

The Potential Impact of Medicaid Reform on the Health Care–Seeking Behavior of Medicaid-Covered Children: A Qualitative Analysis of Parental Perspectives

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Funding/Support: This study was funded through a grant from the Wisconsin Medical Society Foundation, who had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; and preparation, review, or approval of the manuscript.

Objective: To assess perceptions and intended behaviors of parents of Medicaid-covered children regarding the potential impact of recent Medicaid reform on children's health care.

Methods: Qualitative study of parents of Medicaid-covered children in which parents were asked 40 questions to assess knowledge, beliefs, attitudes, and intended behaviors regarding Medicaid reform.

Results: Forty-nine parents were interviewed; their median age was 28 years. Ninety percent were African American, 64% were high school graduates, and 41% had children with chronic conditions. Parents were unaware of or confused by recent Medicaid reform, and a common theme was that the reform was unreasonable. Financial hardship was cited as a major potential consequence of reform, leading to increased use of government entitlement programs, greater debt, and bankruptcy. One mother stated, "What was the purpose of being on Medicaid if you could afford to pay for it?" Parents also expressed concerns about sacrifices they would have to make to pay copayments for their children. Major sacrifices included food, utility bills, clothing, taking additional jobs, working longer hours, and cutting back on parental medications. In response to copays and premiums, parents would defer needed preventive and sick care for children, rely more on charity care, and increase use of the emergency department (ED). Many parents expressed concerns that the reform would negatively impact overall family well-being.

Conclusions: Parents of Medicaid-covered children report that current Medicaid reform will result in increased financial and nonfinancial hardship, deferral of children's preventive and sick care, increased reliance on charity care, increased ED visits, and decreased health and well-being for children and families.

Keywords: Medicaid ■ African Americans ■ children/adolescents ■ socioeconomic status ■ health policy

J Natl Med Assoc. 2009;101:213-222

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Medicaid provides health insurance for nearly 55 million low-income and disabled Americans.¹ Designed as an insurance program for America's disadvantaged, Medicaid spending increased 98% from 1995 to 2004.² On February 8, 2006, President Bush signed into law the Deficit Reduction Act of 2005 (DRA), which includes \$26.1 billion in federal Medicaid program cuts over the next 10 years.³ These Medicaid cuts will be implemented by requiring copayments and premiums for patients, benefit reductions, and citizenship documentation for program eligibility.^{4,5}

Previous research indicates that cost shifting to patients in general results in patients and families foregoing necessary medical care for themselves and their children, as well as causing many to lose medical coverage entirely.⁶⁻⁹ Cost shifting also can lead to more costly and delayed medical care, and deferral of needed care for those with serious and/or chronic conditions.¹⁰ While these studies provide useful theoretical and economic analyses of the general issue of cost shifting, no studies have been conducted on the impact of recent major Medicaid reform on families and children. There are also little data available on the perspective of this population concerning cost sharing and health care usage, as well as the potential impact of documentation requirements.

Approximately 25 million US children will be affected by the DRA.¹¹ Data are thus needed to assess the potential impact that Medicaid reform could have on the health of low-income children. The study objective, therefore, was to use ethnographic interviews of parents of Medicaid-covered children to determine the attitudes, beliefs, and intended behaviors regarding the DRA.

