Insurance + Access ≠ Health Care: Typology of Barriers to Health Care Access for Low-Income Families

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ABSTRACT

PURPOSE Public health insurance programs have expanded coverage for the poor, and family physicians provide essential services to these vulnerable populations. Despite these efforts, many Americans do not have access to basic medical care. This study was designed to identify barriers faced by low-income parents when accessing health care for their children and how insurance status affects their reporting of these barriers.

METHODS A mixed methods analysis was undertaken using 722 responses to an open-ended question on a health care access survey instrument that asked low-income Oregon families, "Is there anything else you would like to tell us?" Themes were identified using immersion/crystallization techniques. Pertinent demographic attributes were used to conduct matrix coded queries.

RESULTS Families reported 3 major barriers: lack of insurance coverage, poor access to services, and unaffordable costs. Disproportionate reporting of these themes was most notable based on insurance status. A higher percentage of uninsured parents (87%) reported experiencing difficulties obtaining insurance coverage compared with 40% of those with insurance. Few of the uninsured expressed concerns about access to services or health care costs (19%). Access concerns were the most common among publicly insured families, and costs were more often mentioned by families with private insurance. Families made a clear distinction between insurance and access, and having one or both elements did not assure care. Our analyses uncovered a 3-part typology of barriers to health care for low-income families.

CONCLUSIONS Barriers to health care can be insurmountable for low-income families, even those with insurance coverage. Patients who do not seek care in a family medicine clinic are not necessarily getting their care elsewhere.

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INTRODUCTION

Children from lower socioeconomic backgrounds have poorer health outcomes.[1,2] These health disparities are due, in part, to barriers in accessing medical care and utilizing primary care services.[3-5] Recent expansions in insurance coverage have improved access to health care for this population,[3,6-8] and the presence of family physicians in underserved communities has made primary care services more widely available.[9] Yet, even with the services of family physicians and expanded health insurance, children from low-income families are not guaranteed access to health care services.[5,10-15] Among the poor, who visits a family physician and who does not? What barriers persist? Family physicians caring for vulnerable populations must understand differences in access to care and utilization of services in their communities.

Recent efforts to better understand these disparities have queried physicians and patients about differing practices based on a patient's health

insurance status and type of insurance.[12-14,16] Other analyses have used vital statistics and Medicaid data to study utilization and coverage patterns.[6,17] Secondary analyses of administrative data are often several steps removed from the real-life experiences of vulnerable families, and studies conducted in physicians' offices miss the invisible families who are unable to visit health care facilities. To our knowledge, limited information has been collected directly from families living in poverty about factors affecting access to medical care and how insurance status affects their situations. This study was designed to add richness and depth to the current research by directly capturing the experiences of low-income families as they navigate the health care system and to determine how insurance coverage affects their concerns.

In collaboration with state policy makers, we designed a cross-sectional survey to collect statewide primary data. More than 25% of the survey respondents provided additional written comments to a concluding open-ended survey question that asked, "Is there anything else you would like to tell us?" We report findings from a mixed methods analysis of this subset of respondents.

METHODS

Study Population and Data Collection

The study population included all Oregon families enrolled in the federal food stamp program at the end of January 2005 with children who were also presumed eligible for publicly funded health insurance. Both programs require a household income of less than 185% of the federal poverty level and proof of the child's US citizenship. A random sample of families was drawn with purposeful oversampling to ensure adequate representation from rural areas and uninsured families. More details about this sampling procedure are reported elsewhere.[18]

The return-mail survey questionnaire was developed to allow parents the opportunity to report about various health-related issues for 1 randomly selected focal child. Survey questions were grouped into 4 major sections: child's health insurance status, child's access to various health care services, child's demographic information, and family information (primarily demographics and parental insurance information). The questionnaire contained 62 questions with multiple-choice response options, and 1 final open-ended question that asked, "Is there anything else you would like to tell us?" These responses were used for our mixed methods analysis.

