Predictors of Delayed or Forgone Needed Health Care for Families With Children

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KEY WORDS

access to care, child health, health care costs, disparities, insurance coverage

ABBREVIATIONS

FPL—federal poverty level

MEPS—Medical Expenditure Panel Survey

MSA—Metropolitan Statistical Area

OOP—out-of-pocket

USC—usual source of care

Ms Wisk has made substantial contributions to conception and design of the study, acquisition of data, and analysis and interpretation of data; specifically, has formed the research question, compiled and edited the data, conducted all statistical analyses for the article, interpreted the data as part of the article, and has been primarily responsible for drafting the article. Dr Witt has made substantial contributions to the study design, acquisition of data, interpretation of data, and drafting the article; assisted with the study design, conceptualization of variables, interpretation of data, has been responsible for drafting the article, and is ultimately responsible for overseeing the data analysis and manuscript preparation.

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WHAT'S KNOWN ON THIS SUBJECT: The past several decades have seen a dramatic increase in the costs of health care and the prevalence of childhood activity limitations. More families with children are experiencing financial burden related to the cost of health care and insurance.

WHAT THIS STUDY ADDS: We find significant inequities in the occurrence of delayed or forgone needed health care for families with children as a result of high health care–related financial burden and having a child with an activity limitation.

abstract

BACKGROUND: We sought to determine how health care–related financial burden, childhood activity limitations, health insurance, and other access-related factors predict delayed or forgone care for families with children, using a nationally representative, population-based sample.

METHODS: Our sample included families with children aged 0 to 17 years whose family was interviewed about their health care expenditures in 1 of 7 panels of the 2001 to 2008 Medical Expenditure Panel Survey ($N = 14\,138$). Financial burden was defined as (1) the sum of out-of-pocket health service expenditures during the first survey year and (2) that sum divided by adjusted family income. Delayed or forgone care was defined as self-report of delayed or forgone medical care or prescription medications for the reference parent or child during the second survey year.

RESULTS: Financial burden, discordant insurance, and having a child with an activity limitation were some of the strongest predictors of delayed or forgone care. Additionally, significant health insurance and income-related disparities exist in the experience of delayed or forgone care.

CONCLUSIONS: Children and their families are delaying or forgoing needed care due to health care–related financial burden. Policies are needed to effectively reduce financial burden and improve the concordance of insurance between parents and children because this may reduce the frequency of unmet need among families. Moreover, reducing the occurrence of delayed or forgone care may improve health outcomes by increasing the opportunity to receive timely and preventive care. *Pediatrics* 2012;130:1027–1037

Recently, the prevalence of childhood activity limitations and children with special health care needs has risen dramatically.^{1–5} Because children with special health care needs and children with activity limitations have higher health care utilization, health care expenditures, and out-of-pocket (OOP) expenses than children without,^{6–9} there is increased concern about the economic impact on children and their families. Furthermore, the past several decades have also seen dramatic increases in the costs of health care, prompting many insurers to shift the burden to the insured by means of increased cost sharing, such as higher premiums, deductibles, copayments, and reduced benefits.^{10,11} Even government-sponsored insurance programs have attempted to increase cost sharing in an effort to combat rising health care costs,^{12,13} placing unprecedented burden on many US families.

Especially in today's economic climate, an increasing number of families with children are faced with financial burden related to the cost of insurance and OOP health care costs. Families who experience excessive financial burden may attempt to reduce this burden by modifying subsequent utilization patterns,¹⁴ which may in turn affect their health and thus future health care needs.¹⁵ Because families of children with activity limitations and low-income families are particularly susceptible to experiencing burdensome health care costs,^{6–9,16–19} disparities in financially burdensome costs may translate into disparities in access to care and then into disparities in health and well-being. However, the extent to which health care–related financial burden directly influences access to care for families with children is currently unknown. To address this critical gap in the literature, we sought to determine how health care–related financial burden and other need and

enabling factors are related to delayed or forgone care for families with children, using a nationally representative, population-based sample.

METHODS

Data Source and Study Population

Data are from 7 full panels of the 2001–2008 Medical Expenditure Panel Survey (MEPS), which collects information from a nationally representative sample of the civilian noninstitutionalized population in the United States (see also Supplemental Information). Our sample included parent-child dyads (hereafter “families”) with children aged 0 to 17 years whose parents were interviewed about their health care expenditures in 1 of the 7 panels ($N = 14\,138$).

Measures

Predisposing Factors

Predisposing factors include child and parent gender and age, family race/ethnicity, number of children in the household, number of adults in the household, US region of residence and urbanicity (by Metropolitan Statistical Area [MSA] status), and survey year.

