A Study of the Health and Sickness Behavior of Selected Adults in Southeastern Kentucky

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THE HEALTH OF THE PEOPLE OF EASTERN KENTUCKY has long been a national concern because the major product of the area is coal. Chronic lung diseases, infections, and bone and joint diseases are but a few of many health problems affecting this population (*1*). Also, severe emotional problems are a frequent occurrence. Additionally, because of the rugged terrain and steep mountains in this region, this population suffers a higher than average accident rate as a result of treacherous mountain roads (*2*).

The low educational level of the general population is another concern. In 1973, the median number of years of school completed in Harlan and Bell Counties was 8.3, and about 27 percent of the population aged 25 and over had completed less than 5 years (*3*). In contrast, in 1973–74 the national median number of years of school completed was 12.3, and about 4.4 percent of persons aged 25 and over had completed at least 5 years (*4*).

In 1973, the health care delivery system in the two counties lacked organization. An insufficient number of physicians functioned almost exclusively in a crisis-oriented system. However, other approaches were proposed and implemented to improve the system. For example, leaders of the United Mine Workers Welfare and Retirement Fund—which recruits practitioners for the area—were instrumental in planning and establishing a health maintenance organization in Harlan County. Also, the work of a group of community members and physicians resulted in the establishment of several clinics in the mountains.

The Clover Fork Clinic had been opened in Evarts, a small coal mining community in Harlan County, in 1971. The staff consisted of two physicians, two registered nurses, and a chaplain-counselor. By 1973, the clinic offered total health care, with emphasis on ambulatory care. The staff visited homes, and a multiphasic screening program was integrated into the clinic operation. Three other clinics were opened in 1973 to serve the tiny mountain communities in Bell County and the surrounding area. A physician from Middlesboro, approximately 25 miles away, visited weekly, and a full-time nurse practitioner worked in the clinics.

Nevertheless, despite efforts to improve the system by establishment of mountain clinics and recruitment of health professionals, the general "hill and holler" living of many mountain families prevented many of them from obtaining services; communications and transportation were the primary barriers. Consequently, in March 1974, a family health survey was conducted to collect data that could be used to devise methods to improve the health care delivery system in Bell and Harlan Counties.

Survey Methods

A family health survey questionnaire was devised and pretested in Bell and Harlan Counties to determine its validity in measuring people's attitudes toward and opinions about health and medical services, their perceived health needs, their knowledge of certain diseases and disease symptoms, and their use of health facilities. Much attention was given to potential cultural and linguistic biases that could have resulted in an insensitive survey instrument. Therefore, the questions were phrased in the respondents' idiom. For example, two common eastern Kentucky phrases "down in the dumps and blue a lot" and "suffering from nerves" were used to elicit responses that might indicate symptoms of emotional illness.

To determine a minimum sample size, the technique developed by the Research Division of the National Education Association was used (*5*). A total of 15 communities was selected, 7 in Bell County

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and 8 in Harlan County. In each community, 20 households were randomly chosen for the survey. The following multistage sampling procedures were employed: (*a*) a sample of geographically defined units—census enumeration districts—was drawn from a box that contained all the defined units of each county; the enumeration districts were identified from census maps for the two counties; and each map was divided into enumeration districts, communities were clearly demarcated, and occupied households were indicated by legend, (*b*) within these sampling units, secondary units—communities—were defined and subsampled in a similar manner, and (*c*) within these secondary sampling units, tertiary units—households—were defined as units of observation.

To enhance the success of the survey and to provide followup for the 300 households after the survey was completed, 1 member of each of the 15 communities was employed as a community health worker. These 15 nonprofessionals worked with me in collecting data. Although several had done such work previously for the Census Bureau, all 15 workers were given intensive instruction in survey methodology for 3 weeks before the survey began. Seminars were held to make them more aware of the health problems of the area, and, in group sessions, they were introduced to the art of conducting a survey. These workers were also taught how to listen and how to record responses. Lecturing and role playing techniques were used, and "An Interviewer's Basic Handbook," provided by the Southeastern Kentucky Demonstration Office, was used as a text.

When the survey was completed, the community health workers and I visited each of the households to answer questions and to help with health problems detected during the survey. The workers were "expediters" in activating service relationships between health agencies and the families. Transportation was provided for patients by agencies in several instances because the workers were able to coordinate the patients' needs and the availability of services. In Bell County particularly, the workers provided valuable service by assisting the staff of the Office of Education, Appalachian Regional Hospitals, Inc., in planning educational programs to meet the needs of the patients.

