

# Awareness of Sickle Cell Anemia Among Negroes of Richmond, Va.

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SICKLE CELL ANEMIA is one of the most common chronic illnesses of Negro children (1). It occurs in approximately 1 of 500 Negro births. (This estimate is based on homozygotes being  $\frac{1}{40}$ th of trait frequency; 8.0 percent  $\times$   $\frac{1}{40}$ th = 0.2 percent, or  $\frac{1}{500}$ th.) Sickle cell anemia is about six times more common than the next most common long-term illness of Negro children—diabetes mellitus (1). A number of serious childhood illnesses are well known to the general public because of massive publicity and public education campaigns sponsored by health agencies and organizations providing support for the prevention, control, or amelioration of the specific illness. The following list shows how the incidence of some widely known childhood illnesses compares with the incidence of sickle cell anemia. All these other conditions occur less commonly in Negroes than in the white population.

Sickle cell anemia.....	1:500 Negro births
Thalassemia major.....	1:2,400 Italian-American births (2)
Acute leukemia.....	1:2,900 children under 15 years (3)
Cystic fibrosis.....	1:3,000 births—98 percent white (4)
Phenylketonuria.....	1:10,000 births—virtually all white (5)

There have been few organized efforts to support programs of research and public information on sickle cell anemia or programs to provide care for patients with this condition. One possible explanation for this lack is that the

public is unaware of the extent of the disease or even of its existence.

To determine the level of awareness of sickle cell anemia in one community, adult Negroes in Richmond, Va., were surveyed. The results demonstrate an appalling lack of awareness of the extent of this condition and of its great effect on a large segment of the U.S. population.

## Methods

The survey form consisted of four questions:

1. Have you ever heard of sickle cell anemia?

If the answer is "yes":

2. What sort of sickness is it?

3. Have you ever known anyone with the disease?

If the answer is "yes":

4. What relation to you was the patient?

The addresses, race, age, sex, and years of schooling of the respondents were also tabulated. Brief statements were taken for the answer to question 2 in an effort to determine

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whether an affirmative answer to question 1 indicated an understanding of the disease process.

The survey was conducted during November 1968, and the majority of the respondents were interviewed during 1 week. The survey was limited to adult Negroes, with the exception of some teenage college students. The survey was conducted in all the predominantly Negro neighborhoods of Richmond. In a given neighborhood, alternate blocks were chosen, and each home on the block was visited. A small number of persons from adjacent areas of two counties were also surveyed. The majority of the interviews were conducted by a group of 11th grade students from Armstrong High School in Richmond and the remainder by volunteers from Club Dejours, a Richmond social organization. All of the interviewers were Negroes.

**Results**

A total of 1,457 interviews were conducted. This number represents about 2 percent of the adult Negro population. The geographic distribution of the persons surveyed corresponded closely with the distribution of the Negro popu-

