African American Adolescents with Sickle Cell Disease: Support Groups and Psychological Well-Being

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Abstract:

There has been little systematic study of the impact of support groups on the psychological well-being (PWB) of adolescents with sickle cell disease (SCD). Questionnaires, administered by group leaders of 12 SCD support groups, were completed and returned from 79 (80%) of the 99 African American adolescent SCD support group members recruited into this study. Multiple regression analysis revealed that PWB was best predicted by fewer physical symptoms and greater satisfaction with the group. To test a buffering hypothesis of social support, two 2 2 analyses of variance (ANOVAs) were computed to test the interaction of group satisfaction and (a) physical symptoms and (b) pain on PWB. Group satisfaction showed a main effect for each ANOVA. An interaction effect between pain and group satisfaction was detected, supporting a buffering hypothesis. This suggests that adolescents with SCD associate pain, but not physical symptoms, as high stressors. Professionals can enhance their effectiveness as providers of social and mental health services by understanding the role support groups play in the overall well-being of adolescents with SCD.

Article:

Sickle cell disease (SCD) refers to a group of inherited disorders that involve the production of abnormal red blood cells. The reduced functioning of these cells, whose sickled appearance gives rise to its name, creates myriad chronic and acute health complications that vary in severity and frequency. In its acute phase, people with SCD experience moderate to intense pain as blood vessels are obstructed by the abnormal cells, initiating a vaso-occlusive crisis (Butler & Beltran, 1993). Long-term complications of SCD include chronic anemia (Vichinsky, Hurst, & Lubin, 1983), seizures, bone necrosis, kidney dysfunction, and stroke (Butler & Beltran, 1993).

In the United States, SCD is found primarily in African Americans, affecting approximately 1 in every 400 live births in this population (Lorey, Arnopp, & Cunningham, 1996; Rooks & Pack, 1983). Because there is no cure for SCD, medical care typically is palliative and focuses primarily on pain management (Butler & Beltran, 1993).

Living with the chronic and unpredictable complications of SCD can have a profound effect on biological, psychological, and social development (Battle, 1984; Hurtig, 1986). This maybe especially pronounced during adolescence, when responsibility for health shifts from the parents to the adolescent. Studies of adolescents with SCD generally have concluded that adolescents who perceive that they have supportive environments have better overall biopsychosocial functioning (i.e., have fewer reports of psychological and physical difficulties) than do adolescents without such perceptions of support (Burlew, Evans, & Oler, 1989; Hurtig, Koepke, & Park, 1989; Kumar, Powers, Allen, & Haywood, 1976).

Support groups have the potential to satisfy needs unmet by other sources of social support such as family and caregivers. Support groups create a natural atmosphere for empowerment and for the giving and receiving of support (Borman, 1992; Katz, 1992). For people with chronic conditions, support groups can play an important part of comprehensive treatment programs (Black & Weiss, 1990; Weiss, 1992). Support groups can teach and promote healthy behavioral change through direct and vicarious learning (Hedrick, Isenberg, & Martini, 1992).

In addition to providing disease- or disorder-specific information, support groups facilitate sharing emotional responses with others facing similar problems and may help to reduce the stress associated with physiological difficulties (Cohen & Syme, 1985).

Although the positive impact of social support on physical and psychological outcomes is well documented, the mechanisms through which social support leads to more favorable outcomes is not well understood. Two divergent hypotheses have been proposed and are widely researched and debated (Taylor, 1995). First, the direct effect hypothesis proposes that social support is beneficial during times of stress and nonstress. The buffering hypothesis (Taylor, 1995), however, contends that the physical and psychological benefits of social support are evident primarily during periods of high stress and are not very evident during periods of nonstress. As such, social support blunts or buffers the effects of high stress, enabling the person to cope more effectively (Taylor, 1995).

