

Family Reports of Care Denials for Children Enrolled in TennCare

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ABSTRACT. *Objective.* Twenty-three million people, accounting for >58% of Medicaid enrollees, are enrolled in Medicaid managed care programs. Although the expectation of management in Medicaid managed care programs necessitates restrictions in use of some services sought by patients and families, the circumstances surrounding care denial and related access problems in vulnerable populations of children have not been studied. The objective of this study was to identify experiences with care denial reported by families in TennCare, Tennessee's managed care program for Medicaid enrollees and uninsured.

Methods. Primary caregivers for 399 children who were enrolled in TennCare and presented for care at 21 pediatric and family medicine sites throughout Tennessee participated in a face-to-face interview.

Results. Of the 399 caregivers who participated in the study, 146 (36.6%) reported that their child experienced denial of care in the previous 12 months at a physician's office (12.5% of those interviewed), dentist's office (13.8%), or pharmacy (20.0%). For denial of any 1 type of care, families of children with chronic conditions (multivariable odds ratio [OR]: 2.05; 95% confidence interval [CI]: 1.41–2.99) and those whose parents had >12 years of education (OR: 1.80; CI: 1.21–2.70) were more likely to report denial of care; families of black children were less likely to report denial than white children (OR: 0.34; CI: 0.20–0.56). Content analysis of caregiver perceptions identified provider concerns about reimbursement as a factor in denials. Of the children who could not be seen by a physician, caregivers perceived that 12.2% became sicker as a result of the delay in care; 16.3% reported an emergency department visit after the denial.

Conclusions. More than one third of TennCare families reported denials of care for their children in the previous year, and factors surrounding these denials were identified. Given the large number of Americans who receive health care through Medicaid managed care programs like TennCare, more research is needed to understand the implications of denied care for children and families who are enrolled in these programs. *Pediatrics* 2004;114:e37–e42. URL: <http://www.pediatrics.org/cgi/content/full/114/1/e37>; *Medicaid, managed care, TennCare, access, denial of care, child health, chronic conditions.*

Managed care programs are designed to optimize quality and minimize cost in part by controlling use of services that are believed to be of marginal value.¹ In many instances, care restrictions and denials of care sought by patients and families may be appropriate because of lack of medical necessity or availability of effective alternative treatments. However, previous work among people with commercial insurance has suggested that restrictions and denials may lead individuals to seek care less often.² Thus, restrictions on access to care might lead to unintended consequences for patients and their families.³

Little is known about family and patient experiences surrounding denials of health care for children since the widespread implementation of Medicaid managed care (MMC) programs. Managed care programs for Medicaid enrollees have expanded dramatically in recent years, with 23 000 000 people who are enrolled in MMC programs composing 58% of all Medicaid enrollees nationally.⁴ In addition, little is known about actions taken by economically disadvantaged families after care denials for their children and the families' perceived sequelae of such denials. Understanding families' experiences with denials and perceived outcomes might provide important insight for policy makers and providers who are charged with ensuring health promotion for children.

This study was designed to identify experiences with health care denials in the previous year among children who were enrolled in TennCare, Tennessee's managed care program for Medicaid enrollees and uninsured individuals. The study included identification of whether families reported care denials, factors associated with the denials, actions taken after care denial, and the family's perceived consequences of the denial on the child's health and the family.

METHODS

From May to August 2002, we conducted structured interviews with families who sought health care for children who were 1 to 18 years of age and enrolled in TennCare at 21 pediatric and family medicine sites across the state of Tennessee. Permission to conduct interviews was obtained from pediatric and family practice offices who served TennCare patients. Practices were identified by the chairs of pediatrics and family medicine at academic medical centers and from the leadership of the state chapters of the American Academy of Pediatrics and the American Academy of Family Medicine. We attempted to achieve a mixture of pediatric and family practice sites in both urban and rural locations and from all geographic regions of the state. The study was reviewed and approved by the Institutional Review Boards of Vanderbilt University, the University of Tennessee at Memphis, the University of

ABBREVIATION. MMC, Medicaid managed care.