Enabling Factors

Child and parent health insurance status was categorized into 4 mutually exclusive categories: private (continuous private insurance over the 2-year study period), public (continuous public insurance over the 2-year study period or 1 year of public insurance and 1 year of private insurance but continuously insured), partial (intermittent coverage, 1 year of public or private insurance and 1 year of no insurance coverage), none. Insurance concordance was categorized as concordant if the reference parent and child had the same type of insurance. The reference parent and child were classified as having a consistent, appropriate usual

source of care (USC) if they reported that they had a USC located in an outpatient clinic or doctor's office during both survey years. USC concordance was categorized as concordant if the reference parent and child had the same type of USC. Family incomes were classified as <100%, 100% to 199%, 200% to 399%, and $\geq 400\%$ of the federal poverty level (FPL). Income change was determined by family incomes that increased or decreased by $>10\%$ from survey year 1 to year 2.

Need Factors

Children were categorized as having (1) no limitations in either year (no limitation), (2) a limitation in year 1 but not year 2 (resolved limitation), or (3) limitations in both years (ongoing limitation). A sensitivity analysis revealed that including children with a limitation in year 2 but not year 1 (new limitation) did not affect the results. However, because it cannot be determined if new limitations are temporary or ongoing, households with these children were not included in the analysis.

Independent Variable: Financial Burden

OOP health care expenditures were self-reported payments made by all members of the entire family for any of the following health care services: inpatient, outpatient, office-based, emergency department, dental, home health, prescription, and other medical expenses. OOP health care expenditures reported for the first MEPS survey year were summed at the family level to determine total health care expenditures, or absolute financial burden.

Relative financial burden was measured as the ratio of total health care expenditures to adjusted household income. Household income in year 1 was adjusted for household composition using the Organization for Economic Cooperation and Development

modified income equivalence scale.²⁰ All measures of income and expenditures were adjusted for inflation based on 2006 US dollars.

Dependent Variable: Delayed or Forgone Care

Respondents reported if either the parent or child was “delayed in getting” or “unable to get” either “medical care, tests, or treatments” or “prescription medications” during the past 12 months and what the main reason was for the delayed or forgone care (hereafter “unmet need”). The reasons for unmet need were collapsed into 2 groups: (1) cost or insurance-related reasons (including couldn’t afford care; insurance company wouldn’t approve, cover, or pay for care; doctor refused to accept family’s insurance plan) and (2) any other reason. To determine a family-level measure of unmet need in the second survey year, a summary measure of these survey questions was created, including 3 mutually exclusive groups: unmet need (1) due to cost or insurance-related reasons, (2) due to any other reasons, and (3) no unmet need.

Analytic Approach

SAS 9.2 (SAS Institute Inc., Cary, NC) was used to construct the analytic files, and Stata 11 (StataCorp LP, College Station, TX) was used to perform all analyses, accounting for the complex design of the MEPS. All results are based on weighted counts. We used χ^2 and Kruskal-Wallis analyses to test for differences in financial burden, and predisposing, enabling, and need factors across the 3 categories of unmet need. Multinomial logistic regression models were used to model the occurrence of any unmet need due to (1) cost or insurance-related reasons or (2) any other reason, compared with no unmet need, adjusting for all predisposing, enabling, and need factors.

Sensitivity Analyses

A series of sensitivity analyses were conducted to: (1) examine how unmet need in year 1 may be affecting the relationship between financial burden in year 1 and unmet need in year 2, and (2) examine how the recession (2007–2008) may have affected the results of our analyses. To perform these analyses we: (1) included unmet need in year 1 as a control variable, and (2) duplicated the analyses with and without families surveyed during the recession (respectively).

RESULTS

Overall, 5.7% and 3.6% of families experienced unmet need due to cost or insurance-related reasons, or any other reason, respectively (Table 1). Families who experience unmet need care due to cost or insurance were more likely to have a child with an activity limitation; a parent or child with public, partial or no insurance; discordant insurance; a parent or child with an inconsistent/inappropriate USC; a female reference parent; older parents and children; income <200% of the FPL; experience a decrease in their income during the survey; be white (non-Hispanic) or of multiple races/ethnicities; smaller families; and be living in the South. Families who experienced unmet need due to other reasons were more likely to have a child with an activity limitation; a parent or child with private insurance; a parent or child with a consistent, appropriate USC; income $\geq$ 400% of the FPL; a female reference parent; be white (non-Hispanic); be a smaller family; and be living in the Midwest or West.

Families who experience unmet need due to cost or insurance had the highest mean relative financial burden of the 3 groups (12.99% vs 9.76% and 8.50%), whereas families who experienced unmet need for any other reason had the highest mean absolute financial

burden (\$1719.21 vs \$1521.49 and \$1470.94; Table 2).

Increased absolute and relative financial burden (Tables 3 and 4, respectively) were associated with increased odds of unmet need due to cost or insurance-related reasons. In both of the models, having a child with an ongoing or resolved limitation, living below 400% of the FPL, and experiencing a decrease in income were also all significantly associated with increased odds of unmet need. Only private insurance for parents reduced the odds of unmet need, compared with uninsured families. Families with public insurance were no less likely to have unmet need compared with their uninsured counterparts; however, those with partial insurance were significantly more likely to delay or forgo care than the uninsured. Concordant insurance for the reference parent and child was significantly associated with decreased odds of unmet need due to cost or insurance, reducing the odds by ~28% in both models.

