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Voting Engagement among Adults with Sickle Cell Disease (SCD): Health Matters

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Abstract

The Voting Rights Act of 1965 was established to enforce voting rights guaranteed by the Fourteenth and Fifteenth amendments. Unfortunately, Blacks faced additional barriers when attempting to exercise their right to vote. Moreover, focusing on voting specifically among adults living with Sickle Cell Disease (SCD), we assessed voter participation as a form of advocacy to evaluate if political involvement was related to psychological status. We found that 72% of adults with SCD in our sample routinely voted in government elections. We examined psychological symptoms using the Symptom Checklist -90 (SCL-90-R). Voters consistently presented with better psychological status than nonvoters. Voters reported significantly lower levels of interpersonal sensitivity, anxiety, specific phobia, and psychosis than nonvoters ($p<.05$). We interpret our findings as a non-characterological and non-volitional explanation for political participation among adults with SCD.

Keywords: Voting, Chronic illness, Sickle cell disease, Advocacy, Government, Bias

Introduction

Voting is one of the major pillars of a strong democracy. Voting is an imperfect tool that assures that democratic governments are proxies for the will of the people toward the best interests of all citizens. Voting, and the infrastructure that underpins a fair and legal process of representation, defines the strength of the democracy, and subsequently informs policies and spending priorities of those it represents. But for non-voters, independent of their motives or rationale, their priorities may not be represented, and consequently, policies and spending priorities will inevitably only favor the motives and priorities of active voters. Additionally, government laws and policies may cease to address the needs and priorities of nonvoters, resulting in a government that represents the majority. When structural and policy obstacles to full participation disaggregate, as a function of racial, ethnic, other demographic, or cultural identity, non-voters may be silenced and disenfranchised from the benefits of a representative government [1].

Voting, in the best of circumstances, can be used as a mechanism to create laws and spending policies that promote health priorities within the citizenship of a society. When access to functional resources for any subpopulation is restricted by systemic or volitional factors, government laws and economic policies and practices contribute to health inequities and the promotion of health disparities [2]. Of the 22 democratic societies on record, The Gini Index of Inequalities (2000-2010) demonstrated that the United States has the highest inequality coefficients (0.247), reflective of a significant potential problem of inequality for all systems, to include healthcare, and major opportunities for positive changes (United Nations Development Programme [UNDP] 2010, 152–55) [3]. Increased awareness of populations that have been disenfranchised from voting may produce opportunities to impact the inequality index of the US and the effectiveness of governance in the delivery of healthcare. To this point, recognizing specific and unique demographical characteristics of a subgroup is salient in understanding their involvement in the political process and voting.

Understanding who participates in the political process via voting is important in determining who and what government laws and policies best represent, and which historically disenfranchised groups are most likely to be less represented by policies and spending priorities. Individuals with disabilities are less likely than non-disabled people to be involved in community life including participation in volunteerism, political, religious, recreational, or other social and interpersonal group activities [4]. Individuals with disabilities vote 10-20% less frequently than their non-disabled peers, and disabled individuals living in states with the lowest voting participation experience the worst self-ratings of health [5]. Older individuals, those with higher levels of education, Caucasians, women, and those with higher incomes tend to vote at higher frequencies than those who are younger, less educated, Black, male, and with lower incomes [4]. Marginalized individuals are generally less politically involved. For this study, we investigated political involvement, as defined by voting participation, in a sample of patients with sickle cell disease.

Sickle Cell Disease (SCD) is characterized by the sickling of red blood cells and is caused when partially or fully deoxygenated Hemoglobin (Hgb) molecules distort the shape of normal red blood cells (RBCs) producing stiff, sticky, and sickle-shaped cells that occlude small vessels. This process can produce periods of hypoxia or anoxia-induced cell and tissue necrosis, chronic pain, and significant long-term disability [6]. SCD is a major public health concern, with healthcare cost estimates amounting to millions of dollars annually [7].