METHODS

Research Design

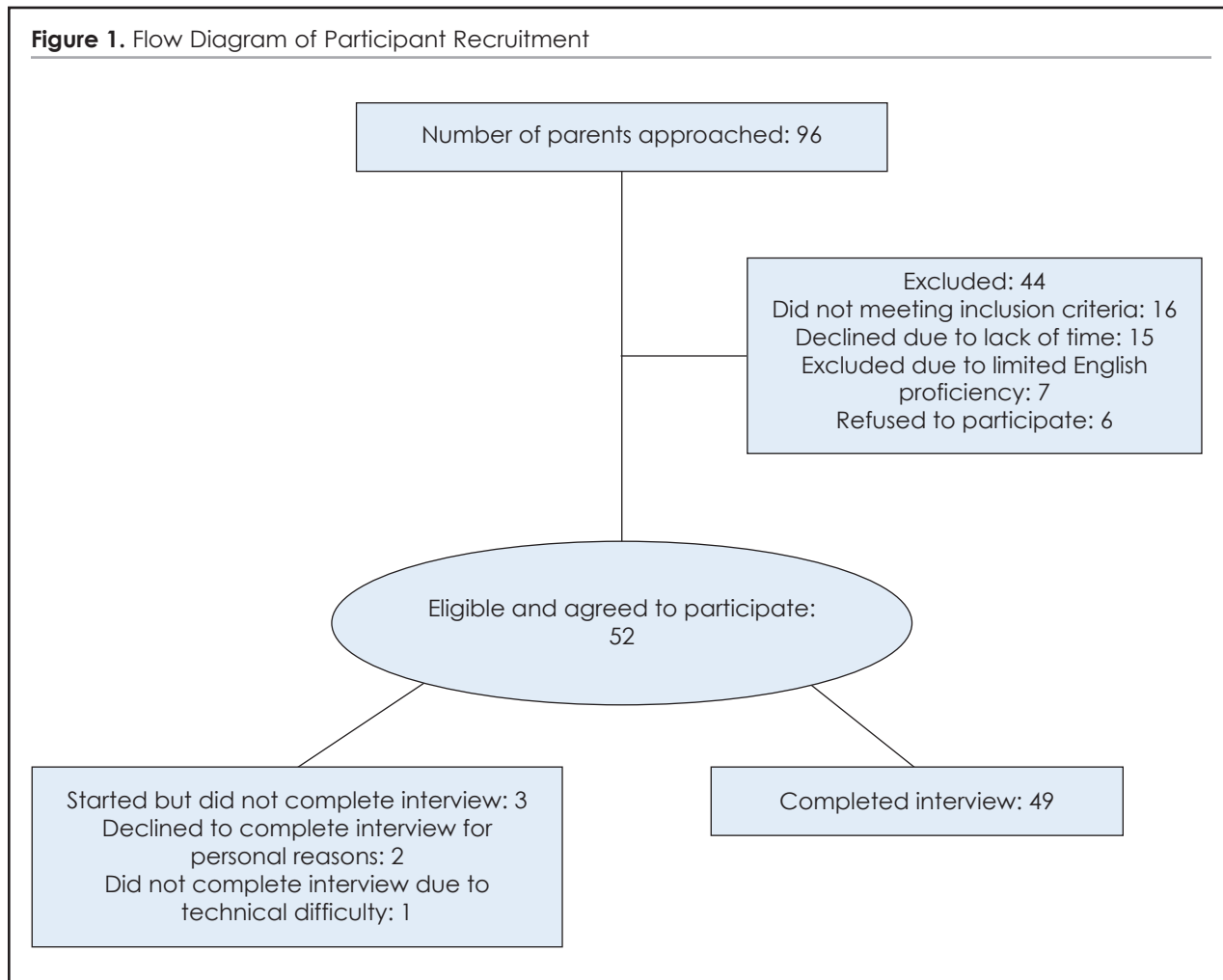
A qualitative study using ethnographic interview methodology was chosen because it is considered one of the most useful mechanisms for in-depth exploration of people’s knowledge, experiences, attitudes, and motivations,¹² and ethnographic interviews have been shown to be a highly effective approach for providing in-depth examinations of a variety of pediatric issues.¹³⁻¹⁵ Forty questions with 82 probes were asked in each interview. The questions addressed a variety of Medicaid reform issues assessed as most relevant by the authors in their review of the pertinent literature, including parental perspectives on awareness and reasonableness of reform, expected behaviors in response to implementation of copayments for their children’s doctor’s visits and prescription drugs, expected behaviors in response to implementation of premiums, expected behaviors in response to implementation of benefit reductions and documentation of citizenship, the anticipated consequences of reform on the overall health and well-being of their children and families, and comments for President Bush and

Congress on Medicaid reform. Questions concerning physician copayments were asked for the amounts of \$10, \$20, and \$30; concerning pharmacy copayments, in the amounts of \$5, \$10, and \$15; and concerning monthly premiums, in the amounts of \$30 and \$50. The differing dollar amounts were used to determine if any potential changes in behavior exist as cost sharing was increased. All questions were formulated based on 6 careful reviews of the DRA¹⁶ (because no states had yet instituted any of the Medicaid changes at the time of the study). An analysis of the Health Interview Study revealed that interview questions have been shown to be a reliable and valid method for examining the effects of cost on health care use behaviors;¹⁷ this analysis provided the conceptual framework for the cost questions in our study.

