometric test of the chronic illness quality of life ladder. *Quality of Life Research, 15*(5), 777-789.
40. U.S. Census Bureau. (2005). *United States census 2000.* Retrieved 1/06/06, from http://www.census.gov/main/www/cen2000.html.
41. U.S. Census Bureau. (2007). *Two-year-average median household income by state: 2004-2006.* Retrieved 1/23/08, from http://www.census.gov/hhes/www/income/income06/statemhi2.html.