A limitation of the survey surfaced during the data collection process. Since the survey was conducted during the mornings and afternoons of the traditional work week, Monday through Friday, most of the men were not at home. Therefore, the adult population for the study was skewed toward women. However, in the rural, mountainous area of eastern Kentucky, the families are often matriarchal (*6, 7*). The mothers' immediate concern is the family, but they exercise wide influence throughout the community. The primary duties of the men are to provide economic livelihood, to protect the family honor, and to shield the family from intruders.

Survey Sample

Of the 300 household respondents—249 women and 51 men—75 percent were married and 96 percent of these lived with their spouses, 63 percent had completed less than 8 years of school, and 67 percent had an annual family income of less than $5,000. By age groups, 27 percent were 15–34 years old; 14 percent were 35–44; 36 percent were 45–64; and 22 percent were 65 or older. White women represented 80 percent of the total sample and black women 13 percent.

Survey Findings

Early in the interview, the respondents were asked about specific illnesses—if they now had a particular illness or if they had it in the past. The most frequently mentioned current illness was "nerves," as shown in table 1. In response to questions about various conditions, the following percentages of those

who reported having them suggest that emotional problems and organic illness were significant.

Condition questions	*Percent answering "yes"*
Do you eat good when you sit down at the table?	79
Do you have trouble with your eyes?	62
Do you often have backaches?	48
Have you been down in the dumps and blue a lot lately?	46
Do you have bad headaches?	46
Do you feel tired all the time for no special reason?	46
Do you have trouble sleeping?	44
Do you ever have a pain in the chest?	42
Are your ankles often swollen?	38
Are you troubled most of the time with aches and pains?	35
Do you have any bad teeth?	34
When you are sick do you often have to go to bed?	31
Do you have trouble breathing?	30
Do you suffer from indigestion a lot?	28
Do you have trouble with your hearing?	28
Are your joints ever painfully swollen?	27

Eleven symptoms that included common ailments such as sore throat and backache to more severe conditions such as lumps on the body were read to the respondents near the end of the interview. The respondents were asked what persons with these conditions should do. Their responses (table 2) indicate the importance assigned to care by a physician. However, only 36 percent believed that medical care should be sought for "feeling down in the dumps and blue most of the time," a possible sign of depression. The 38 percent who stated that a person with this symptom should care for it himself and the 17 percent who said a person should not bother with it may reflect the mountain people's attitude toward obtaining treatment for emotional disorders. It has been reported that only persons with the most noticeable psychiatric disorders receive medical attention because the mountain people traditionally care for the "odd" and the retarded at home (2). The geographic isolation tends to provide a protective environment for "odd" behavior, and the population generally accepts such behavior.

When the respondents were asked if they were satisfied with their health, signs of pessimism surfaced —52 percent were dissatisfied with their present health status. Asked to rate their health and the health of their spouses and children, 64 percent rated their health and their spouse's health as fair or poor, and 73 percent rated their children's health as good or excellent.

Responses to several questions are indicative of the respondents' concern about health. When asked if

Table 1. Past and present illnesses reported by 300 respondents (249 women and 51 men), in percentages

Illness	*Percent*		
	Has now	*Has had, but not now*	*Total*
Nerves	59	5	64
Arthritis	49	2	51
Sinus trouble (stuffiness with pain in the face)	35	9	44
Hemorrhoids	26	10	36
Allergies (rash, hay fever, or others)	23	12	35
High blood pressure	23	10	33
Kidney or bladder disease	16	13	29
Varicose veins	26	3	29
Heart trouble	19	4	23
Serious lung trouble causing trouble in breathing	18	1	19
Stomach ulcers (peptic ulcers)	13	5	18
Hardening of the arteries	9	2	11
Diabetes (sugar)	7	2	9

Table 2. Opinions of 300 respondents about need for medical care for selected conditions, in percentages

Condition	*Percent*			
	See doctor	*Care for self*	*Should not bother*	*Do not know*
Coughing up blood	98	1	1	0
Pain in chest a lot	97	2	..	1
Lump or discolored patches, not bruise marks	96	1	1	2
Can't breathe good after light work	95	3	1	1
Cough for several weeks	93	4	2	1
Feeling of dizziness a lot	91	5	3	1
Backaches fairly often	84	9	4	3
Headaches a whole lot	84	11	4	1
Diarrhea or constipation for a week	80	16	1	3
Sore throat, running nose for 2 or 3 days	50	44	4	2
Feeling down in the dumps and blue most of the time	36	38	17	9

they thought about and talked about their health "a whole lot," "every now and then," or "hardly ever," 68 percent said they thought about their health, but only 39 percent said that they talked about it. To the question "Would you say you take the best possible care of your own health or could you take better care of your health than you do?" 33 percent replied that they took the best possible care of their health. The most frequent reasons given for not taking the best possible care of their health included lack of rest, poor dietary habits, infrequent visits to a physician, and inability to pay for medical care.