For parents who were unaware of recent Medicaid reform, we stated and asked the following to address whether parents believed the reform was reasonable:

Congress recently made changes to the Medicaid program which mean that you may need to pay some amount every month to keep Medicaid coverage for your child, and/or every time you take

Figure 1. Flow Diagram of Participant Recruitment



your child to the doctor or fill a prescription for your child. Do you think this is reasonable? Why or why not?

Study Setting

The subjects were parents with Medicaid-covered children who were being seen at the Downtown Health Center (DHC), an urban pediatric clinic in Milwaukee, Wisconsin. DHC cared for 4331 patients in 2005, who made a total of 12 910 visits; 93.4% of DHC patients are covered by Medicaid.

Subject Recruitment and Eligibility

A cross-sectional convenience sample of parents was recruited by the first author in the clinic's waiting room. Parents were eligible for study participation if they had 1 or more children aged less than 18 years old with Medicaid coverage. Children covered by State Children's Health Insurance Program were not included. We excluded parents with limited English proficiency (due to lack of interpreter availability) and children not accompanied by a parent or legal guardian. Parents were interviewed in an examination room of the clinic while awaiting pediatric care from the physician, with the interview concluded after care was given, if necessary. Written informed consent was obtained from each participant, and the study protocol was approved by the institutional review board of Children's Hospital of Wisconsin. Recruitment and interviews were performed on weekdays between June 2 and June 29, 2006. Each participating family was provided with a \$5 cash honorarium for participation, with interviews averaging 25 minutes in duration.

Analysis

Each interview was audiotaped and transcribed by an administrative assistant unaware of the study aim. To ensure accuracy of the final transcripts, the first author simultaneously reviewed the audiotape and transcript of each interview at least once. Each transcript was analyzed by the first author, with the second author and another researcher providing further independent analyses. Transcript-based analysis was used to examine the data,^{18,19} with highlighting and margin coding of relevant themes. To validate the thematic coding, each reviewer analyzed transcripts independently and then met to resolve any differences by consensus. Themes common to interviews were then identified and recorded. Thematic analysis was performed using grounded theory, in which new theory was generated from the data, and appropriate existing theory modified or refined by comparison with incoming information.^{20,21} Finally, a taxonomy of oft-repeated themes was created to reflect the range of responses regarding Medicaid reform.

RESULTS

Recruitment and Sociodemographics of Participants and Their Children

Ninety-six parents initially were approached for ethnographic interviews; 44 were excluded because they did not meet inclusion criteria, did not have enough time, were limited in English proficiency, or refused participation (Figure 1). Of the 52 parents initially agreeing to participate, 3 failed to complete the interview (due to technical difficulties or declining after initiating the study). Of the 73 potential subjects who were eligible to participate (including 15 who declined due to lack of time and 6 who refused participation), 49 completed interviews, for a response rate of 67%. The median age of participating parents was 28 years, and of their children, 1.3 years; 90% of parents were African American, about two-thirds had graduated high school, and three-fourths had more than 1 child (Table 1). More than one-third of children had a chronic condition (by parental report), including asthma, cerebral palsy, attention-deficit/hyperactivity disorder, epilepsy, diabetes, and various mental disabilities. Fifty-four percent of children's visits were for sick care.

During the 1-month study period, 429 patients made 711 visits at DHC, 55% of which were for sick care.²²

Parental Responses

Analysis of parental responses yielded a taxonomy consisting of 58 themes in 7 categories (Table 2).

Awareness of Medicaid reform. Most parents were unaware of the recent Medicaid reform. Those who were familiar with the reform were confused by it and what it meant. One mother said, "There's been some changes, but exactly what it all [is], I don't really know." Parents

Table 1. Sociodemographic Features of Interviewed Children and Parents (N = 49)

Feature	% or Median (Range)
Median child's age, y	1.3 (0.01-16)
Number of children in family	
1	25%
2	20%
3-4	29%
≥5	26%
Child has chronic condition ^a	41%
Visit type	
Sick visit	54%
Preventive care visit	46%
Race/ethnicity	
African American	90%
Latino	4%
Other, nonwhite	6%
Median parental age, y	28 (17-56)
Parental educational attainment	
Less than high school graduate	36%
High school graduate	30%
Some college	34%