For validity testing of the self-administered questionnaire, cognitive interviews were conducted during a pilot test phase with a small sample of low-income parents that were representative of the study population. Surveys were translated into Spanish and Russian (the 2 most common non-English languages among this population), and then independently back-translated to ensure fidelity of translation. The questionnaire was written at a fifth-grade reading level. All aspects of the study protocol were approved by the Oregon Health and Science University Institutional Review Board (OHSU eIRB# 1717).

Analysis

We confirmed that our subsample of respondents to the open-ended question had demographic characteristics that were similar to those of all survey respondents and to the total eligible survey population. We also conducted bivariate and multivariate analyses to confirm that the experiences of our subsample in accessing care were similar to previous reports about the strong association between insurance status and different utilization of primary care services.[3,5,8] Covariates were selected based on the conceptual model of Aday and Andersen and the work of others on predictors of access to care.[8,19,20] These analyses were conducted using SPSS 14.0 software (SPSS Inc, Chicago, Illinois) with the complex samples module to account for the complex survey design and to ensure proper weighting back to the Oregon food stamp population.

After the preliminary quantitative review, our qualitative analysis team began the process of identifying major themes. The team included a family physician researcher (J.E.D.) and a health services investigator skilled in quantitative and qualitative research (P.A.C.). For further diversity in analysis, we included a medical student jointly enrolled in a public health master's program (A.B.) and a research associate from our rural practice-based research network (H.A.). Feedback throughout the process was also received from 2 authors with expertise in evidence-based state policy development and implementation (L.K. and C.E.).

Each team member independently read all written comments and grouped them into categories. We then met to discuss the items and agree upon a common cataloguing of themes. Once consensus was reached, we organized the categories into a codebook of tree nodes using NVivo qualitative software 7.0.[21] Tree nodes are used to represent categories that are catalogued in a hierarchical structure, moving from a general category at the top (parent nodes) to more specific categories (child nodes). We repeated our individual reviews with codebook guidance and met regularly to conduct a series of immersion/crystallization cycles.[22] During these meetings, specific categories were grouped into more general categories, and the codebook of tree

nodes was revised to reflect the multiple interpretations of all team members. The use of NVivo also facilitated line-by-line coding of each text entry for further review. After multiple reviews of all 722 responses to the open-ended survey question, we had reached saturation on 3 dominant themes, each with several subthemes.

For further in-depth analysis to determine whether experiences with each of these themes varied among subgroups, we imported several pertinent demographic attributes from the SPSS data set into NVivo and conducted univariate matrix-coded queries. The quantitative variables used in the matrix coding queries were chosen for 1 of 2 reasons: (1) relevance to the themes (measures of insurance status, access to and utilization of health care services); and (2) demographic predictors of access to care (age, ethnicity, and household income).

RESULTS

Demographics and Different Patterns of Utilization

Completed questionnaires were received from 2,681 of 8,636 (31%) eligible households. Among the survey respondents, a subsample of 722 wrote responses to the open-ended question, "Is there anything else you would like to tell us?" Although this subsample was demographically similar to the overall study population, it had a slightly higher percentage of uninsured children, uninsured parents, and children with a gap in coverage, when compared with all survey respondents (Table 1).

Among this group, after adjusting for age, race/ethnicity, parental insurance status, region of residence, and household income, children with health insurance (private or public) were more likely to have a usual source of care and to have seen a doctor in the past year (Table 2). These findings confirm that the low-income families in our subsample had utilization patterns based on insurance status similar to those previously reported.[23] The