The relationship between support group involvement and the psychological well-being (PWB) of adolescents with SCD has not been studied systematically. The purpose of this study, therefore, is to begin a program of research that explores this issue. In particular, we examined the relationships of PWB to satisfaction with the support group, group attendance, physical symptoms, psychosocial interference, and pain. PWB was operationalized as the absence of emotional distress. The anxiety and depression subscales of the How I Feel (HIF) questionnaire (Kellam, Bornstedt, & Ensminger, 1983) were combined to tap emotional distress. Based on the direct hypothesis, we expected that high levels of group satisfaction, increased group attendance, fewer psychosocial interferences, fewer physical symptoms, and lower levels of pain would predict lower levels of emotional distress, that is, higher levels of PWB. To test the buffering hypothesis (our second aim), we examined whether group satisfaction was interrelated with levels of pain and physical symptoms to influence our outcome variable, PWB.

METHOD

PARTICIPANTS

A total of 20 SCD adolescent support groups were located using personal contacts and two directories that listed the locations and contact persons of SCD groups1 in the United States and Canada. Of the 20 groups located, 4 (20%) were defunct, and 12 of the 16 existing groups elected to participate in the present study. Of these groups, 4 were community based and 8 were in pediatric acute care settings. Of the 12 groups, 11(94%) were led by females, the majority of whom were African American (81 %). None of the leaders had SCD. Slightly more than half of the group leaders were social workers (56%); the rest were either community-based staff members (31 %) or nurse coordinators (13%). All group leaders were involved as part of their profession. The average group met once a month and had been operating for 3 years. No attempts were made to distinguish or standardize groups by format or content of sessions, frequency of meetings, or group type.

Group leaders or facilitators contacted all active group members for inclusion in the study. Active group membership was operationalized as (a) having attended at least one group meeting during the past year, (b) voluntary inclusion on the group's roster, and (c) having been formally diagnosed with SCD. Each group identified an average of 10 members for inclusion, with a range of 5 to 18 active members. A total of 110 active group members were identified across the 12 participating sites, of which 99 (90%) elected to participate in the study. Fully completed questionnaires were received from 79 (80%) active group members/study participants.

There were no significant differences in participation rates or response rates among groups. No effort was made, however, to determine whether group members declining participation varied from those participating in the study. Similarly, no steps were taken to determine differences between group members who fully completed the questionnaire and those who returned partially completed questionnaires.

PROCEDURE

Data were collected between March and September 1992. Leaders of the SCD groups were mailed packets containing the study instruments and protocol. After obtaining informed consent from members, leaders of the

12 SCD groups administered an in-depth written questionnaire to group members who agreed to participate during group sessions. Every effort was made to keep responses confidential (e.g., sitting members in every other chair); no names were requested, and each member was assigned both a site and individual identification number. Questionnaires were administered at various points in time over the 7-month period to members who might have missed a group session but wanted to participate in the study. This was done to maximize the number of group members participating, helping to ensure a more representative sample. Each adolescent participant was reimbursed $20 for his or her time, and $75 was donated to each group after completed data packets were returned to researchers.

MEASURES

The questionnaire used in this study consisted of (a) original questions emerging from focus groups with SCD self-help group members in North Carolina and refined using concepts from the literature (Kramer & Nash, 1992) and (b) portions of standardized scales used in previous SCD investigations. The resulting instrument consisted of 39 main questions. Several of these questions contained multiple items. Prior to data collection, two rounds of pilot testing were conducted by the first author to determine appropriateness for use with adolescents.

Demographics. Standard demographic characteristics were measured. These included age, gender, race, highest grade completed, marital status, and household size. In addition, distance traveled to the meeting place was measured with a single item using a 5-point checklist with responses ranging from *less than 1 mile* to *more than 50 miles.*

Psychological well-being. PWB was measured using the anxiety and depression subscales of the HIF questionnaire from the Woodlawn Mental Health Community Intervention Study (Kellam et al., 1983). These subscales were combined to form a 10-item scale assessing how often the adolescent was bothered by feelings of emotional distress. Responses using a 4-point Likert scale ranged from *very often* to *never*. Scores were summed and divided by the number of items answered (maximum =10) to yield a composite PWB score ranging from 1 to 4 (Cronbach's alpha = .91). Higher scores were indicative of less emotional distress and higher PWB. This composite scale has been used successfully in a previous study of African American adolescents with SCD (Telfair, 1992).