^a By parental report

Table 2. Taxonomy of Parental Responses to Recent Federal Medicaid Reform

Awareness of Medicaid Reform
Lack of awareness about reform
Aware but confused about reform
Confusion between Medicaid and Medicare
Reasonableness of Medicaid Reform
No
Unaffordable
Frustration due to changes
Unfairness
Yes
Results in increased financial responsibility/accountability
More appropriate use of health care services
Impact of Copays and Premiums on Children
Deferral of needed medical care
Preventive care (well-child visits and immunizations)
Sick care
Specialty care
Prescription drugs
Preference for emergency department care
Use of alternative treatments
Increased use of home remedies
Increased use of over-the-counter drugs in place of prescription drugs and doctor's visits
Greater reduction in use of health services as copayment and premium amounts increase ("dose-dependent response")
Children with chronic conditions affected most
Older children affected more than younger children
Increased number of missed school days due to illness
Limitations of children's activities to prevent health deterioration
Increased emotional hardship
Impact of Copays and Premiums on Families
Necessity of major sacrifices
Food
Utilities
Household essentials
Time and involvement with family
Parent's medication
Increased financial hardship
Unaffordable
Additive hardship
Increased debt
Increased reliance on charity care
Increased reliance on other government entitlement programs
Employment issues
Increased number of missed workdays
Cannot afford health care due to high unemployment
Necessity of working more hours
Necessity of taking on a second job
Necessity of finding job with better pay and/or benefits
Increased emotional hardship
Moral dilemmas
Considering committing crime to obtain money for health care
Benefit Reductions
Frustration
Unfairness
Defeats purpose of coverage
Payment for hospitalization results in declining credit
Results in an increase in filing for bankruptcy
Documentation for Citizenship
Requirement can be met
Frustration with new requirement
Messages for President Bush and Congress about DRA
Frustration
Unfairness
Unaffordable
Cannot increase health payments without first increasing job availability
Inability to improve financial position due to reform

Table 3. Interview Quotes on Selected Key Medicaid Reform Issues by Parents of Medicaid-Covered Children

Affordability

"Some parents don't have [the money]. They're already struggling to try to take care of their children and everything and then you come and throw a payment on to them? They can't afford that, really, you know, especially single parents. You have single moms that can't really afford that."

"I probably couldn't afford it. I have a lot of kids. I wouldn't be able to afford to just get regular health care and my job doesn't offer it yet."

Unfairness

"Some of the families are just struggling, just making it, you know, including myself. And it can really be hard to try to come up with money for prescriptions or to see the doctor. Mostly the people that probably be paying are the people that's on public aid or, you know, basically just working, just making it, so I don't really think it's fair."

"Maybe it's reasonable if you don't have so bad of conditions. But when you got a medical [condition] like hers, a deterioration of the brain, I would think that no, you shouldn't pay nothing because she's not abusing the [Medicaid] card. She's using it, cause she needs it."

Copayments for physician's visits and prescription drugs

"If we gotta pay for it, I mean, we're gonna have second thoughts or notions about bringing our baby in."

"If he had a chronic [condition], I hate to say it, but yes—he won't get his medicine."

Missed school days

"I'm very keen on perfect attendance at school, but \$10 [for a doctor's visit]? I'd probably keep them home from school for the day."

Major sacrifices to afford copayments and premiums

"Somebody ain't eating somewhere or somebody ain't going to no doctor."

"I would have to sacrifice everything. I wouldn't get to see them because I'd probably have to work 2 or 3 jobs just so that they can have coverage."

"I'd probably ask my job if I can get some more hours, you know, miss out on being at school with them, cause I like to be at school to see what's going on."

Increased reliance on charity care

"I would try to find a free clinic, because I wouldn't be able to afford it." (in response to a \$10 copay for immunizations)

Employment problems

"I'm not employed at all, no one's hiring me, so I have no job and I have no way to pay the \$10 every time I bring my child to the doctor."

"I have a good job, but it doesn't matter how good of a job I have when they're not, my job is not covering all of my children for health insurance."

"It's hard taking care of 8 kids, and then to have to pay all that money when we visit the doctor. But if I have to, I've got to get a better job."