Table 1. Comparison of Respondent Characteristics to Overall Sample Population

Demographic Characteristic	Overall Random Sample (n = 10,175) No. (%)*	Eligible Survey Population (n = 8,636) No. (%)*	Survey Respondents (n = 2,681) No. (%)*	Respondents To Open-Ended Survey Question (n = 722) %*
Race/ethnicity†				
White	7,528 (74.0)	6,369 (73.7)	2,026 (75.6)	76.7
Black	270 (2.7)	218 (2.5)	50 (1.9)	0.7
Hispanic	1,864 (18.3)	1,600 (18.5)	475 (17.7)	19.3
Asian	110 (1.1)	95 (1.1)	31 (1.2)	0.6
American Indian	324 (3.2)	286 (3.3)	74 (2.8)	2.4
Pacific Islander	13 (0.1)	12 (0.1)	6 (0.2)	0.3
Other/unknown	47 (0.7)	40 (0.7)	16 (0.7)	0.1
Sex, child				
Female	4,983 (49.0)	4,227 (48.9)	1,295 (48.3)	44.5
Male	5,192 (51.0)	4,409 (51.1)	1,386 (51.7)	55.5
Age				
1-4 years	2,728 (26.8)	2,259 (26.2)	687 (25.6)	24.5
5-9 years	2,943 (28.9)	2,495 (28.9)	811 (30.2)	27.6
10-14 years	2,520 (24.8)	2,192 (25.4)	707 (26.4)	27.8
≥15 years	1,984 (19.5)	1,690 (19.6)	476 (17.8)	20.1
Region				
Northwest Coastal	1,685 (16.6)	1,459 (16.9)	504 (18.8)	19.3
Portland area	1,702 (16.7)	1,387 (16.1)	417 (15.6)	15.2
Central Western	1,701 (16.7)	1,448 (16.8)	427 (15.9)	16.3
Southwest Coastal	1,696 (16.7)	1,462 (16.9)	435 (16.2)	16.2
North Central, Columbia Gorge	1,695 (16.7)	1,422 (16.5)	409 (15.3)	14.7
Southern and Eastern	1,696 (16.7)	1,461 (16.9)	489 (18.2)	18.3
Monthly income				
<$500	3,109 (30.6)	2,589 (30.0)	770 (28.7)	27.4
$501-$1,000	2,628 (25.8)	2,221 (25.7)	711 (26.5)	27.3
$1001-$1,500	1,976 (19.4)	1,666 (19.3)	487 (18.2)	17.6
$1501-$2,000	1,434 (14.1)	1,249 (14.5)	412 (15.4)	17.5
>$2000	1,028 (10.1)	911 (10.5)	301 (11.2)	10.2
Current enrollment in program sponsored by OMAP				
At least 1 child enrolled in OMAP	5,087 (50.0)	4,346 (50.3)	1,471 (54.9)	54.0
No child enrolled in OMAP	5,088 (50.0)	4,290 (49.7)	1,210 (45.1)	46.0
Insurance status‡				
Child uninsured	NA	NA	16.8	19.0
Child had gap in insurance coverage in past 12 months	NA	NA	34.8	39.0
Parent uninsured	NA	NA	35.8	37.7

NA = not available; OMAP = Office for Medical Assistance Programs.

* All percentages are unweighted.

† Race and ethnicity are combined into 1 variable in this table because the administrative data available to us had only 1 combined variable.

‡ Insurance status was based on self-report and not included in the administrative data, so it was only known for respondents to the survey.

associations between parental insurance status and children's utilization of primary care services were not significant after adjusting for children's insurance status.

Dominant Themes and Different Patterns of Experience

In the qualitative analysis, 3 major themes emerged as factors affecting access to and utilization of health care services for children. First and most commonly reported, parents were concerned about getting and keeping health insurance coverage for themselves and their children. Parents repeatedly stated that they need insurance coverage not only for their children, but also for themselves so that they can be healthy enough to care for their children. They also expressed frustrations about not being able to meet all the restrictive criteria for continuous Medicaid enrollment. Second, gaining access to services and finding providers was a big challenge. Parents described feeling unwelcome at medical practices and traveling long distances to seek care. Finally, unmet health care needs were attributed to the high costs of medical care (Table 3). These responses largely focused on unaffordable private insurance premiums and a hesitancy to seek care because of the high deductibles and co-payments.

Among several demographic characteristics and other family circumstances, insurance status was the factor associated with the most disparate reporting of the 3 themes (Table 4). More than 87% of uninsured parents commented on difficulties obtaining insurance coverage compared with approximately 40% of those who were insured. Only 14% of parents with uninsured children wrote about access concerns in their responses to the open-ended question, whereas more than 25% with publicly insured children and 20% with privately insured children were concerned about access to health care services. More than 30% of privately insured parents and those whose children had private coverage mentioned costs compared with less than 20% in the other insurance groups (Table 4). In summary, obtaining and maintaining insurance was the most important theme among all families. Comparing families in all insurance groups, insurance coverage issues were more often reported by families with uninsured parents or uninsured children. Access concerns were mentioned most often among those with public health insurance, whereas privately insured families more commonly mentioned unaffordable medical costs.