The survey explored the sample's attitudes toward and opinions of health and medical care by eliciting responses to questions and statements on (*a*) health and medicine, (*b*) physicians, and (*c*) costs of care. In response to "What are some of the things that make it easier to have good health today than it was 30 years ago?" the sample most frequently cited more physicians, hospitals, and clinics. Only 5 percent stated that people were more careful today, and 12 percent said that people care more about their health. A list of items was read, and the respondents were asked if the cost of each item was much too high, a little too high, or about right. As shown in table 3, they considered the costs of medical care, clothing, and food to be much too high.

Questions asked about physicians' services included one designed to determine a measure of satisfaction with the care received. Of those who had visited a physician during the past 12 months, 57 percent were satisfied with the care received, and 38 percent indicated some dissatisfaction. A number of negative statements were read to the respondents, and they were asked if they thought that these statements were true of most physicians. Their responses are shown in table 4.

The value of getting annual medical and dental examinations was recognized by 83 percent of the respondents. However, only 43 percent received a medical examination regularly, and the majority of this group stated that their reason for their last examination was a symptom or complaint. In response to a list of statements read in an effort to identify reasons for failing to visit a physician when perhaps they should have, 50 percent cited high costs, 51 percent said they had not wanted to spend the money, and 53 percent said they did not like to bother a physician unless absolutely necessary.

Questions about specific diseases were limited to cancer, diabetes, and heart disease, three diseases with a high incidence in eastern Kentucky (*1*). The number of correct symptoms of these diseases named by the 300 respondents were as follows:

Number of symptoms named	*Percent of respondents*		
	Cancer	*Diabetes*	*Heart disease*
Five or more	3	1	1
Three or four	23	10	15
Two	19	16	19
One	16	15	24
None	39	58	41

The high percentages of those who were unable to name any symptoms are significant. However, because of the population's low educational level, they may be hampered in verbalizing things that they actually know. Moreover, most of the respondents understood that a person can have a serious illness without knowing it. They were also aware that these diseases are not contagious.

Table 3. Opinions of 300 respondents about costs for certain services, in percentages

Question	*Percent*			
	Much too high	*A little too high*	*About right*	*Do not know*
Do you feel that (each item below) are much too high, a little too high, or about where they should be?				
Food prices, generally	93	5	1	1
Clothing prices, generally	89	7	3	1
Charges to fix TVs, automobiles, and things like that	73	10	9	8
The cost of medical care in general	84	10	3	3
Well, under medical care would you say that (each item below) generally are much too high, a little too high, or about where they should be?				
Doctors' fees, generally	66	19	9	6
Hospital charges	80	7	5	8
Dentists' fees	56	13	17	14
Costs of prescriptions	74	12	5	9

Table 4. Opinions of 300 respondents about physicians, in percentages

Statement	Percent		
	True of most	Not true	Do not know
Doctors make you wait entirely too long when you try to see them in their office or clinic	80	16	4
They don't take enough personal interest in you	64	31	5
They don't tell you enough about your condition; they don't explain what the trouble is	62	32	6
They don't give you a chance to tell them exactly what your trouble is	60	32	8
Doctors like to give medicine even if you don't need it	43	46	11
They tell you there's nothing much wrong with you when you know there is	43	43	14
Doctors don't like to get other doctors opinions about a condition	41	40	19
Doctors will tell you frankly they don't know what your trouble is	40	51	9
Doctors give quite a bit of their time free to people who need it	28	56	16

When asked their sources of information about health and disease, the respondents most frequently mentioned relatives, friends, and television; only 15 percent mentioned physicians and clinic personnel. At the end of the interview, the respondents were asked which health topics they would like more information about. Their responses indicate specific areas for educational programs. Lung diseases, including pneumoconiosis and emphysema; diabetes; proper dietary habits; and family planning were mentioned most frequently.