To date, few research studies have investigated the intersectional factors associated with political involvement and voting participation in Black patients with chronic diseases like SCD. A recent Cooperative Congressional Election Study (CCES) assessed structural obstacles to voting as a function of zip code. They assessed the time voters spent waiting in line during the 2016 election by using geospatial data generated by smartphones. Researchers found that not only did voters from Black neighborhoods experience longer wait times to vote compared to voters from White neighborhoods, but Black voters themselves encountered significantly longer wait times than their White voter counterparts [4]. These prolonged wait times during elections stand as a structural obstacle to voting, particularly for those with chronic illnesses or disabilities like SCD and may serve to discourage voters from Black neighborhoods or Black voters themselves from voting. The current study evaluated whether psychological and health factors contributed to voting participation in a sample of adult black patients with SCD.

Methods

Design

The current project employed a cross-sectional survey that utilized first-year data from a larger longitudinal survey and medical records study of psychosocial, medical, and genetic factors associated with pain in Black adult patients with SCD.

Subjects

During routine clinic appointments, 178 patients were recruited into an IRB-approved study at a major southeastern regional medical center. Of the 178 patients, 90 provided full data for participation in the present analysis. We note that almost ½ of the 178 subjects did not report their voting behavior. All participants were Black men (49.12%) and women (50.88%) averaged age 33.11 years (SD= 12.48), women (M= 35 years, SD=12.89), and men (M = 31 years, SD=11.81). Regarding political involvement, almost 3/4 (72 %) of the sample reported that they routinely voted in governmental elections (38 % were women, 34% were men). Whereas 28% of the sample reported that they did not vote in national or local elections (11% were women, and 17% were men).

All patients were provided informed consent prior to participation. Any participants with missing data related to voting were excluded from the analysis. The study's inclusion criteria required the participants to have a sickle cell diagnosis and be 18 or older. The study did not include individuals with a sickle cell trait diagnosis. Physicians or lead researchers administered surveys during patients' scheduled clinic appointments.

Psychosocial factors were measured using a custom battery of psychometric tests and surveys, and the collection of demographic data by a demographic assessment form. Subjects who were not able to read or write were not considered for the current study. All instruments were administered while participants were in Hematology clinic and located in a small private room near the examination. The room was made comfortable and kept at a constant temperature (70 degrees Fahrenheit). The paper and pencil survey administration took approximately two and 1/2 hours. When participants required a break, they were encouraged to take one, and administration was purposefully made flexible to accommodate the characteristics of patients with SCD (water for hydration, a blanket if they were cold, etc.).

Measures

Voting participation: At the time of data collection, patient hematologists and their trained to criterion representatives collected surveys to assess a wide range of psychosocial, medical, and demographic factors from patients with SCD. Voting participation was reviewed and assessed by the endorsement of the survey item, "Do you vote in local or national elections?". Participants indicated either "Yes" or "No". Affirmative responses were summed to indicate voting participation.

Symptom Checklist-90-Revised: The Symptom Checklist-90-Revised (SCL-90-R) [8] consisted of 90 items that assessed a broad range of psychological symptoms in adolescent to adult patients. Scale items are rated on a 5-point Likert scale ranging from 0 (*not at all*) to 4 (*extremely*) based on symptoms experienced over the past 7 days. The SCL-90-R yields nine subscales including Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, and Psychoticism. The SCL-90-R also produces three global indices Global Severity Index (GSI; overall psychological distress), Positive Symptom Distress Index (PSDI; symptom intensity), and Positive Symptom Total (PST; number of self-reported symptoms). Scores above the T score of 60 were indicative of more symptom intensity. The SCL-90-R demonstrates sound psychometric properties with internal consistency reliabilities ranging from 0.77 to 0.90.

Procedures

A full and detailed description of the methods associated with the current study can be found in 2018 previous publications [9,10]. In this retrospective study, we used preexisting data collected as part of a larger longitudinal study to evaluate medical factors associated with voting.

