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Final Project Report

Obtaining Care: Self-Care Practices and Barriers to Accessing Health Care Services Among Poor Families with Children in the Rural Northeast

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EXECUTIVE SUMMARY

Date of Submission:
July 30, 1999

Title of Project:
Obtaining Care: Self-Care Practices and Barriers to Accessing Health Care Services Among Poor Families with Children in the Rural Northeast

Principal Investigators:
Cathy Kassab, Ph.D., Institute for Policy Research and Evaluation, Penn State University
Deborah Bray Preston, Ph.D., R.N., Associate Professor, School of Nursing, Penn State University

Objectives:
This project has three objectives:
1) To discover and describe the types of barriers rural limited-resource families encounter when attempting to access health care services, and what these families do when barriers are encountered;
2) To investigate and describe ways in which these families cope with illness through self-care practices, that is self-treatment;
3) To explore the consequences of illness for the well-being of these families.

Approach:
We selected nonmetropolitan counties (one in New York State and two contiguous counties in Pennsylvania) in the Appalachian region of rural New York and Pennsylvania for our study; these counties exhibit a fairly high level of poverty and are fairly similar to each other demographically. We conducted unstructured in-depth personal interviews with the primary female caregiver (the mother) in 37 limited-resource families with children living in those counties. At the conclusion of the interview with each participant, we administered a face-to-face structured survey instrument designed to obtain standardized, close- and open-ended responses to a series of questions about the family's health care practices, experiences, and perceptions. This information was used to study self-care practices, access to professional health care services, and barriers to access in the sample. This approach allowed us to simultaneously triangulate both qualitative and quantitative methods. Our New York sample is racially diverse; African-American, Native American, and Caucasian women were interviewed. The Pennsylvania sample is more homogenous; it is predominantly Caucasian.

Key Results:
During the past year (12 months), between 24% and 40% of the respondents indicated that they or a household member needed help from a health care provider, such as a doctor, nurse, dentist, or optometrist, for a health care problem but did not get that help. Typically, the reason for not getting help was the lack of insurance or a money-related reason. Respondents were more likely to indicate having problems gaining access to a

dentist for problems with their teeth or gums than some other health care provider. This problem was particularly evident in the Pennsylvania sample.

Initial analyses from the in-depth (unstructured) interviews indicate that those women with at least a few strong ties with local family members were best able to access needed health care services and to function effectively within the local health care system. Some of these women also had friends and neighbors they could draw on for support and help when needed. We characterized a few of these respondents as "survivors" -- these women expressed feelings of empowerment and of being a primary participant (along with the doctor) in their own and their children's health care decision-making process. They managed their own and their families health care, and they navigated the health care system with competence.

In contrast, some of the other women felt more challenged by the local health care system. Women who were most isolated from family (even if family members lived in the local area) seemed to face steeper barriers than those discussed above. Many of these women were extremely self-reliant but they had only themselves and their children to consistently rely on for unconditional support.

Publication:
We prepared an article describing our project for *Dimensions*, which was published by the Penn State Harrisburg Centers. The article was published in the Summer 1998 issue, and is titled "Obtaining Care: Access to Health Care Services and the Use of Self-Care Practices Among Low Income Families in the Rural Northeast."

Positive Impact of Project and Potential Applications of Findings:
The impact of our project is indirect. In general, results from our study will help service providers identify ways in which current organizational practices can better incorporate self-care practices of low income families into their delivery systems while taking into account the limitations faced by these families (i.e., lack of a supportive family network, financial, transportation). Data from the study may be used in the preparation of grant proposals aimed at alleviating local barriers to health care services or more large-scale demonstrations of the need for health care services in the area (such as dental).

Keywords:
health care, access, barriers, low-income families, mothers

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Principal Investigators:
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Other Team Members:
Janice Penrod, School of Nursing, Penn State University
Barbara Piwowar, School of Nursing, Penn State University
Tia Jones, School of Nursing, Penn State University

Areas of Work Emphasis:
Drs. Kassab and Preston shared responsibilities for the project. They collaborated in the design of the data collection instruments; one instrument was an interview schedule for conducting unstructured personal interviews, and the other was a structured face-to-face interview schedule. In addition, Drs. Kassab and Preston shared responsibilities associated with the identification and selection of the samples, data collection, and coding of data. Moreover, they shared qualitative data analysis responsibilities as well as the preparation of manuscripts. Dr. Kassab was responsible for the analysis of data from the structured survey instrument and the preparation of the Progress and Final Reports, and the submission of Human Subjects forms.