In a 1968 study, Andersen found that the number of disability days was the best single predictor of total family use of services (*8*). To determine the eastern Kentucky population's perception of sickness and disability the sample was asked a series of questions, including "During the last 12 months about how many times were you so sick that you could not do your regular work or carry on your daily activities?" Of the 300 respondents, 42 percent had been too sick to carry on their daily activities for 2 weeks or longer in the past 12 months, and 62 percent said that the lengths of their periods of illness were not unusual.

The following summary of the findings characterizes the perceptions of health and sickness of a "typical" woman in Bell and Harlan Counties.

- She perceived a number of organic and emotional illnesses as major health problems; these included depression, arthritis, allergies, heart conditions, and serious lung conditions.
- She rated her health and that of her spouse as fair to poor but considered her children's health good.
- She thought about her health frequently but seldom talked to anyone about it.
- She realized that a person can have cancer, diabetes, or heart disease without knowing it, but she was unable to verbalize her knowledge of symptoms of these diseases.
- She was concerned with the costs of medical and dental care, and this concern influenced her decision to seek care.
- She was unhappy with certain aspects of the care that she received in the present health care system. Among the areas of dissatisfaction were (*a*) the long wait to see the physician, (*b*) the lack of interest in her by health care personnel, (*c*) the lack of information about her condition, and (*d*) the high cost of care.
- She placed a high value on the need for annual medical and dental examinations, but she did not obtain them regularly.
- She relied primarily upon relatives and friends for her limited information about health and diseases.
- She would like to know more about diseases such pneumoconiosis, emphysema, and diabetes. She also desired information on family planning and nutrition.

Although public health statistics tend to support the conclusion that sickness and disability are common throughout the population of eastern Kentucky (*1*), the data presented here indicate that the people perceive sickness and disability to be an inherent part of their lifestyle. This social characteristic may be an important factor in the use of services by the people, although no study has been undertaken to determine the relationship of family characteristics to the amount of health services obtained.

Implications

An examination of the responses to the questions about physician services and the costs of care reveals

several aspects of the services with which the respondents were unhappy. They obviously believed that the costs of care were much too high, and apparently this factor influenced the decision of some not to seek care when perhaps they should have. Koos' classic study of health in a community he called Regionville tends to support this behavior (*9*). The influences of class position on attitudes of Regionville people toward illness resulted in significantly different patterns of behavior, and the concern about cost was one factor that influenced these patterns. Although cost was not a variable in a study of 60 white, native-born Protestant families in Yonkers, other variables influenced the attention that the families paid to their health needs (*10*). Fear of physicians, the tendency to gratify their materialistic needs immediately, and concern about the opinions of others were indicators of those who were more likely to be less concerned with their health. Hochbaum, however, may have explained clearly why people do not seek care when perhaps they should in his statement that the population in general is alienated from the delivery system because the health care practitioners are not concerned with any value other than health (*11*).

The use of the interview technique in health surveys is a principal source of health indicators for the United States. The indicators should emphasize health problems that result in disease or disability and require medical care, but their main purpose should be to help planners understand why various populations have different levels of morbidity, disability, and health actions. Thus, the indicators should focus on the social and psychological factors that influence health behavior.

In this study, the data provide indicators of numerous problems resulting in disease and disability in the coalfields of eastern Kentucky. In turn, these problems and diseases and disability are perceived by women as an inherent part of their lifestyle. It is unfortunate that most health care practitioners in the region are concerned exclusively with the treatment of pain, illness, and inappropriate organic responses. On the other hand, social scientists have been studying communities in the region to understand the interaction of people with different statuses and roles in their daily routines of social survival. Despite the interests peculiar to each discipline, little interaction has occurred between the disciplines and the families that could result in a sociomedical approach toward resolving some of the major health problems. Nevertheless, I believe that most practitioners in the medical sciences see a need for the highly skilled social scientist in patient care. Consequently, priority should be given to developing a model that links the various disciplines and the families through common problems and solutions in the delivery of care.

It is certain that socioeconomic characteristics of the family are crucial in determining whether a member will seek medical care before an illness occurs or will recuperate fully after an illness does occur. A family that has little knowledge or money for dealing with health problems in the recommended "rational" fashion will definitely handle situations differently from families who have more of such resources. Furthermore, since many primary care workers' major role is helping the family cope with the patient's illness, resources within the family structure must be identified and mobilized to increase the potential for health. When common objectives and problem solutions have been determined co-equally by health care practitioners, social scientists, and the families, the use of sociopsychological factors—such as priorities on how families spend their incomes, their knowledge of disease and health, their perceptions of health and health services, and their general life values—can be maximized in planning efficient and effective services for the greatest number of people.

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