Satisfaction with the group. Overall satisfaction with the support group was measured with a single item using a 5-point Likert scale ranging from *not very satisfied* to *very satisfied*.

Group attendance. How frequently a participant attended group meetings was measured by a single 4-point checklist (1= *less than half of the time*, 2 = *about half of the time*, 3 = *about every time*, 4 = *every time*).

Physical symptoms. A modified version of the National SCD Adult Self-Help Study's Sickle Cell Disease Problem Scale (Nash, 1991a) was employed to assess the presence and the extent of physical symptoms experienced by participants during the past 30 days. Modifications involved simplifying the language of the items to make them more understandable for adolescents. The seven items assessing physical symptoms common in SCD (e.g., pain, shortness of breath, threw up/vomited) were measured using a 3-point Likert scale ranging from *never a problem* to *very much a problem*. A composite score was computed by summing responses and dividing by number of response items answered (maximum = 7). Higher scores indicated that the member experienced a higher number of physical symptoms or problems (Cronbach's alpha = .91).

Psychosocial interferences. How often SCD caused a problem or interfered with day-to-day activities was measured using a modified version (15 items) of the National Adult SCD Self-Help Study's Psychosocial Interferences Scale (PIS) (Nash, 1991b). Modifications involved simplifying the language of the items to make them more understandable for adolescents. The 15 items of the PIS were measured using a 4-point Likert scale ranging from *never* to *very often*. Responses were summed and divided by the number of response items

(maximum =15) to yield a composite PIS score (Cronbach's alpha = .95). A high score indicated that the member experienced a large number of sickle cell-specific psychosocial interferences (Kramer & Nash, 1995).

Pain. The severity of pain experienced over the past 30 days that could be attributed to SCD was assessed with a single item using a 5-point Likert scale ranging from *no pain* to *very severe pain*.

DATA ANALYSIS

To determine whether significant item response differences existed among group members, all study variables were examined in a series of one-way analyses of variance (ANOVAs) that included the characteristics of age, gender, educational status, and time in group. Race was not included in the analysis because 95% of the sample participants were African Americans. Furthermore, data were aggregated by group to determine whether any significant differences existed among groups on demographic variables or the study variables of interest.

To test the differential hypotheses, a stepwise multiple regression was computed with SPSS. Using the dependent variable of PWB, the following variables were entered into the equation: group satisfaction, frequency of attendance, pain, physical symptoms, PIS, gender, and age.

To test the buffering hypothesis, two separate 2 x 2 ANOVAs were conducted— (a) Satisfaction x Pain and (b) Satisfaction x Physical Symptoms—to test for interactions between satisfaction with the group and pain and physical symptoms for the dependent variable of PWB. For purposes of these analyses, the grouping variables (scores for satisfaction with the group, level of pain, and degree of physical symptoms causing problems) were dichotomized into a high versus low level using a median split. Scores for each variable then were recoded to reflect this dichotomization. Hence, group satisfaction was recoded into high versus low level of satisfaction with the group; pain was recoded such that high reflected an experience of medium to high levels of pain during the past 30 days, whereas low reflected minimal to no levels of pain during the past 30 days. Finally, scores on the physical symptom scale were dichotomized into high versus low to reflect a high frequency of physical problems (high) versus a low frequency of physical problems (low).

RESULTS

Selected demographic characteristics are presented in Table 1. Most group members were female (59.5%), were in middle or high school (75.6%), reported attending the group every or almost every time it met (67.1 %), and lived within 10 miles of the group meeting place. There were no significant differences between any demographic characteristics and the study variables of interest.

PREDICTORS OF PSYCHOLOGICAL WELL-BEING

Test of the Direct Hypothesis

Bivariate analyses are presented in Table 2. As expected, physical symptoms were negatively associated with PWB scores, and group satisfaction was positively correlated with PWB score. In addition, level of pain and PIS both were positively related to symptom levels. No other significant bivariate associations were observed.