Ms. Penrod is an expert in qualitative data collection and analysis, particularly with respect to health-related behaviors and systems. She provided input and guidance in the construction of the data collection instruments, particularly the unstructured interview schedule. Ms. Piwowar conducted the literature search for the project, and Ms. Jones entered data from the structured survey instrument into an SPSS-PC data file.

Objectives:
This project has three objectives:
1) To discover and describe the types of barriers rural limited-resource families encounter when attempting to access health care services, and what these families do when barriers are encountered;

2) To investigate and describe ways in which these families cope with illness through self-care practices, that is self-treatment;
3) To explore the consequences of illness for the well-being of these families.

This project will increase our awareness of what limited-resource families with children do when someone is sick and how these families interact with the local health care system, which aspects of the local health care system facilitate access, as well as the types of barriers influencing their interaction with professional health care providers. Because state and national health care policies are changing, it is important to have a better understanding of the potential consequences of various policies on the ability of this vulnerable population to gain access to needed health care services.

Accomplishments to Date:

We were successful in meeting most of the objectives stated above. We worked with Cooperative Extension personnel at the state and county level in order to identify and recruit women for the study. We designed our data collection instruments and obtained Human Subjects approval for them. In addition, we conducted a library search for relevant literature

We completed in-depth personal interviews with the primary female caregiver (the mother) of 37 limited-resource families in two nonmetropolitan counties in Pennsylvania and a nonmetropolitan county in New York State. Originally, we had planned on conducting interviews with only 30 families. However, the opportunity to interview an ethnically and racially diverse population in New York dictated that we interview a greater number of women.

The interview schedule we developed addressed all three objectives through a series of open-ended questions. In addition, we administered a (face-to-face) structured survey instrument to each caregiver. Data from this latter instrument provided us with quantitative information that we entered into an SPSS-PC for data analysis. We coded all open-ended responses to the survey, and these data also have been entered into the SPSS-PC file.

Our structured survey instrument provides systematic and detailed data regarding the use of various health care services among all members of the family, the type and availability of health care coverage for each family member as well as member's health status, the extent to which illness in the family has created financial problems, barriers to the use of health care services, satisfaction with health care services, financial and other forms of hardship, use of social welfare services, preventive health behaviors, and demographic and employment information.

We have completed initial analyses of the quantitative data for the entire sample (n=37). Moreover, we completed similar analyses for the Pennsylvania and New York samples. In addition, all 37 open-ended interviews have been transcribed, and we have begun the qualitative analysis of these interviews.

We are in the process of preparing "fact sheets" summarizing our findings from the unstructured interview schedule and the structured survey instrument for the two Cooperative Extension Offices helping us recruit participants for the study (one in New York State and the other in Pennsylvania). Information from the unstructured personal interviews to be incorporated into the fact sheets will include a description of the barriers faced by project participants in accessing the local health care system, self-care practices used by study participants, the avenues used by these people to manage their own health and the health of their families, and the types, reliability, and quality of resources available for doing so. Information to be included from the structured survey instruments will provide a fuller understanding of the health care status of participants and the participant's family, health care coverage, access to and use of health care services, barriers to health care services, socio-economic status, financial distress, and access to and use of human and social capital resources.

Scientific Rationale for the Project:
The goal of our project is to produce a conceptual model of the process of obtaining health care among low-income rural northern Appalachian families. Grounded theory provides the means for accomplishing this goal. This approach provides a guide for generating an explanatory model from qualitative data obtained through field methods, such as what we used. Sampling, data collection, and analysis of data are closely linked and occur repeatedly as the study progresses using the grounded theory method. Participants for the study were chosen on the basis that they would provide data that would help flesh out the patterns emerging from the interviews. Sampling, interviewing, and analysis continue until the data become saturated, that is no new information is forthcoming. At the same time, there should be no gaps in the data either.

Reasons for Being Unable to Accomplish All Objectives:
Due to the unexpected termination of the project, we were unable to complete all of our objectives. We had planned to interview male head-of-households during the summer of 1999. Our interviews with the mothers indicated that fathers were likely to go without health care when ill, particularly those who were employed. Interviewing this population would have provided valuable information on family dynamics involved in accessing health care services among limited-resource families. These interviews would also have provided information on the extent to which employment in the low-wage job sector can act as a barrier as well as a facilitator to accessing health care services for different family members. Also in the New York county, we had planned to interview families residing in more remote and isolated areas. Moreover, we were unable to complete the qualitative analysis of the transcripts using grounded theory because of the unexpected termination of the project.