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The interview took ~10 minutes to complete and was administered by 2 of the authors (R.S.V. and D.F.K.) in a private area of the waiting room or in the examination room, depending on the practice's space availability. Consecutive patients were interviewed at practices on varying days of the week, and all families who were enrolled in TennCare and presented for care were invited to participate. Respondents were asked to describe experiences with denial of care for the child being brought to the provider on that day. When >1 potentially eligible child was presenting for care (2% of families), respondents were instructed to describe experiences for the oldest child present to allow sufficient representation of older children in the sample. In addition to child and respondent demographic information, the interview incorporated a 5-item validated survey instrument to determine whether the child had a chronic health condition.⁵ For assessing whether denials occurred, caregivers were asked, "In the past 12 months, have you ever been told that your child couldn't be seen by a doctor," and "...couldn't be seen by a dentist," and "...couldn't be seen in an emergency department," and "...couldn't get a prescription filled at a pharmacy?" Descriptions of events surrounding the denials were recorded by the interviewer. The interview included open- and closed-ended questions about actions taken by families after denials and the perceived sequelae of denials (eg, "In your opinion, did your child get sicker because he/she wasn't able to get care right away?"). The content of the interview was reviewed by experts in the delivery of pediatric health care and piloted with a small number of families before field implementation. Interrater reliability was established during the piloting sessions by having both interviewers record responses for a series of interviews; agreement was found on >90% of the key variables.

A total of 442 families were enrolled in TennCare and sought health care at 1 of the practice sites for a child who was 1 to 18 years of age and had been enrolled in TennCare for at least 1 year. Of the 442 eligible families, 32 families declined, yielding a participation rate among eligible families of 92.8%. After exclusion of 11 families because of incomplete data, responses from 399 families were included in the final analysis.

Strata were defined by study covariates, including child's age, gender, race, presence of a chronic health condition, caregiver education level, practice location, and practice environment. We used χ^2 analysis to assess differences in rates of denial across strata. Multiple logistic regression models included chronic health condition, race, caregiver education level, and practice environment. Regression models accounted for clustering by practice site.⁶

In addition, we performed content analysis on the caregivers' verbatim descriptions of denials. Responses were reviewed by 3 of the authors (R.S.V., D.F.K., and W.O.C.) to identify themes among the reported reasons for denial, actions taken by the family, and perceived sequelae. Themes were grouped, and responses were reclassified for each outcome.

RESULTS

Demographic Characteristics of the Study Population

Characteristics of families and their children are presented in Table 1. Most of the children were between 1 and 5 years of age, and more than one third had a chronic health condition. Most of the primary caregivers had completed high school, and more than one third had received education beyond high school. With respect to the practice site, 57% of the interviews were in an urban practice site; 77% of interviews were in pediatric practices, and 72% of interviews were in private practices.

Denials of Care

Among the respondent caregivers, 146 (36.6%) reported experiencing 1 or more denials of care for their child in the previous 12 months. Denials were experienced at physician's offices ($n = 50$; 12.5% of

TABLE 1. Characteristics of Children and Caregivers Who Participated in the Survey

	%
All <i>N</i> = 399	100
Child's Age, <i>y</i> (<i>N</i> = 395)	
1–5	54.9
6–12	31.1
13–17	13.9
Child's gender (<i>N</i> = 399)	
Female	47.8
Male	52.3
Child's race (<i>N</i> = 399)	
White	48.5
Black	44.5
All other	7.0
Child with a chronic health condition (<i>N</i> = 399)	37.2
Respondent education (<i>N</i> = 382)	
Did not complete high school	20.4
Completed high school	45.3
Some college	34.3
Practice location (<i>N</i> = 399)	
Rural	42.6
Urban	57.4
Practice type (<i>N</i> = 399)	
Pediatrics	77.3
Family practice	22.7
Practice environment (<i>N</i> = 399)	
Private	71.6
Academic	28.4

respondents), dentist's offices ($n = 55$; 13.8%), emergency departments ($n = 8$; 2.0%), and pharmacies ($n = 80$; 20.0%; Table 2). Several families ($n = 45$; 11.3%) experienced denials at >1 provider site.