The disproportionate reporting of themes based on insurance status illustrates different patterns of experience among this population of low-income families. Parents made clear distinctions between insurance and access, and there appeared to be a hierarchical order for obtaining both. Insurance coverage was the primary concern; access and costs were secondary. Families without insurance were most focused on obtaining insurance and tended not to write as much about access or cost. Families with insurance were worried about whether they could use the insurance. These access concerns had 2 major subthemes: clinician acceptance of insurance and insurance coverage of services at a level that makes them affordable. Cost was less a concern to this group because without access, the service was unobtainable. For example, as shown in Table 4, a smaller percentage of parents with children who had not visited the doctor in the past year reported cost concerns. For those with access, cost played an important role. Although there is a hierarchical order to the themes, all 3 themes—insurance, access, and cost—are interrelated. Families can achieve both emotional and financial security when all 3 are balanced. If insurance coverage is unstable, access and cost are also jeopardized. Alternatively, once insurance is solidly in place, it still takes continued effort to achieve optimal access at an affordable cost.

Table 2. Insurance Status and Child's Utilization of Primary Care Services

Insurance Status	Child Has Usual Source of Care		Child Had Doctor Visit in Past Year	
	Weighted %	AOR* (95% CI)	Weighted %	AOR* (95% CI)
Child's insurance status				
Private	96.8†	10.72 (3.30-34.89)	90.2†	5.04 (1.71-14.85)
Public	90.4†	5.35 (2.21-12.97)	89.2†	4.82 (1.98-11.76)
Uninsured	58.9	1.00	56.6	1.00
Parent's insurance status				
Private	92.8‡	1.58 (0.57-4.40)	87.6‡	1.50 (0.53-4.19)
Public	90.5‡	1.06 (0.41-2.79)	90.1‡	1.33 (0.57-3.11)
Uninsured	80.1	1.00	77.4	1.00

AOR = adjusted odds ratio; CI = confidence interval.

*Adjusted for age, race/ethnicity, household income, region of residence, parental insurance status (for children)/children's insurance status (for parents).

† $P < .01$ for the comparison with uninsured children.

‡ $P < .01$ for the comparison with uninsured parents.

DISCUSSION

These study findings are in agreement with previous findings about the importance of stable insurance coverage for the entire family in gaining access to care.[24-34] Our study advances