Results

Experimenters used descriptive statistics, Pearson correlations to analyze the study's sample. The average education level for the sample was 13.5 years, encompassing trade school, college courses, and college degrees. Yet the average income level for the previous year was reported to be between $16,000 and $24,999 for total household income. Out of the 114 participants, 72% (n=82) of patients self-identified as voters who actively participated in governmental elections, whereas 28% (n=32) self-identified as non-voters. Dependent variables were derived from the 12 subscales of the SCL-90-R using separate Mann-Whitney U Non-parametric two-group tests. Groups were created based on self-reported voting behavior with active voters comprising one group and nonvoters comprising the second group.

Figure 1 shows a comparison of adult with SCD who voter compared to the overall population of the US as well as voters from the major demographic groups that suffer with SCD. Adults with SCD tend to vote at a level that is consistent with the rates of White Americans and greater than Blacks or Latino voters. As can be seen in **Figure 2**, adults with SCD vote at a rate that exceeds Black and White Americans. In **Figure 3**, we stratified each of our SCL-90-R indices of psychopathology by voting behavior (Yes/No). As can be seen on every index, non-voters displayed greater and functionally significantly more psychopathology than did their voting counterparts.

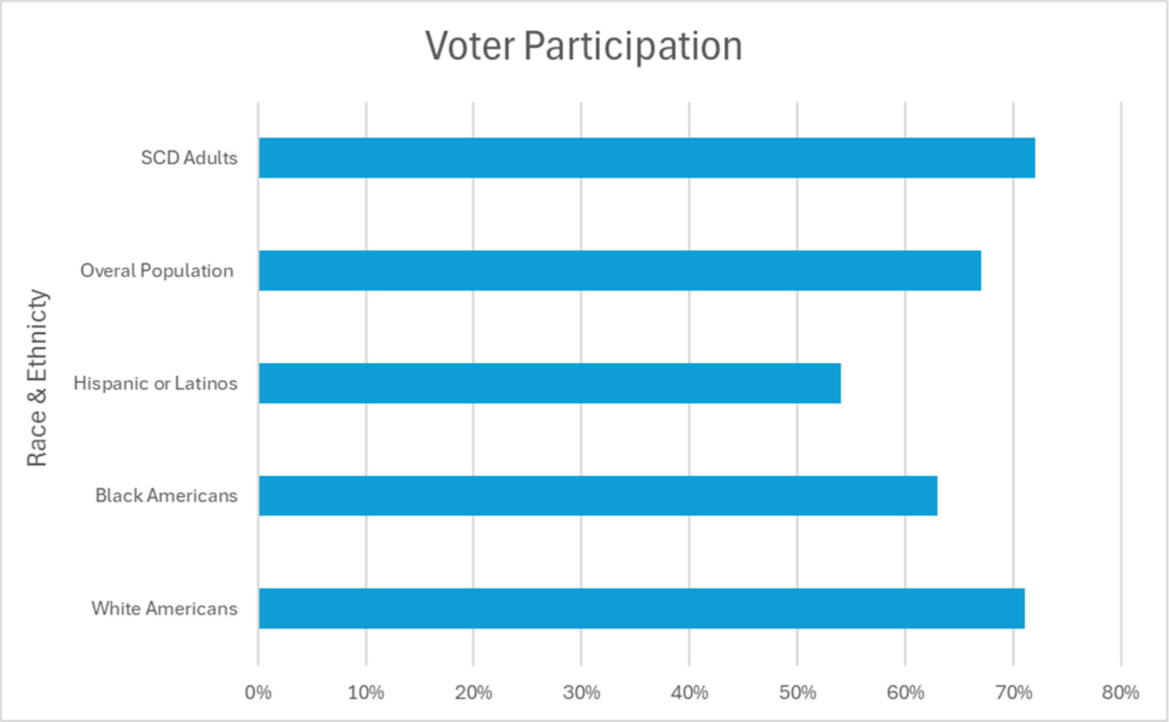

Figure 1. Comparison of Adult Voting Engagement in SCD.