Stepwise multiple regression analysis then was conducted to determine the variables predictive of PWB. The following predictors were entered: group satisfaction, group attendance, physical symptoms, PIS, and pain. As can be seen in Table 3, group satisfaction entered at Step 1, $F(1, 69) = 9.72$, $p < .003$, and physical symptoms entered at Step 2, $F(2, 68) = 7.88$, $p < .0008$. No other variables entered into the regression model.

Test of the Buffering Hypothesis

Two sets of ANOVAs were conducted with PWB scores as the dependent variable. The first ANOVA, Physical Symptoms (high level of pain vs. low level of pain) x Group Satisfaction (high satisfaction vs. low satisfaction), was significant, $F(3, 75) = 8.15$, $p < .01$. A significant main effect was observed for group satisfaction, $F(1, 75) = 19.13$, $p < .01$, wherein PWB scores were higher among participants with high group satisfaction scores (2.61 ± 0.43) than among participants with low group satisfaction scores (1.87 ± 0.70). Neither the main effect for physical symptoms nor the interaction was significant.

TABLE 1
Selected Demographic Characteristics of Participants

Characteristic	n	*Percentage*
Age		
12 years or under	10	12.8
13-15 years	41	52.6
16-18 years	22	28.2
19-21 years	5	6.4
Gender		
Female	47	59.5
Male	32	40.5
Last grade completed		
Lower than Grade 7	17	21.8
Grades 7-8	26	33.3
Grades 9-12	33	42.3
Beyond Grade 12	2	2.6
Meeting attendance		
Less than half of time	18	22.8
Half of time	8	10.1
About every time	33	41.8
Every time	20	25.3
Distance to meeting		
Less than 1 mile	10	12.7
1-10 miles	44	55.7
11-25 miles	15	19.0
26-50 miles	5	6.3
More than 50 miles	5	6.3

TABLE 2
Pearson Correlations of Predictor Variables and Psychological Well-Being

	1	*2*	*3*	*4*	*5*	*6*
1. Psychological well-being	1.000					
2. Attendance	.144	1.000				
3. Satisfaction	.351**	–.060	1.000			
4. Physical symptoms	–.238*	–.017	.047	1.000		
5. Pain	.006	–.127	.077	.577***	1.000	
6. Psychosocial Interferences Scale	–.030	.095	.040	.256*	–.020	1.000

*$p < .05$. **$p < .01$. ***$p < .001$.

TABLE 3
Summary of the Stepwise Regression Analysis

Variable	B	SE	β
Step 1 ($R^2 = .12$)			
Group satisfaction	.18	.06	.35**
Step 2 ($R^2 = .19$)			
Level of physical symptoms	–.04	.01	–.25*

*$p < .05$. **$p < .01$.

The second ANOVA, Pain (high level vs. low level) x Group Satisfaction (high satisfaction vs. low satisfaction) also was significant, $F(3, 75) = 8.30$, $p < .01$. As with the first ANOVA, a significant main effect was observed for group satisfaction, $F(1, 75) = 20.30$, $p < .01$, wherein participants with high satisfaction with the group had higher PWB scores (2.6 ± 0.43) than did participants with low satisfaction with the group (1.87 ± 0.70). This main effect, however, was qualified by a significant two-way interaction effect of Group Satisfaction x Pain, $F(1, 75) = 4.26$, $p = .043$ (Table 4). When group satisfaction was low, those individuals with higher levels of

pain had lower PWB scores than did those persons with lower levels of pain. However, when level of group satisfaction was high, the relationship between level of pain and PWB scores was much weaker (Table 4).

DISCUSSION

This study examined factors associated with the PWB of adolescents with SCD participating in SCD support groups. In this study, PWB was measured by a composite score representing anxiety and depression. The findings from our regression analysis revealed that enhanced PWB could be best explained by fewer physical symptoms and greater group satisfaction. Increased group attendance, severity of pain, and psychosocial interferences were not significant predictors of PWB among the adolescents participating in this study. Note that the amount of variance explained in the multiple regression analysis was small, suggesting the need to look at other related factors such as how active members have been in the group and what participants do during meetings. As an aside, it is important to keep in mind that multiple regression is a more sensitive test of the relationship between physical symptoms and wellbeing because it allows for the variability on the physical symptom scale. By contrast, ANOVA is less sensitive because some information from the independent variables is lost due to data collapsing into categories.