Method:
We selected nonmetropolitan counties (one in New York State and two contiguous counties in Pennsylvania) in the Appalachian region of rural New York and Pennsylvania for our study; these counties exhibit a fairly high level of poverty and are fairly similar to each other demographically. We conducted unstructured in-depth personal interviews with the primary female caregiver (the mother) in 37 limited-resource families with children living in those counties. At the conclusion of the interview with each participant, we administered a face-to-face structured survey instrument designed to obtain standardized, close- and open-ended responses to a series of questions about the family's health care practices, experiences, and perceptions. This information was used to study self-care practices, access to professional health care services, and barriers to access in the sample. This approach allowed us to simultaneously triangulate both qualitative and quantitative methods.

Our New York sample is racially diverse; African-American, Native American, and Caucasian women were interviewed. The Pennsylvania sample is more homogenous; it is predominantly Caucasian. Our study included limited-income rural families with children who were enrolled in Medicaid, as well as limited-income rural families with private health insurance for at least one of its members, and limited-income rural families with no health coverage for at least one of its members.

Data from the structured survey instrument were entered into an SPSS-PC system file. Responses to open-ended questions were coded and entered into the SPSS-PC data file, as well.

Results:
Respondent and Household Characteristics
All participants in the study were female and ranged in age from 18 to 48 years. On average, women were 33 years old. Nearly one-third (30%) of the women were married, and another 35% were living with their partner but not married. On average, there were three people living in the respondent’s household (including the respondent). Typically, two children lived with respondents in their household fulltime during the year. For the most part, ages of children in the household ranged from infants to young adults.

Most of the women indicated that they had some form of health care coverage; three out of the 37 (8%) did not. Typically, women who had coverage indicated that they were covered through Medicaid (Medical Assistance).

Only about one-half (53%) of the women indicated that the household received welfare or public assistance. Also, 41% indicated receiving Supplemental Security Income (SSI), and three-fourths (76%) of the women indicated receiving foods stamps.

One-third (32%) of respondents indicated that they were a worker-for-pay, while nearly one-half (43%) defined themselves as stay-at-home moms. Nearly three-fourths (73%) of the women indicated that they were a high school graduate or had a G.E.D. Moreover,

22% indicated that they had some post-secondary schooling, such as trade school or some college. Only 27% indicated that they did not complete high school or have a GED. Nearly one-quarter (24%) indicated that they were currently a student.

Respondents demonstrated considerable self-reliance. Most (73%) of the participants indicated that they currently owned a reliable car that is legal to drive on the street. However, over one-half (57%) of the women with cars reported that they had trouble making car insurance payments. Over one-half (56%) of the 16 women who typically have someone else drive them to places that are too far to walk indicated that they generally use a taxi, despite the expense associated with that mode of transportation. Initial impressions from the interviews indicated that a taxi is the only reliable means of transportation for these women; typically, they did not have a supportive network of family or friends to rely on for transportation needs.

Most (89%) of the women reported having telephone service in their home. Women often indicated that they did not subscribe to long-distance service.

Health Status and Use of Health Services

Respondents typically rated their health as being either good or excellent. However, there was a tendency for mothers to rate their own health status as somewhat worse than others in the household. In five of the 37 households (14%), illness had caused major financial problems during the past year. The majority of respondents (57%) indicated that they smoked. Less than one-third (30%) of the women indicated that no one in their household smoked cigarettes.

Over two-fifths (41%) of the respondents reported that someone in their household was chronically sick or had a serious illness, and about one-half (55%) of these respondents indicated that the person needed someone with them at all times.

During the past year, 40% of the respondents indicated that had stayed in bed no more than one-half of the day because of illness or injury. On average, respondents spent two days in bed during the past year because of illness or injury. However, five women indicated spending at least two months in bed because of illness or injury.

Most (73%) of the women usually went to a private doctor's office for medical care rather than the emergency room or some other place. Also, the majority (73%) of respondents indicated that they talked on the telephone with a doctor or nurse during the past year; on average, these women received medical advice on the telephone from health care providers four times during the past year. While most of the respondents were satisfied with the quality of care they received from the doctor on their last visit, six out of 37 (16%) women were dissatisfied.

Barriers to Health Care Services

The percentage of respondents reporting the presence of barriers to accessing various health care services is pictured in the attached figure. The findings are discussed in detail below.

A significant minority (14%) indicated having problems getting to the doctor on their last visit; typically, problems were due to transportation difficulties. On average, respondents indicated that their regular doctor is five miles from their home.