Reported denials of care differed among children by sociodemographic characteristics (Table 2). Denials were reported more commonly for white children and children with chronic health conditions. Denials were reported less commonly for black children and by caregivers with a lower level of education. Most relationships between child and caregiver characteristics and denials identified in univariate analyses remained significant in multivariate analyses (Table 3). For denial of any 1 type of care, families of children with chronic conditions and those whose caregivers had >12 years of education were more likely to report denials of care. Families of black children were less likely to report denial than white children. Similar patterns were seen for other types of denial of care examined, although chronic health status was not significant for denial of dental care, and caregiver education level was not significant for dental or prescription denial (Table 3).

Circumstances Surrounding Denial of Care

Many families reported denials of care for administrative reasons (eg, the provider does not accept the child's TennCare plan). However, several families reported perceptions that reimbursement was driving provider decisions to deny care or seek payment from the family (which is in violation of provider TennCare contracts). For example, 1 family who described denial at a dentist's office said, "The receptionist told us we had to pay. She said the office took TennCare but she wanted me to pay because TennCare is not reimbursing the dentist." Another

TABLE 2. Univariate Analysis: Children Whose Parents/Caregivers Reported That the Child Had Experienced Denial of Care in the Previous 12 Months

	Denial at a Physician's Office (%)	Denial at a Dentist's Office (%)	Denial at a Pharmacy (%)	Denials at 1 or More Provider Types (%)
All children	12.5	13.8	20.0	36.6
Child's age, y				
1-5	11.5	8.8*	18.9	32.9
6-12	10.6	18.7	22.8	39.0
13-17	20.0	21.8	20.0	45.5
Child's gender				
Male	13.4	13.5	22.5	37.5
Female	11.5	14.1	17.3	35.6
Child's race				
White	14.9	21.6†	25.3*	45.9†
Black	9.6	3.5	14.0	24.7
All other	14.3	25.9	21.4	48.1
Child with a chronic health condition				
No	8.7†	12.0	13.5†	29.6†
Yes	18.8	16.8	30.9	48.3
Practice location				
Rural	8.8	18.7*	22.8	38.0
Urban	15.2	10.1	17.9	35.5
Practice environment				
Academic	20.2†	12.3	16.7	35.1
Private	9.4	14.4	21.3	40.4
Respondent education				
<12 y	6.4†	12.8	16.7	33.3*
12 y	9.2	12.7	17.9	31.2
>12 y	19.8	16.2	25.2	45.4

* $P = .05$ (χ^2 analysis for each group having denial at a site of care).

† $P = .01$ (χ^2 analysis).

mother reported, "The nurse told us that TennCare doesn't give the doctor enough money for the procedure, so the doctor wants us to use a medicine instead." Another mother who alleged that her child was denied care by an emergency department physician stated, "[The physician] said Medicaid wouldn't cover the ER visit and that we were tying up the ER for a condition that primary care could handle. They told me that I would have to pay if I wanted my child to be seen." A mother whose child was denied a prescription reported, "The pharmacist said the child was given the medicine before and it didn't seem to keep him from getting sicker. [He said] they wouldn't cover it again."

Actions Taken by Primary Caregivers After Denial

After any reported denial of care by a physician, the most common action (51%) was to change providers (Table 4). After denial of care by a dentist's office, 26% of primary caregivers changed their child's provider, whereas 17% paid for dental care out of pocket. After denial of a prescription, 49% of primary caregivers reported paying for their child's medication out of pocket, at a mean cost per prescription of \$43.71 (range: \$6-\$200). Among families who reported denial of prescriptions, 26% reported contacting TennCare or their health plan to appeal, whereas 20% contacted their doctor for a new prescription (Table 4). One mother reported, "The medicine wasn't covered by TennCare. I tried to talk the pharmacist into giving us a discount on the \$85 medicine. He wouldn't. So I went to the doctor's office and tried to get a different prescription, but the doctor told the people at the front desk that no other

medicine would work. Finally the people at the front desk gave me enough samples to cover it."