**Table 1. Age distribution of 1,366 persons<sup>1</sup> and distribution expected based on 1960 census data**

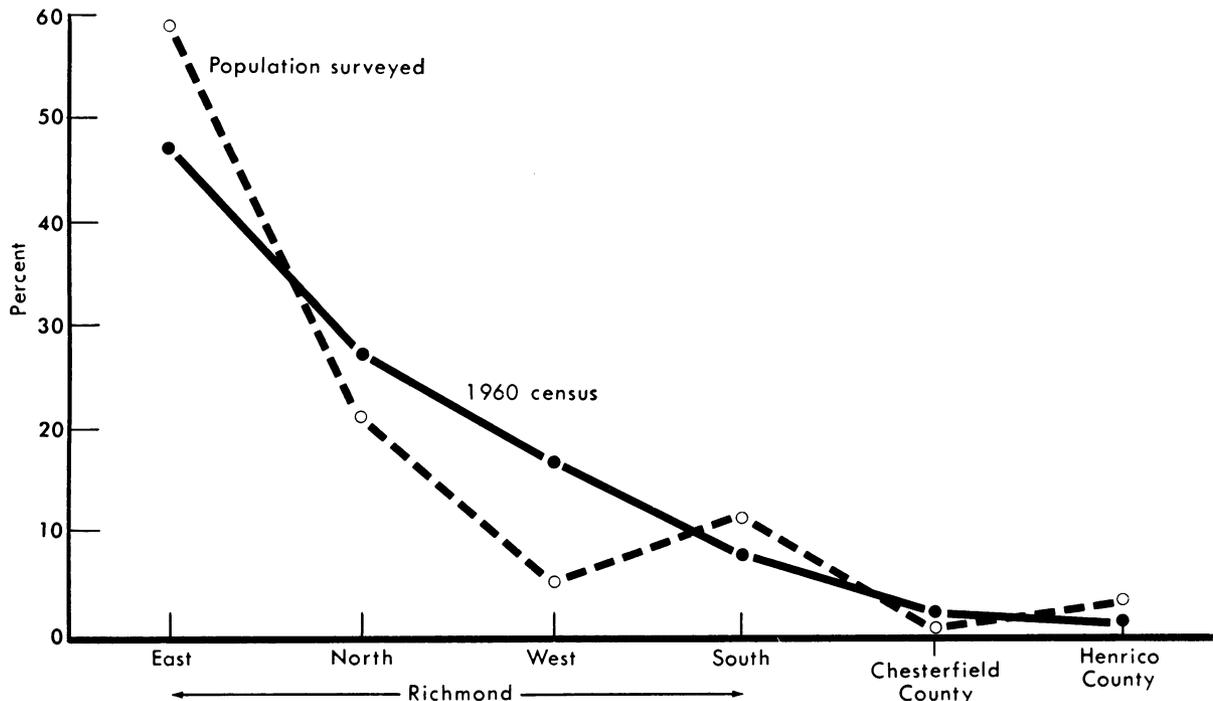
Age group (years)	Number surveyed	Percent of total	Percent distribution expected
15-19	150	11.0	10.3
20-29	327	23.9	19.8
30-39	321	23.5	21.7
40-49	267	19.6	19.5
50 and over	301	22.0	28.7

<sup>1</sup> 91 of the 1,457 persons surveyed did not state their age.

lation in the survey area (fig. 1). The expected distribution is based on 1960 U.S. census data (6). The age distribution of the persons surveyed is shown in table 1. Their distribution in the various age groups corresponded closely to the distribution shown in the 1960 census data except that somewhat fewer persons in the survey were in the age group over 50 years and there was a slight excess of persons in the 20- to 29-year-old age brackets.

Table 2 shows the distribution of the surveyed

**Figure 1. Percentage distribution of Negroes surveyed, by residence in Richmond, Va., or in surrounding counties of Chesterfield and Henrico**



population according to educational level. This table indicates that the population sample that we surveyed in November 1968 contained many more well-educated persons than would be expected on the basis of the 1960 census data. The educational level was higher than would be expected probably in part because a portion of the survey was carried out at Virginia Union University. Also, the level of education of the Negro population had increased since the 1960 census data were compiled. In 1960, the median number of years of schooling completed by Negroes was 8, whereas in the survey sample, the median number was 11.9 years.

Of the 1,457 persons questioned, 441 or 30.3 percent answered "yes" to question 1. Only an estimated 20 percent of this number knew that sickle cell anemia is a blood disease predominantly affecting Negroes. Of the 88 who gave "good" definitions of sickle cell anemia, 30 were nurses, five were physicians, 25 were teachers, 15 were medical technicians, eight were practical nurses, and five persons knew of the disease because members of their families were afflicted with it.

The awareness of sickle cell anemia at varying age levels is shown in figure 2. At all age levels from 15 to 49 years, slightly more than 30 percent had heard of the disease. Only in persons 50 years and over, was there a difference in awareness. In this group, slightly less than 15 percent knew of the disease.