Increased debt

"I know I wouldn't be able to get a house. We're trying to buy a house. You can't buy a house if you've got hospital bills on your debt. So to me, it's like putting you in financial ruin."

Documentation of citizenship

"If these kids already on Medicaid, why do you have to go through all this stuff? They're already struggling, and this will just make them struggle even more, because a lot of people that don't have birth certificates, that don't have documentation or whatever's going on, don't have the resources to buy or go get it, you know."

often confused Medicaid and Medicare, particularly the Medicare Modernization Act of 2003.

Parents’ perspectives on the reasonableness of Medicaid reform. Parents repeatedly stated that recent Medicaid reform was unreasonable. A principal theme was the inability to afford new Medicaid charges for children’s medical care (Table 3). One parent stated, “It’s not everybody that can afford it, you know. If you can afford it in the first place, we wouldn’t be in the situation we’re in right now. If I was able to afford it in the first place, I wouldn’t be applying for Medicaid.”

Parents stated that Medicaid reform was unfair and expressed frustration with reform (Table 3). One mother stated, “I feel they [are] not looking at what people need. It’s a lot of people out there that need help and they [are] not giving it to them. I think that’s all jacked up, I really do, because it’s

like people are struggling and they’re not helping them.”

Medicaid reform was occasionally viewed positively, with identification of the need for families to be more accountable and to use health services more appropriately. One mother said,

I figure everybody can pitch in something on it. But, I mean, if I had to actually pay for some of our medicine, I wouldn’t find it to be no problem. You gotta be responsible for some of your things, don’t just expect everything to be handed to you.

Impact of copays and premiums on children’s health and health care. A recurrent theme was that Medicaid copays and premiums would cause parents to defer needed medical care for their children, including

Table 4. Summary of Parental Messages for President Bush and Congress on Deficit Reduction Act Medicaid Reform and the Impact on Children

Frustration

“They have children and, I mean, they are able to afford what they can afford simply because of the situation they are in. You have to walk in my shoes to know what I feel, you know, for being on the Medicaid program.”

“Our kids lives would be in jeopardy, especially those of us that have children that have chronic illness. We need that medical [coverage] for our children or they’ll miss out of school because they’re too sick and their education would go lacking and we really can’t afford that, not in today’s society. So our Medicaid is very important. Even though I have three years of college, I don’t even have a job I feel I should have, because they looking for experience, and I’m still working for eight dollars an hour when I know with my skills, that’s not enough. If we have to pay for our medical [care] that’d be too hard on us, our kids would go sick, our kids would go very sick, and they would be losing and lacking in a whole lot of stuff.”

Unfairness

“They need to think twice about what they doing, because some people out here that really needs Medicaid, it’s a whole lot of people out here that’s on a fixed income, no matter how good of a job we have it’s still, we still on a fixed income and we need the assistance. I have a good job, but it doesn’t matter how good of a job I have when my job is not covering all of my children for health assistance.”

“That is a little bit absurd, especially for mothers who taking care of their children by themselves, it’s already hard, with no help. At least do it for the child. I think they are against abortion and stuff like that. Well, they have to be against this too because a child would have no way for them to get help or medical attention, most parents won’t even bring their child, and then what’s worse, getting a child aborted or seeing a child suffer because he doesn’t have no medication, can’t see the doctor? That would make a woman wish she did do it. That’s not fair.”

Unaffordable

“That is too much money to pay every month. A lot of people are not fortunate enough to pay that every time they see the doctor, and I’m one of those people.”

Cannot increase health payments without first increasing job availability

“He keeps forgetting there’s people in poverty, and there ain’t no jobs out here. So if we don’t got no jobs, how do you expect us to pay for Medicaid?”

Inability to improve financial position

“You are able to get your benefits. What about the rest of the people that’s out here that needs help? You know, that can’t strive and can’t provide? That’s doing the best they can to provide, and then you steady taking money out of their pocket, but you want them to get off welfare. How are you helping them to try to get off [welfare]?”

preventive, sick, and specialty care (Table 3). One mother stated,

He won't get the care, so he's gonna get sicker. It's gonna spread through the house, so then that means my other children gonna get sicker and that means that's more money I gotta try to find to get them all medication that I don't have the money for. And then rent's due, too? That's too much.