Table 3. Themes and Subthemes of Barriers to Care Among Low-Income Families

Themes and Subthemes	Examples
Getting and keeping health insurance coverage	
Insurance coverage for parents; keep parents healthy to keep kids healthy	"Yes. I would like to be on OHP with my 3 girls because if I get sick and can't go to the doctor, who is going to take care of my girls?!!"
	"Yes! I want my OHP health insurance back.... My children have no one else to turn to if I get sick and die because of a lack of health care."
	"I am terrified of losing my OHP coverage.... What good does it do to provide coverage for children without coverage for the parents that care for them? Not much."
Unfairness of selective Medicaid coverage	"OHP sometimes does not accept adult applications unless they are pregnant. I think that is dumb and unfair. This is racist to men and to women who can't have kids or have their tubes tied or already have kids and are done having kids. Because of this, it encourages women or teens to get pregnant."
	"The only reason why I can get OHP right now is because I am pregnant. I do not know what I will do after I have the baby."
	"The only reason I get health insurance is because I am currently pregnant. After I have the baby, I will get kicked off."
System requirements and age limits	"Although we are thankful for OHP, they make it very hard to keep and complicated."
	"I feel it's not right that a family that is trying to make it in life gets knocked back and down. My 10-year-old son lost his health insurance because I got a 39-cent raise in pay."
	"My 18-year-old daughter has been hospitalized for complications due to anorexia.... She is in desperate need of either a residential program or continuing coverage past her 19th birthday. My daughter was told that OHP is not accepting any new adults.... Is the state of Oregon going to let my daughter die?"
Access to health care services	
Difficulty finding physicians; traveling long distances	"Everyone who takes OHP takes no more new patients."
	"There's never space for my children at the dentist."
	"I've heard that it's hard to find doctors who are accepting new OHP patients. We are generally healthy, so we are risking it."
	"It is impossible to find a dentist that will take OHP. The only one I could find is 3 hours and at least 2 mountain passes away, making getting there almost impossible, especially in the winter."
	"My daughter got a severe sore throat, and absolutely no doctors in Bend would accept OHP. We were referred to the local free clinic but weren't accepted there because we had OHP. The nearest medical service was in Prineville (40 miles away). And I had no means of transportation."
Costs associated with medical care	
Unaffordable health care services; services not covered by insurance	"I can't afford to pay co-pays or prescriptions when all I have is $200 child support for rent, gas, diapers, and anything else I need for my apartment like dish soap or toilet paper."
	"We make sure our children get the medical care and medications they need, but sometimes this leaves us without money for other things."
	"I have worked my way off welfare and OHP. I have become eligible for and elected to receive medical insurance through my employer.... I cannot afford to use the insurance.... That is not fair to my child and makes me feel I am failing him as a parent. I'm afraid to drop the coverage because of possible accident or emergency, but we sure could use the money."
Unaffordable private insurance premiums	"I have to pay a lot out of pocket (for employer-sponsored insurance) and can't afford it, so my son goes without."
	"We have tried to get assistance but were told we make too much money, but we can't afford it on our own! Please help us."
	"I was actually relieved when my husband lost his job because it made my son eligible for coverage again. There is no feeling in the world worse than trying to figure out if you should really take an injured child to the doctor or not because of lack of money."

OHP = Oregon Health Plan (public insurance in Oregon for anyone eligible for Medicaid and children eligible for the Oregon children's health insurance program).

this literature by creating a more in-depth understanding of the hierarchy of barriers faced by low-income families and the interactions that exist between insurance, access, and cost. For parents surmounting the insurance barrier was most important, but then access became a bigger issue. Families that got over the insurance and access humps were still struggling to get care as a result of unaffordable costs, such as co-pays for office visits, insurance deductibles, and prescription drug costs. This hierarchical model emphasizes that there is no single struggle in obtaining health care—there are 3 successive barriers to care.

Interestingly, we found a wide variation in concerns among parents depending on insurance status. Because fewer uninsured families were accessing primary care, they were not experiencing the barriers to access and the costs associated with care. For those who had secured public health insurance for the entire family, the major challenge became access. Perhaps costs were not mentioned as a major problem by these respondents, because if the insurance plan did not have provisions for access or if providers did not accept the coverage, there were no options for obtaining care. In this case, cost was not a barrier because the children went without the services, which might explain why a smaller percentage of parents with children who had not visited a doctor in the past year reported cost concerns. For those with private insurance, access was better but at higher, and often unaffordable, costs. The motto for these families might be: "We have insurance and we have a family physician, but we cannot afford to get health care."

In the examination of the interrelationships between insur-

ance, access, and cost, our in-depth analyses uncovered a 3-part typology of health care access barriers. First, many families without insurance are invisible to health care providers. These families no longer call the clinic for fear of hearing the opening question: "What is your insurance?"[23] They feel intimidated and helpless because their infrequent interactions with the health care system have resulted in denied care or unaffordable medical charges. Occasionally these families make an appointment for someone in the family who has insurance, then seek care for the uninsured family members during the single visit. The second group, often with public coverage, spends much of its time searching for clinicians and facilities that accept public insurance. Family physicians are more likely to care for these patients compared with other primary care physicians,[9] but these are the patients who cannot get into the specialists' offices.[12-14] Finally, there is a growing number of low- and middle-income families with private health insurance who gain access to most services, but the high deductibles and co-pays prevent them from getting necessary care. These are the patients who prefer to call clinicians for advice rather than be seen, and they often have difficulty filling expensive prescriptions and rely more heavily on pharmaceutical samples.