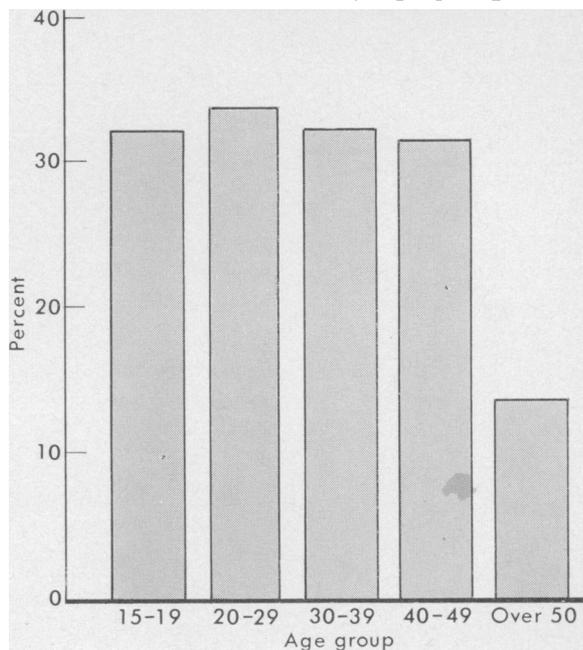
Awareness of sickle cell anemia is strikingly related to educational level (fig. 3). Of the 217 adults who had completed no more than 8 years of school, only 10.6 percent had ever heard of sickle cell anemia. Of the 505 who had attended

**Table 2. Distribution of 1,408 persons,<sup>1</sup> by educational level, and level expected based on 1960 census data**

Highest educational level	Number	Percent of total	Percent distribution expected
Grade 8.....	217	15.4	59.4
Grade 11.....	505	35.9	19.7
High school.....	344	24.4	13.2
Attended college....	342	24.3	7.7

<sup>1</sup> 49 of the 1,457 persons surveyed did not state their educational level.

**Figure 2. Percent of Negroes who knew of sickle cell anemia, by age group**



high school but did not graduate, 17 percent had heard of it. Among the 344 who had completed high school but had not attended college, 29.4 percent knew of the disease. A total of 342 college students, college graduates, and persons who had attended college were questioned. Of these, 65.5 percent responded that they knew about the disease.

### Discussion

The results of our survey reveal that the lack of awareness about this serious and common disorder is grossly out of proportion to its importance in the community.

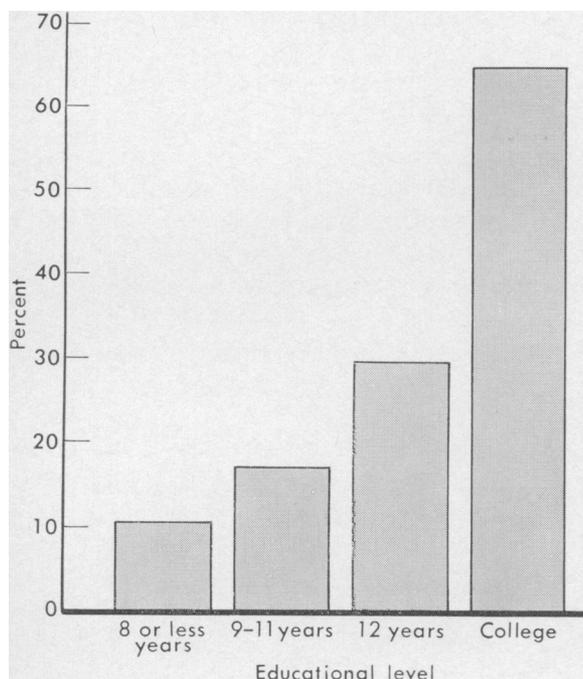
The population surveyed included more highly educated persons than the population as a whole. Thus, since the results demonstrated that knowledge of the disease was closely related to educational level, the 30.3 percent in the survey who knew of the disease was a higher proportion than would be expected in the population as a whole. Using data from the 1960 census and the levels of knowledge of sickle cell anemia that we observed at different educational levels, we arrived at a more accurate estimate of the general population's knowledge of this condition. In 1960, 59.4 percent of the adult Negro population in the survey area had not advanced

beyond 8 years of schooling; only 7.7 percent had attended or completed college (table 2). From these data we calculated that at the time of our survey 17.6 percent of the adult Negroes in the population knew about sickle cell anemia. Because educational levels may have increased significantly since the 1960 census, this figure may be considered the minimum. Nevertheless, whether two of 10 or three of 10 knew about this illness, the level of knowledge was low in proportion to the effect of the illness.

The level of awareness of sickle cell anemia in other communities cannot be deduced from these data. Public knowledge of the condition, however, is probably low throughout the nation. Since such awareness is closely related to education, a program of public information seems indicated. Only when people are informed, will public support be generated. And only with the broad support of the Negro community will programs of research, public information, prevention, and patient care be possible.