A copay of as little as \$5 for the purchasing of prescription drugs would cause parents to be less likely to obtain needed medication for their children. One mother stated that if a copay was required to obtain her son's asthma medication, she would "be more cautious with him so I don't give it to him as much."

Some parents expressed a preference for taking their children to the emergency department (ED) for care, instead of paying a copayment for an office visit. One mother said, "I'd rather take him to the ER [than pay a \$10 co-pay]." Another mother said in regards to implementing copayments of \$20, that "the emergency room is really gonna be full if they do that."

Parents reported that they would resort to alternative treatments for their children, such as home remedies and over-the-counter drugs, rather than pay a copayment for their child's sick visit. One parent responded,

[If] I have to get charged \$10 every time I come, I probably wouldn't be here. I would just go run and buy some over-the-counter drug and see if it works for the baby. Did you guys consider what am I going to put the money to, the medicine or the visit? So, I would choose the medicine.

Parents stated that children with chronic conditions would be affected more than other children. Reasons given for this included the higher frequency of visiting physicians (both specialists and generalists); greater need for and higher frequency use of medications; and greater potential for long-term damage to the child if not seen by a physician. A mother of a boy with cerebral palsy stated, "He sees a lot of different specialists at the clinics at Children's Hospital, so that would probably tap my pockets, because he goes to the clinics quite often, probably like 5 or 6 times a month."

Another negative effect on children that parents detailed was missing more days of school due to illness. Parents stated that they would rather keep their child home from school than make a copayment for a physician's visit.

Parents reported that they would limit their child's activities to prevent health deterioration and resultant copays for a sick visit and/or medication. One mother said, "I would try to keep him away from outside cause that's when his asthma usually acts up. I would do every-

thing I could to make him stay, cause [\$5 is] a lot of money [for medication]."

While parents consistently expressed frustration with the implementation of copayments of any amount, the severity of negative reactions increased with each incremental increase in copays and premiums.

Potential impact of copays and premiums on families. In addition to affecting the well-being of children, parents brought up many ways that Medicaid copays and premiums would affect the entire family. Parents described major sacrifices that would have to be made to afford Medicaid copayments and premiums for their children (Table 3). One parent stated, "A lot of people are going to be out on the street if they have to pay this and then try to pay bills. A lot of kids going to be in the cold, a lot of kids going to be hungry." In addition to food and utility bills, parents acknowledged that they would sacrifice needed clothing purchases for their children to afford Medicaid copayments.

One parent stated that she would sacrifice her own medication to pay for care for her children:

I take over, what, \$1500 worth of medicine every month, and I can't afford it. So why, how, could I afford medication for myself and them, pay for my own medication and pay for theirs too? [I would make] a lot of different changes [to afford a monthly premium], food, utilities, my medicine, things like that.

Parents also expressed frustration at having to sacrifice time and involvement with their children to work more to afford the new Medicaid copayments and premiums. Other sacrifices that would be made by parents to pay for new Medicaid charges included foregoing household essentials, such as cleaning products, toilet tissue, shampoo, soap, toothpaste, and toothbrushes.

Parents reported that the DRA Medicaid reform would cause extreme financial hardship. Those with chronically ill children particularly expressed concern about the additive hardship of paying for multiple visits per month: "He has asthma problems, so he's in the hospital a lot. He's in the emergency room, he has to come for follow-up appointments and stuff like that. I don't think I can afford something like that." Many parents were worried that inability to pay for copayments and premiums would lead them into significant debt. Parents stated that, as a result, they would seek charity care for their children.

One notable financial hardship described by parents was the necessity to utilize other government services in response to the DRA reform. One mother said, "There's help out there with food stamps and stuff like that. It would hurt more of my budget to get on food stamps and stuff like that, but if I had to make those sacrifices to do it, I would."

Certain parents related that they could not afford to pay Medicaid copays and premiums for their children

because they were unemployed and found it difficult to find adequate employment. Employed parents responded that it would be necessary to work more hours or take on additional jobs to afford copayments and premiums. Some parents mentioned that even though they worked a lot already, their jobs did not pay enough or offer enough benefits for them to pay these added costs. A recurrent theme was that parents would stay home from work to care for their sick children, rather than pay copays for their children to see a physician.