Voter Engagement in Adults Living with SCD (https://www.brennancenter.org/our-work/analysis-opinion/large-racial-turnout-gap-persisted-2020-election)

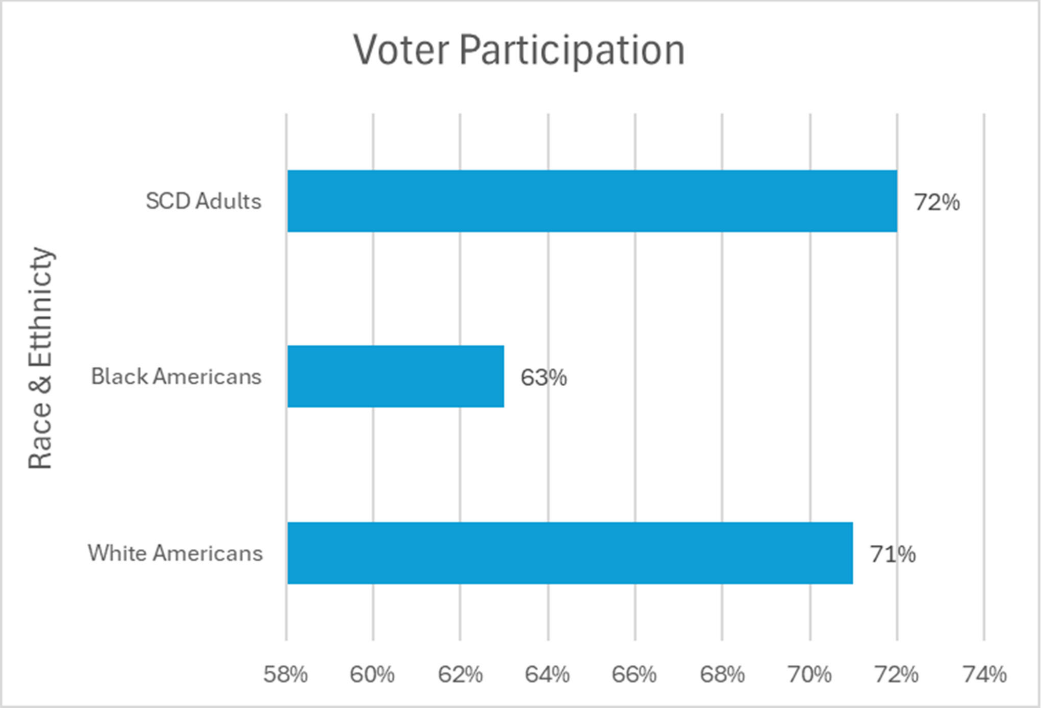

Figure 2. A comparison of Adults with SCD and Black and White Americans on Voting Percentage.

Voter Engagement in Adults Living with SCD (https://www.brennancenter.org/our-work/analysis-opinion/large-racial-turnout-gap-persisted-2020-election).