Perceived Sequelae of Denial

Nearly half of the families who reported denial of care by a physician perceived that their child experienced negative sequelae, including the child's being unable to do regular activities such as attend school (20%), worsening of the condition or failure to improve (12%), need for a parent to stay home with the child (14%), or the child's being taken to the emergency department (16%; Table 4). Another mother reported, "The doctor in the ER told us the child would be better off at a different ER because his ER did not take my son's type of TennCare. I drove him to a different ER, but he stopped breathing and turned blue on the way." Among families who reported denial of dental care, 19% reported that their child's condition worsened or failed to improve, and 15% reported that their child experienced more pain or continuing pain. One mother whose child was denied care at a dentist in the child's hometown said, "It's very difficult to travel with a child who has disabilities. We had to drive to a town 60 miles away. I can't take him by myself and have to find someone to come along. Some days [the child] is too sick to make the trip." Most (79%) caregivers reported no sequelae after denial of a prescription. However, some families reported that the child was unable to do regular activities (15%), the child's condition worsened or failed to improve (8%), the child had to miss school or child care (8%), or the child was taken to the emergency department (4%).

TABLE 3. Multivariate Analysis: Children Whose Parents/Caregivers Reported That the Child Had Experienced Denial of Care in the Previous 12 Months

	OR*	95% CI
Denial at a physician's office		
Chronic health condition		
Yes	2.00	1.40–3.68
No	Referent	—
Child's race		
Black	0.43	0.17–0.94
Other	0.68	0.20–2.29
White	Referent	—
Respondent's education level		
>12 y	4.23	1.37–13.03
12 y	1.79	0.49–6.55
<12 y	Referent	—
Practice environment		
Academic	2.97	1.46–6.05
Private	Referent	—
Denial at a dentist's office		
Child's race		
Black	0.10	0.04–0.29
Other	1.57	0.47–5.20
White	Referent	—
Denial at a pharmacy		
Child with a chronic health condition		
Yes	2.68	1.37–5.21
No	Referent	—
Child's race		
Black	0.47	0.26–0.85
Other	0.75	0.17–3.28
White	Referent	—
Denial at any site		
Child with a chronic health condition		
Yes	2.05	1.41–2.99
No	Referent	—
Child's race		
Black	0.34	0.20–0.56
Other	0.96	0.36–2.54
White	Referent	—
Respondent's education level		
>12 y	1.80	1.21–2.70
12 y	1.03	0.64–1.67
<12 y	Referent	—

OR indicates odds ratio; CI, confidence interval.

* Multivariate models included chronic health condition, race, caregiver education level, and practice environment. Regression models accounted for clustering by practice site.

DISCUSSION

Study results suggest that denial of health services is relatively common among children who are enrolled in TennCare and whose family sought care in pediatric and family medicine practices. Nearly 40% of respondents in this sample reported some kind of denial of care in the previous 12 months. Differences in care denial were seen among children with different sociodemographic characteristics. Specifically, white children, children whose caregivers had more education, and children with chronic health conditions reported more care denials. In addition, many families perceived negative sequelae to their children as a result of denials, including the need for additional care, missed school or work, or pain and worsening of the child's condition.

Although it is expected that managed Medicaid will inevitably lead to some care denials, unanticipated consequences may occur. Reimbursement procedures implemented by health plans might affect provider behavior, as was suggested by families who reported their belief that payment to providers drove some denial decisions. Previous work has demon-

strated the role of provider reimbursement on providers' care behavior and that the behavioral changes may not be perceived by providers who are affected by reimbursement.⁷ Both physician and nonphysician providers (eg, pharmacists, hospitals) may be affected by the administrative barriers imposed when care is restricted. For example, some providers may believe that it is easier to collect payment in full from a family rather than process necessary appeals. Indeed, families in this study reported that they were told that they would have to pay for the care themselves because of low reimbursement by health plans. Families may seek care less often in anticipation of denials or to avoid arduous appeals processes, as was seen in the Rand Health Experiment studies in the 1980s.²

Most prescription denials were reported to occur because medicines were not on approved formulary lists. However, such denials should not occur under a court-ordered consent decree handed down in 2000 in a case in which the state of Tennessee was sued on behalf of TennCare enrollees. The Grier Consent mandated that pharmacies provide a 14-day supply

TABLE 4. Denials in the Previous Year Reported by Parents of Children Who Were Enrolled in TennCare