During the past year (12 months), nearly one-quarter (24%) of the respondents indicated that they or a household member needed help from a doctor or nurse for a health care problem but did not get that help. Typically, the reason for not getting help was the lack of insurance or a money-related reason.

An even larger percentage of respondents indicated that they or a household member needed help from a dentist because of problems with their teeth or gums, but they did not get the help needed; 40% indicated that this occurred over the past 12 months. Again, reasons for not getting help were related to the lack of insurance or money. Several respondents indicated that they could not find a dentist that accepted their Medicaid (Access) card. This problem was particularly evident in the Pennsylvania sample. Some respondents reported that the only dentist they could find who would accept their Access card (medical assistance) was an hour or more from their home.

Nearly one-third (30%) of the respondents indicated that they had trouble getting a prescription for medicine filled during the past year. During the past year, over one-quarter (27%) indicated that they or a family member failed to get their vision checked even though they needed to do so, and one-third (32%) indicated that they needed new glasses but did not get them. Again, primary reasons for the lack of access to prescriptions or vision care were related to the lack of insurance coverage or money.

Financial Distress

Four-fifths (40%) of the respondents indicated that they were very worried about their financial situation, and 27% indicated that they frequently have trouble meeting monthly payments on bills. Over one-half (54%) of the women indicated that their total household income in 1997 (before taxes) was less than $10,000, and another 31% indicated that their income was $10,000 to $19,999 in 1997. However, only 16% of the women indicated that they were barely able to make a living.

Nearly one-half (46%) of the respondents indicated that they frequently did not have enough money to afford the kind of clothes they wanted. In contrast, only 14% indicated that they frequently did not have enough money to afford the food they wanted.

Management Strategies

In general, mothers of children with serious or chronic health problems learned about the illness from their health care providers and managed it using a medical model. In addition, a few of the women used home remedies to help treat their children's health problems (i.e., blowing smoke in the ear for an earache).

Initial analyses from the in-depth (unstructured) interviews indicate that those women with at least a few strong ties with local family members were best able to access needed

health care services and to function effectively within the local health care system. Some of these women also had friends and neighbors they could draw on for support and help when needed. In some cases, family members served to reinforce the mother's impressions that they were not receiving needed health care services; these family members were able to buttress respondents when they were forced to question current treatments strategies.

Women who were most isolated from family (even if family members lived in the local area) seemed to face steeper barriers than the former. Many of them were extremely self-reliant but they had only themselves and their children to consistently rely on for unconditional support.

We characterized a few of the respondents as "survivors" -- these women expressed feelings of empowerment and of being a primary participant (along with the doctor) in their own and their children's health care decision-making process. They managed their own and their families health care, and they navigated the health care system with competence. Getting what they needed from the health care system did not appear to be a challenge. In contrast, some of the other women felt more challenged by the local health care system.

Survivors were characterized by the presence of a supportive local family network, and some of these women expressed strong religious beliefs. The presence of just one or two family members enabled these women to access services when needed. These family members also provided a source of advice and a sounding board for the respondent's thoughts and feelings. In contrast, familial support among those women who were more challenged by the health care system tended to be limited or conditional. In addition, "survivors" tended to be somewhat older than the others. It is important to note that these conclusions are preliminary.

Publications and Other Outputs:
We prepared an article describing our project for *Dimensions*, which was published by the Penn State Harrisburg Centers. The article was published in the summer 1998 issue, and is titled "Obtaining Care: Access to Health Care Services and the Use of Self-Care Practices Among Low Income Families in the Rural Northeast."

We are currently in the process of preparing two "fact sheets" (one for the New York CES office and the other for the Pennsylvania CES office which have worked with us). These fact sheets will provide a descriptive analysis of the study participants and their families; the health status of participants and their families, their access to local health care systems, and related issues.

Positive Impact of Project and Potential Applications of Findings:
The impact of our project is indirect. The Cooperative Extension team working in the New York County in which we conducted our research has requested a copy of the

results for their county. They would like to use the information from our study in the preparing a proposal for alleviating barriers to health care services. The fact sheet we are preparing for them should provide them with information they can use for this purpose.

Data from many of the Pennsylvania participants in our study exhibited a need for dental care, yet they cited the presence of barriers to accessing these services. This information may be used in a dental education intervention grant application to the Center for Rural Pennsylvania; the purpose of the grant would be to document the need in this geographic area.

In general, the results from our study will help service providers identify ways in which current organizational practices can better incorporate self-care practices of low income families into their delivery systems while taking into account the limitations (i.e., financial) faced by these families.

Keywords:
health care, access, barriers, low-income families, mothers

For more information about this project, contact:

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