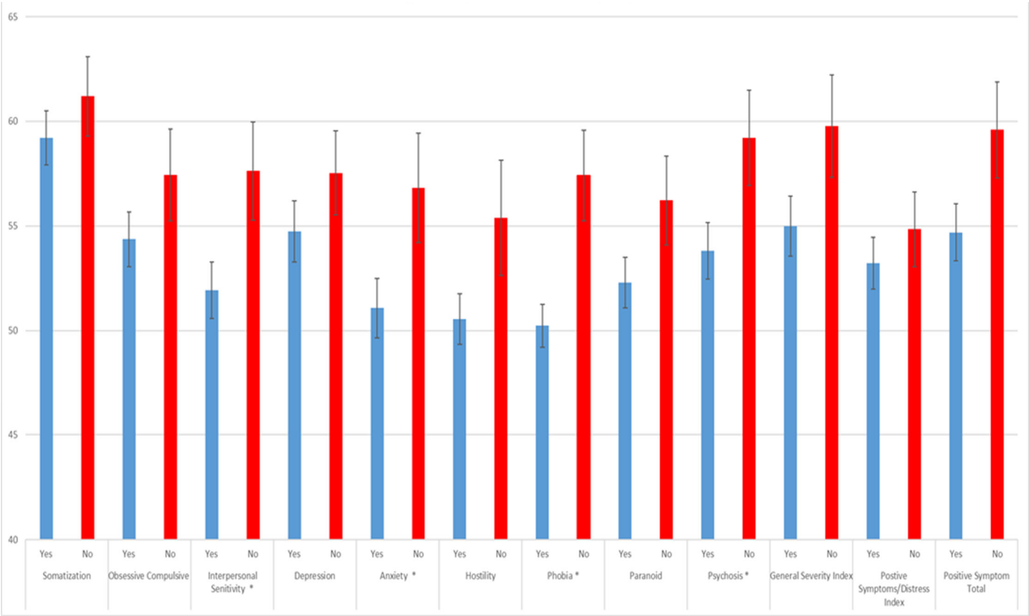

Figure 3. Comparisons of Individuals Who Vote to Those Who Didn't on SCL-90-R.

Indices of the SCL-90-R stratified by Yes and No self-identified voting behaviors.

As can be seen in **Table 1**, SCD patients who did not vote reported significantly more Psychosis (p = .03) and Phobia (p = .00) and marginally reliable increased levels of Interpersonal Sensitivity (p = .07), Anxiety (p = .08), and Hostility (p = .06). Generally, patients who participated in voting suffered less emotional distress as measured by psychopathology, than patients who were not politically involved. In **Tables 2, 4, and 6**, we present the means and standard deviations for variables used in our regression analyses. We present regression coefficients in the prediction of Hostility, Phobic Anxiety, and Psychosis, respectively, from age, education, income, and voting behavior in **Tables 3, 5, and 7**.

Table 1. Symptom Checklist 90 Revised Subscales by Did Not Vote/ Voted for SCD patients.

SCL90-R Subscale	**Did Not Vote (n)** **Mean Rank**	**Voted(n)** **Mean Rank**	**p-value**	**r**
Somatization	60.47 (31)	54.98 (81)	.42	-.08
Obsessive Compulsive	62.62 (32)	54.78 (81)	.25	-.11
Interpersonal Sensitivity	66.26 (32)	54.04 (82)	.07	-.17
Depression	62.44 (32)	55.57 (82)	.32	-.09
Anxiety	66.22 (32)	54.10 (82)	.08	-.17
Hostility	66.66 (32)	53.93 (82)	.06	-.11
Phobia**	72.84 (32)	51.51 (82)	**.00**	**-.29**
Paranoid	64.70 (32)	54.69 (82)	.14	-.14
Psychosis*	68.05 (32)	53.38 (82)	**.03**	**-.20**
General Severity Index	65.11 (32)	54.53 (82)	.12	-.14
Positive Symptoms Distress Index	60.34 (32)	56.39 (82)	.56	-.15
Positive Symptoms Total	65.02 (32)	54.57(82)	.13	-.14

Note... *The significance level is 0.5. ** The significance level is < .01

Table 1. Suggests that on most indices of the SCL90-R adults with SCD who voted did not differ from those who did not vote. However, we found significant differences between these two groups on Phobia and Psychosis. Not voting tended to be associated with greater Phobia and Psychosis, p=.03 and p= .001, respectively.

Table 2. Descriptive Statistics for potential covariates in Adults Living with SCD.

Mean		Std. Deviation	N
Hostility	51.8444	12.45659	90
Age	35.88	11.319	90
Education	13.5833	1.77886	90
Income	2.00	1.081	90

Table 3. Regression Coefficient for Hostility in Reported Voters Living with SCD.