	Denial at a Physician's Office (n = 50)	Denial at a Dentist's Office (n = 55)	Denial at a Pharmacy (n = 80)
Actions taken by family			
Changed providers	51.0%	26.4%	—
Contacted TennCare or MCO	18.4%	7.5%	26.3%
Waited	12.2%	7.5%	9.2%
Paid out of pocket	8.2%	17.0%	48.7%
New prescription/care	—	—	20.1%
Unable to receive care	12.2%	56.6%	13.2%
Perceived sequelae			
Child made emergency department visit	16.3%	—	4.0%
Required hospital admission	6.1%	—	—
Missed school/child care	12.2%	1.9%	8.0%
Child unable to do regular activities	20.4%	3.8%	14.7%
Condition worsened/not better	12.2%	19.2%	8.0%
Parent stayed home with child	14.3%	1.9%	6.7%
Embarrassment/inconvenience	6.1%	—	1.3%
Pain	2.0%	15.4%	6.7%

MCO indicates managed care organization.

Among the families who experienced each type of denial, those circumstances surrounding denial were reported.

of medication to TennCare enrollees when any prescription is presented, regardless of whether the medicine is listed on the health plan's formulary.⁸ Whether the reported denials of care reflect a misunderstanding of the court decree or a misapplication is not known. Education of physicians, pharmacies, and families about existing policies and procedures may improve access to prescriptions so that physicians stay within formulary whenever possible and pharmacies do not deny children temporary supplies of needed nonformulary medications when the medicine is off formulary.

The observation that children with chronic health conditions experience a higher rate of denial of care is consistent with previous work.⁹ However, the lower reported denial of care among blacks compared with whites and among children of less highly educated caregivers compared with those with more education was unexpected. There are at least 3 potential explanations for the findings. First, families in some sociodemographic groups may seek care less often for their children, resulting in fewer opportunities for denial of care. For example, one study found that black families reported less frequent filling of prescription medications for asthma as a result of cultural beliefs about the need for medications and perceived risks from their use.¹⁰ Second, TennCare offers more comprehensive benefits for low-income families.^{11,12} Because black families and families whose caregivers have less education have been shown to have higher rates of poverty, these families may qualify for TennCare through programs that allow for more generous benefits. Finally, providers may decide that families who are able to pay copays may have the ability to pay total costs out of pocket and thus may be more likely to deny care.

Although a large proportion of children in the study sample had chronic health conditions, this proportion is consistent with studies in other Medicaid populations in which the presence of chronic health conditions has been described for 15% to 32% of

children, depending on the population studied.^{5,13,14} Parents with more education were not more likely to be parents of children with chronic health conditions.

Although most parents did not report negative consequences to their children's health as a result of denial of care, some did. The reported impact of denials, including worsening of the child's health conditions, pain, and the child's not being able to attend school or engage in regular activities, indicate that denial of health care has concrete implications in the daily lives of children and may increase use of other types of services such as emergency departments.

Limitations of this study include the nature of the sampling. Participants were identified in physicians' waiting rooms and thus represent a group to some extent already able to access care. If anything, this limitation should result in an underrepresentation of denial experiences for Tennessee children. However, all children in TennCare are assigned to a primary care provider, and there are no restrictions or special procedures to follow for families to obtain care from their primary care provider in TennCare. Thus, all of the visits for children in the study were equally available to all TennCare children.¹⁵ An additional limitation is the study's reliance on caregiver recall of denied care experiences, which may be subject to recall bias, especially for families who perceived negative sequelae. For minimizing bias, families were told that the study had to do with families' experiences in TennCare. However, we were unable to verify that the family did indeed experience the reported denial. Finally, we were unable to determine whether denied care was for a treatment that would be interpreted as medically necessary by most providers or whether families' expectations were reasonable concerning covered care.

Study strengths include the geographic and practice type representativeness of the sample. Children were identified at 21 pediatric and family medicine sites in all 3 grand regions of the state and repre-

sented a group with similar characteristics to the overall TennCare population. Another strength includes the use of interviews to collect information. Talking with families about their experiences with denied care provided important insight into the perceptions of their experiences that could not be identified through other means, such as secondary analysis of claims data.

TennCare is a Medicaid demonstration program approved under a federal waiver. As MMC programs continue to expand and as models for health care delivery are developed, important lessons can be learned from such demonstration programs. Additional research regarding denials of care in similar systems and the reasons for such denial will be helpful as future models of population-based health insurance coverage are explored.

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