Parents expressed frustration about moral dilemmas caused by DRA reform, such as deciding between getting care for their child vs buying food, and choosing which child should get care if more than 1 were sick. A recurrent theme was parents suggesting that they might consider committing crimes to pay for the health care of their child in response to Medicaid reform: "You got some people [that] just might take a gun and go put it to somebody's head and say give me \$10, I need to get my baby to the hospital."

Benefit reductions. Benefit reductions are another source of frustration and concern for parents. In response to the example of not having a hospitalization covered for their child, one parent said: "I wouldn't feel that they was right. What if you end up with a really life-threatening illness, and ain't nobody to pay for it, so you'd just have to be sick?"

A recurrent theme was that Medicaid benefit reductions would drive families deep into debt, and some even thought it might drive them to bankruptcy. When asked what benefit reductions would do to her financially, one parent responded, "Bankruptcy. Seriously."

Documentation of citizenship. The DRA requires documentation of citizenship. None of the parents interviewed would have trouble producing required DRA documentation, though concerns were expressed with the requirement (Table 3).

Parents' messages for President Bush and Congress about Deficit Reduction Act reform. Parents expressed frustration with the president and Congress, consistently describing the DRA reform as unfair and unaffordable (Table 4). Parents also expressed concern that reform would cause an inability for families to improve their financial position, and that Medicaid reform should not be implemented without a concomitant increase in employment availability.

DISCUSSION

Deficit Reduction Act and Deferral of Needed Health Care

A common parental reaction to DRA Medicaid reform is delaying and even foregoing needed preventive and sick care for children. This is concerning, given that research documents that utilization of primary care is associated with higher rates of vaccination; less obesity; higher use of seat belts; earlier detection of many

cancers; more-effective prevention in patients with hypertension, non-insulin-dependent diabetes, and depression; and increased disease-focused preventive care.²³ The DRA may therefore result in impaired preventive care for children, and associated worse health status and outcomes.

Parents also stated that the DRA reform will decrease continuity of care. Continuity of care has been shown to be associated with greater patient adherence; higher immunization rates; fewer hospitalizations; fewer visits to the ED; greater patient, parental, and physician satisfaction; and lower resource use.²⁴ Continuity of care is also associated with fewer ED visits and hospitalizations in children with asthma and other chronic conditions.²⁵

Deficit Reduction Act, Increased Utilization of Government Entitlement Programs, and Bankruptcy

To offset new DRA copayments, premiums, and benefit reductions, parents reported that they will enroll in or depend more on other government entitlement programs for their children and their family. Such increased use of food stamps, welfare, Supplemental Security Income (SSI), and other entitlement programs may further increase state and national government spending, potentially negating any expected savings from DRA reform. In addition, it is not clear that all families would newly qualify for such entitlement programs to offset DRA-induced out-of-pocket payments, which therefore could cause further financial hardship for many parents.

Bankruptcy was cited as a major consequence of the DRA. Medical debt is the number 1 cause of bankruptcy in the United States, affects 29 million Americans, and is a substantial burden on the health care system and national economy.²⁶ The study findings therefore suggest that the DRA could result in more poor families filing for bankruptcy.

Deficit Reduction Act and Economic Sacrifices by Families

Parents reported that they would have to sacrifice paying utility bills, needed clothing for the family, and even food for their children and family to pay for new costs under the DRA. The sacrifices, thus, are for basic needs, rather than on items considered to be discretionary spending (such as entertainment, vacations, etc.). The potential large-scale increase in food insecurity due to the DRA is concerning, given the multiple documented adverse consequences of food insecurity, including nutritional deficiencies, underweight, lower test scores in mathematics and reading, lowered social skills,²⁷ and greater rates of childhood behavioral problems and mental depression and anxiety.²⁸ It is especially disturbing that the DRA could cause parents to sacrifice

purchasing their own prescription medications and to consider crime and prostitution to meet the costs of needed medical care for their children. These findings suggest that the DRA could have far-reaching deleterious effects on the health, well-being, and integrity of poor families and communities.

Deficit Reduction Act and More Missed School Days

Parents stated that they would rather keep their child home from school than make a copayment for a physician's visit. School attendance is associated with school success and high school completion,²⁹ and high school completion is associated with employment and higher income and occupational status (compared with those not completing high school).^{30,31} Racial/ethnic minorities continue to have the highest risk of high school dropout;³² the results of this study, in which the sample was 90% African American and 94% minority, suggest that the DRA may possibly increase the risk of poor school attendance, thereby potentially contributing to higher rates of school dropout and lower earning power among today's children as they become tomorrow's adults.