TABLE 4
Interaction of Group Satisfaction and Pain With Psychological Well-Being

	Level of Pain	
	High	*Low*
Level of group satisfaction		
High	2.12	2.55
Low	1.55	2.65

The significant negative correlation between physical symptoms and PWB supports findings from the National Cooperative Study of Sickle Cell Disease. A strength in the measurement of these variables is that both take into consideration a temporal component; that is, both were measures of experiences during the past 30 days rather than global assessments of experiences. Therefore, these data are less subject to recall and selectivity bias.

The frequency with which adolescents attended the support group was not predictive of PWB, nor was it significantly correlated to satisfaction with the group. However, future studies should employ multiple items to assess these constructs. On a practical level, this finding is an important message to deliver to group leaders and facilitators who might feel discouraged by waning or small group attendance. Theoretically, this finding, which is partly contrary to our hypothesis, raises an interesting question that merits further investigation: Does merely belonging to and having the group as a source of social support serve as a mechanism by which PWB of group members is enhanced? If so, then this finding could be viewed as supporting literature regarding the buffering hypothesis in that it is the quality of the perceived availability of support (satisfaction with the group) rather than quantity (frequency of attendance) that produces beneficial effects (Cohen & Willis, 1985). However, because participants self-select into support groups, those who choose to do so may differ significantly from those who elect not to participate. Thus, the generalizability of these findings is limited.

As evidenced by findings supporting our second hypothesis, support groups for adolescents with SCD appear to serve as a buffer to the stressors of coping with the disease. The use of satisfaction with the group as a proxy measure of social support is reasonable given that the adolescents were aware of the group's purpose—that is, to provide support. Satisfaction with the group therefore can be construed as the quality of support or the degree to which members believe that the group provides them with needed support. Thus, the interaction between pain and group satisfaction is consistent with literature on the buffering effects of social support (Cohen & Willis, 1985; House, Umberson & Landis, 1988).

The negative correlation between physical symptoms and PWB suggests that these physical symptoms could be viewed as stressors. Yet, these physical symptoms were not significantly associated with psychosocial interferences and did not interact with group satisfaction, as one would expect, in testing the buffering hypothesis. An explanation of this finding is that severe pain is an acute and intermittent complication of SCD. It can be debilitating, so its strong positive association with psychosocial interferences is quite expected. Given that the buffering effect is evident only during periods of high stress, the lack of an interaction effect between physical symptoms and group satisfaction suggests that these physical symptoms are viewed as less distressing than is pain. Furthermore, although physical symptoms were a predictor of PWB, they were not associated with psychosocial interferences. This could imply that adolescents view these physical symptoms not as distressing but rather as routine stressors of SCD.

This study provides much needed preliminary data on the relation of support group and physical factors to PWB among adolescents with a chronic condition such as SCD. However, several limitations must be noted. First, only 12 of the 16 support groups and 79 of the 99 eligible members participated in the study, which might limit the generalizability of the study. Second, the cross-sectional design of the study does not allow for causal statements about the findings. Third, the absence of a comparison group of adolescents with SCD who do not attend support groups renders it impossible to rule out potential confounds that might further explain findings.

Despite these limitations, it is reasonable to suggest that support groups have the potential to mitigate the detrimental effects of living with a chronic disease among adolescents, especially during times of acute pain. Thus, health professionals should be encouraged to promote the active involvement in support groups to adolescents with SCD and other chronic conditions.

This study provided the unique opportunity to examine African American adolescents successfully engaged in an activity designed to empower them to cope with the many stressors associated with SCD. It demonstrates the potential impact that mutual and positive regard can have on overall functioning. Future outcome-based and longitudinal studies are needed to investigate the evolution of the SCD support groups overtime. Both the short- and long-term impact of group involvement on the psychosocial well-being of African American adolescents with this condition should be analyzed.

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