The situation is far more complex than assuming that expanding health insurance or increasing the primary care workforce will solve the problem. Whereas many primary care providers are already aware of the complexity of these issues,[16] our study was designed to explore the issues from the patients' perspectives. Understanding this hierarchy and these families' varied experiences is essential for the redesign of primary care practices and training of future family physicians. The typology of access barriers displayed in Table 5 may help further our understanding of these important issues. In all 3 scenarios, patients cannot get necessary care but for different reasons. Most alarming is that health care services are not obtainable for low-income families, even those with insurance coverage and access to primary care.

Study Considerations

Interpreting the data reported here requires consideration of some important issues. Several factors about the sample population and fielding of the survey are described

Table 4. Frequency of Families Reporting Each Major Theme by Demographic Characteristics and Other Pertinent Factors

Demographic Characteristics and Other Factors	Getting and Keeping Health Insurance Coverage %	Access to Health Care Services %	Costs Associated With Medical Care %
Total subsample responding to open-ended survey question	56.9	23.1	19.9
Age			
1-4 years	66.7	16.4	20.9
5-9 years	50.3	23.6	16.6
10-14 years	56.5	27.4	17.9
≥15 years	55.9	18.6	22.8
Ethnicity			
Hispanic	51.8	20.1	13.4
Not Hispanic	59.5	22.6	20.5
Household income percentage of federal poverty level (FPL)			
0%	32.5	23.4	13.0
1%-50% FPL	52.4	24.7	11.3
51%-100% FPL	68.3	20.2	23.6
101%-133% FPL	65.1	19.4	25.6
>133% FPL	54.9	22.5	26.8
Child's current insurance status			
Public only	55.1	25.9	15.2
Uninsured	72.6	13.3	14.8
Private or combination	50.0	19.9	32.4
Parent's current insurance status			
Public only	39.2	28.1	12.2
Uninsured	87.2	19.3	18.9
Private or combination	42.8	18.6	30.3
Did child have an insurance gap?			
No gap, continuous 12-month coverage	54.1	22.5	18.9
Yes, gap in past 12 months	63.6	20.0	19.5
Does child have usual source of care?			
No usual source of care identified	57.6	19.6	15.2
Yes, usual source of care identified	57.2	22.5	20.0
Did child have a physician visit in past year?			
No physician visit in past 12 months	58.5	0.3	12.7
Yes, physician visit in past 12 months	57.0	22.3	20.5

Table 5. Barriers to Care Typology

Patient Circumstances	Why Patients Report They Do Not Get Care?	Who These Patients Are in Our Practices
No insurance and not getting care	Need coverage	Patients who fear the first question on the phone: "What's your insurance?"
		Parents who get care at their children's visits
Have insurance but not getting care	Need access	Patients who referring providers cannot get into specialists' offices
		Patients traveling long distances to see clinicians
Have insurance and access but not getting care	Unafforable costs	Patients calling for advice to avoid visit co-payments
		Patients struggling to get their medications and asking for pharmaceutical samples

in detail elsewhere.[18] Responses to the open-ended question may have been biased by the content of the survey questionnaire, which included specific queries about health insurance coverage for both children and parents, access to health care, and costs of health care. These questions did, however, provide several opportunities for respondents to report barriers and concerns about access to health care. It is telling that after completing the questionnaire, many parents were motivated to comment further. Finally, it is possible that we received responses to the open-ended question from only those families who encountered the most difficulties with the system, so the results may not be generalizable to all families. Our subsample, however, did have demographic characteristics similar to those of the original population.

Policy Implications

It is essential for policy makers to understand the barriers faced by low-income families when trying to access necessary medical care. Insurance does not guarantee access, and having access to primary care does not guarantee receipt of all necessary care. Clinicians must understand that many patients who are not coming to see them are not necessarily going somewhere else, such as a safety net clinic. Additionally, family physicians who are familiar with this complex situation can help patients navigate the system and can be advocates for vulnerable patients in policy discussions. As evidenced here, health insurance is an essential foundation for all families, but it does not solve all problems. Policy reforms need to address all 3 issues: insurance, access, and cost.

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