Deficit Reduction Act and Use of the Emergency Department and Charity Care

In response to the DRA, parents responded that they would increase use of the ED care for their children's nonurgent care to avoid higher cost sharing associated with pediatric primary care visits. Multiple studies document that EDs nationwide are experiencing overcrowding, closures, and high rates of visits for nonurgent conditions.³³⁻³⁵ The use of EDs for nonurgent care when primary care would be more appropriate has been identified as 1 of the main causes of increased Medicaid costs.³⁶

Parents also reported that the DRA would force them to seek out charity care for their children. This would place a greater financial burden on society and health care systems, especially at a time when some hospitals and clinics have closed due to financial crises caused by providing a large amount of charity care.³⁷⁻³⁹ The increased use of both EDs and charity care in response to the DRA also could impair continuity of care for many Medicaid-covered children.

Messages for President Bush and Members of Congress about the Deficit Reduction Act

Parents consistently expressed frustration with the president and Congress for passing the DRA. Parents emphasized that they feel that lawmakers do not sufficiently understand the struggles confronted by poor families with children. Parents cited that federal employees have excellent health insurance coverage and so cannot comprehend what it is like to live in poverty and face higher health costs

for their children. Parents also challenge the stereotype about low-income Americans being "lazy" and "entitled".⁴⁰ Parents wanted Congress and the president to know that they are working hard to overcome their circumstances but find it difficult to outgrow public assistance with the increasing financial responsibility being placed on families due to legislation such as the DRA.

Limitations

Certain study limitations should be noted. Study participants were predominantly African American residents of Milwaukee. The findings therefore may not generalize to other racial/ethnic groups covered by Medicaid, and to other regions of the country or nonurban areas. Further research is warranted comparing the findings of this study with similar data on other racial/ethnic groups. The study findings may also be limited by the relative small sample size (N = 49), but this sample size allowed fulfillment of the qualitative research standard of thematic saturation, and this sample size was comparable to or greater than sample sizes in other recent ethnographic interview studies in the pediatric literature.¹³⁻¹⁵ As most of the parents were unaware of reform, their opinion of the DRA was based on the 1-sentence summary provided to them by the first author. While such a brief description could limit parents' understanding and consequent behavioral projections, the authors believe that the statement provided was the most accurate and concise summary of the DRA. Every effort was made to eliminate biased answers by phrasing all questions as neutrally as possible, but it is possible that the wording of certain questions may have resulted in biased responses. Due to the lack of available medical interpreters, parents with limited English proficiency (N = 7) had to be excluded; this study, therefore, may have had a limited ability to identify barriers associated with producing required DRA documentation.

Implications for Pediatric Practice

Pediatricians and the American Academy of Pediatrics have already expressed concern regarding the potential consequences of the DRA on the health and well-being of children and their parents.⁴¹ The study's findings suggest that pediatricians could see their Medicaid-covered patients less frequently as a result of the DRA, which would impact numerous aspects of medical practice, including delayed or missed immunizations, increased home safety issues for families due to decreased opportunity for instruction and reminders by physicians, increased disease and illness due to lack of prevention, and worse outcomes in illness due to delayed or neglected treatment.

CONCLUSIONS

The study findings indicate that parents of Medicaid-covered children believe that the copayments, premiums, and benefit reductions enacted by the DRA will be detri-

mental to the health and health care of their children. Parents were largely unaware of recent reform and often confused by it. Parents stated that they will face increased financial and nonfinancial hardship as a result of the DRA, causing them to defer needed preventive and sick care for their children; to substantially reduce spending on food, utilities bills, and essential clothing for their family; and to increase reliance on charity care, over-the-counter drugs, and use of the ED. These findings suggest that recent Medicaid reform could cause less continuity of care, greater unmet health care needs, greater societal burden, and higher future health care costs.

ACKNOWLEDGMENTS

We are grateful to Jacqueline Gonzales, Kristen Costello, the staff at DHC, and the DHC children and families for their contributions to this study. We thank Emmanuel Ngui for providing assistance with analyses and for reviewing an earlier manuscript draft, and John Meurer for making DHC facilities available to us and for reviewing an earlier manuscript draft.

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