Model	β	t	p	R square Change
Hostility		6.288	0.000*	
Age	-0.367	-3.500	0.001*	
Education	0.057	0.519	0.605	
Income	-0.045	-0.414	0.680	0.135
Hostility		6.228	0.000*	
Age	-0.360	-3.361	0.001*	
Education	0.064	0.572	0.569	
Income	-0.044	-0.399	0.691	
Vote1	-0.041	-0.386	0.700	0.149

Note: $R^2 = 0.135, 0.137$, P *<.05

Table 4. Descriptive Statistics for Phobia in Adults Living with SCD using variables Voter Engagement, Age, Income, & Education. (Regression)

Mean		Std. Deviation	N
Phobia	52.0111	10.37661	90
Age	35.88	11.319	90
Education	13.5833	1.77886	90
Income	2.00	1.081	90

Table 5. Regression Coefficient for Phobia in Reported Voters Living with SCD.

Model	β	t	p	R Square Change
Phobia		7.681	0.000*	
Age	-0.234	-2.153	0.034*	
Education	-0.067	-0.589	0.557	
Income	-0.019	-0.173	0.863	0.070
Phobia		7.756	0.000*	
Age	-0.188	-1.752	0.083	
Education	-0.022	-0.201	0.842	
Income	-0.011	-0.097	0.923	
Vote1	-0.256	-2.417	0.018*	0.060

Note: $R^2 = 0.070, 0.130$, P *<.05

Table 6. Descriptive Statistics for Phobia in Adults Living with SCD using variables Voter Engagement, Age, Income, & Education. (Regression)

Mean		**Std. Deviation**	**N**
Psychosis	55.2889	11.66021	90
Age	35.88	11.319	90
Education	13.5833	1.77886	90
Income	2.00	1.081	90

Table 7. Regression Coefficient for Psychosis in Reported Voters Living with SCD.

Model	**β**	**t**	**p**	**R Square Change**
Psychosis		6.266	0.000*	
Age	-0.444	-4.371	0.000*	
Education	0.150	1.420	0.159	
Income	0.106	1.003	0.319	0.187
Psychosis		6.255	0.000*	
Age	-0.410	-4.030	0.000*	
Education	0.184	1.739	0.086	
Income	0.112	1.082	0.282	
Vote1	-0.193	-1.926	0.057	0.034

Note: $R^2 = 0.187, 0.221$, P *<.05

We found that voting behavior was significantly predicted by Hostility, Phobic Anxiety, and Psychosis when covaried for Age, Education, and Income. Adding voting behavior to the regression models produced statistically significant changes in variance accounted for (R^2) for all three outcome variables. In our models, younger age was always a significant predictor of greater psychopathology.

Discussion

Structural and volitional models have historically been posited to explain low-frequency voting behaviors among minority populations [11]. Quite different from previous studies, we evaluated whether health-related factors influenced voting among an adult sample of adults seeking treatment at a regional medical center with SCD. We found that patients with SCD who exercise their right to vote demonstrate a healthier psychiatric functioning than those who did not vote. More specifically, voters reported better ratings across all domains of psychiatric functioning with significantly lower ratings for phobia and psychosis. We interpret these findings to suggest that health-related factors among Black patients with chronic illnesses may play a more contributory role in voting rather it serving as social and structural obstacle as previously founded. It stands to reason that patients living with SCD are voting at a disproportionate rate when compared to the general population because they are physically and potentially psychologically debilitated by disease. Even with their struggles, we were surprised to find that almost ¾ of patients with SCD vote. A plausible explanation may lie in the disability induced by SCD that serves as a source of empowerment and agent of change.

We believe that our findings introduce the potential for a new narrative as to the obstacles that prevent Black patients from voting. Attending to factors like health and mental health status may open new doors for increased self-advocacy and political participation in a government that needs to be more responsive to the needs of this population. Although this study has limitations, such as its cross-sectional design and the fact that data was collected from a single site, we believe that our findings are significant enough to warrant replication. We further believe that the models established by the current paper may apply to other rare diseases that occur in other races and cultures, where disability and psychiatric disturbances are common (i.e. Cystic Fibrosis, Polycythemia Vera, Subcutaneous Panniculitis, Intrahepatic Cholestasis) [12-14].

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