The most immediate need is for public information about sickle cell anemia. Moreover, a program of public information is feasible in view of the success of present-day communications and educational media. A more serious

**Figure 3. Percent of Negroes who knew of sickle cell anemia, by educational level**



difficulty is that few young Negroes know whether they are at risk of having children with this disease. Sickle cell anemia is not curable, and treatment is unsatisfactory. While patients with the disease are living longer, they still have a shortened life expectancy, require repeated hospitalizations, and suffer chronic disability. Even now, Negroes are not routinely tested for the trait and do not have the opportunity to approach parenthood knowing whether or not they risk having children with sickle cell anemia. The proportion of Negroes with the sickle trait is about 8 percent, or about one in 12. The chance, then, of two trait-carriers marrying is about one in 144. Thus, one family in 144 is at risk of having children with severe illness. These young people deserve to know of this risk before they begin their families. But providing them with adequate knowledge of the disease and setting up the requisite programs for mass screening will require a significant increase in the public's awareness of the extent of sickle cell anemia.

### Summary

A survey of the adult Negro population of Richmond, Va., was conducted to determine the level of awareness of sickle cell anemia. Only 30 percent of those questioned had heard of this disease. Of those who had heard of it, many apparently did not understand the nature of the illness.

Awareness of sickle cell anemia was closely related to the educational level of the persons surveyed. Although the condition is one of the most common chronic illnesses among Negro children, the survey showed that the level of public knowledge of the condition is grossly disproportionate to its importance to the Negro community.

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**Tearsheet Requests**

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## Dietetics and Computers

A series of 12 videotape programs, covering the application of computers to everyday dietary practices, has been designed as a basic resource for hospitals with dietetic internship programs, State and local professional meetings, colleges, and universities. It can be helpful to hospital dietitians currently working with or planning to work with computers.

The videotapes, consisting of lectures, demonstrations, and discussions, were taped during a 4-day workshop co-sponsored by the Health Facilities Planning and Construction Service, Public Health Service, and the Ohio State University. In addition to helping viewers to understand the broad applications of electronic data processing to dietetics and some basic planning requirements for use in a dietary system, the programs are aimed at fundamentals which include menu planning, computing nutrient intake, forecasting cost and nutrient levels, and identifying, organizing, collecting, evaluating, and recording required data for a dietary information system.

Following are the titles, faculty, and descriptions for each videotape.

1. Introduction and Orientation to the Conference and Evolution of Electronic Data Processing, 14 minutes—John P. Casbergue. Orients participants to the need and use of the computer.
2. Dietetics and Computers, Their Role in Community Health, 17 minutes—George Christakis, M.D. Illustrates how computers may initiate a new era in medical dietetics.
3. Basic Computer Concepts in Review, 10 minutes—John P. Casbergue and James Griesen. Relates electronic data processing and systems design to dietary concepts.
4. Medical Information Systems and Their Implications for Patient Medical and Dietetic Care, 15

minutes—Jordan Baruch. Reviews and compares systems connected with patient care.

5. Systems Analysis and the Role of the Dietitian in Planning the Use of Electronic Data Processing, 13 minutes—James Griesen. Designs a data processing system in relation to hospital dietary functions.

6. Planning a Dietary Information System: Goals and Data Requirements, 12 minutes—John P. Casbergue. Identifies the kinds of information necessary to meet established goals.

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GOLLY! WHAT A LOVELY HOME, POP!  
IT'S PERFECT... AS LONG AS THEY DON'T CLEAN UP!  
WHAT HAPPENS IF THEY GET SMART?

## GET SMART! MAKE THE FIRST MOVE CLEAN UP!

THE POSTERS, placed in schools, stores, and other public buildings, were developed by the Bureau of Rodent and Insect Control to promote the rat eradication program of the Baltimore City Health Department. The department's war on rats is a block-by-block effort in central city areas, which have approximately 116,500 dwell-

ing units. A staff of 50 health aides, chiefly inner city residents, is directing the program which involves cleaning up trash, debris, and food, exterminating rats, correcting housing conditions so that rats have no harborage, and maintaining the corrections achieved.