At the overall mean for absolute financial burden (\$1482.79), the predicted probability of unmet need due to cost or insurance was 0.111 and 0.066 for families of children with and without an activity limitation, respectively (Fig 1A). At the overall mean for relative financial burden (8.81%), the predicted probability of unmet need due to cost or insurance was 0.116 and 0.070 for families of children with and without an activity limitation, respectively (Fig 1B).

Families with any endorsement of unmet need due to cost issues or because a doctor refused to accept the family insurance plan were significantly more likely to have a child with a limitation, lack private insurance, and have lower incomes. Families with any endorsement of unmet need due to insurance denial of coverage were

TABLE 1 Distribution of Predisposing, Enabling, and Need Factors by Occurrence of Delayed or Forgone Care Among US Families

	Total	Delayed or Forgone Care?			P Value
		Yes, Due to Cost or Insurance	Yes, Due to Any Other Reason	No Delayed or Forgone Care	
Unweighted <i>n</i>	14 138	855	456	12 827	
%		6.0	3.2	90.7	
Weighted <i>n</i>	15 909 213	900 379	576 008	14 432 826	
%		5.7	3.6	90.7	
Need factors					
Childhood activity limitation, %					<.0001
Ongoing	7.8	9.8	6.0	84.1	
Resolved	5.2	9.3	5.4	85.3	
None	87.0	5.1	3.3	91.6	
Enabling factors, %					
Child insurance					<.0001
Private	64.6	3.5	4.0	92.5	
Public	26.4	9.2	3.1	87.7	
Partial	4.2	12.5	2.5	85.0	
None	4.8	8.9	2.6	88.5	
Parent insurance					<.0001
Private	70.0	3.7	3.8	92.5	
Public	11.6	7.5	4.3	88.2	
Partial	6.5	14.7	2.6	82.8	
None	11.9	10.6	2.3	87.1	
Insurance concordance					<.0001
Concordant	78.6	4.3	3.9	91.8	
Discordant	21.4	10.7	2.6	86.8	
Child USC					<.0001
Consistent, appropriate	84.9	5.3	3.8	91.0	
Inconsistent, inappropriate	15.1	8.0	2.8	89.2	
Parent USC					.0003
Consistent, appropriate	65.3	5.0	3.9	91.1	
Inconsistent, inappropriate	34.7	6.8	3.1	90.1	
USC Concordance					.0431
Concordant	74.6	5.3	3.8	90.9	
Discordant	25.4	6.6	3.2	90.2	
Family income as % of FPL					<.0001
<100%	14.2	9.5	3.5	87.0	
100–199%	19.4	8.1	3.5	88.5	
200–399%	34.7	5.5	3.2	91.3	
≥400%	31.7	2.6	4.3	93.1	
Change in income					<.0001
Decrease >10%	34.9	7.0	3.3	89.7	
No change	26.6	4.0	4.3	91.7	
Increase >10%	38.5	5.6	3.5	91.0	
Predisposing factors, %					.5104
Child gender					
Male	52.3	5.9	3.7	90.4	
Female	47.7	5.4	3.5	91.1	
Parent gender					<.0001
Male	40.2	4.2	2.9	92.9	
Female	59.8	6.6	4.1	89.3	
Child age, mean (SD)	8.6 (5.1)	9.4 (5.1)	8.6 (4.7)	8.5 (5.1)	<.0001
Parent age, mean (SD)	37.7 (8.6)	37.5 (9.1)	38.2 (7.7)	37.7 (8.6)	.4895
Family race/ethnicity, %					<.0001
White (NH)	59.0	6.0	4.2	89.8	
Black (NH)	12.7	4.3	2.9	92.7	
Hispanic	16.7	5.1	2.3	92.6	
Other (NH)	6.0	3.1	2.9	94.1	
Mixed race/ethnicity	5.6	10.0	3.7	86.3	
Number of adults in household					<.0001
1	12.3	8.7	5.0	86.3	
2	50.8	4.9	3.9	91.3	
≥3	36.9	5.7	2.8	91.4	

TABLE 1 Continued

	Total	Delayed or Forgone Care?			P Value
		Yes, Due to Cost or Insurance	Yes, Due to Any Other Reason	No Delayed or Forgone Care	
Number of children (<18) in household					<.0001
1	15.3	7.1	4.4	88.5	
2	40.6	6.6	3.7	89.7	
≥3	44.1	4.3	3.3	92.4	
MSA					.0871
Urban	83.1	5.4	3.6	90.9	
Rural	16.9	6.8	3.5	89.7	
US region					.0020
Northeast	18.8	4.1	3.3	92.6	
Midwest	22.6	5.3	4.1	90.6	
South	35.4	6.9	3.1	90.0	
West	23.2	5.3	4.3	90.4	

Column percentages are displayed in the total column; row percentages are displayed in the 3 delayed or forgone care columns. Percentages may not sum to 100 due to rounding. Source: 2001–2008 MEPS. Data are weighted percentages unless otherwise indicated. FPL, Federal Poverty Level; MSA, Metropolitan Statistical Area; NH, non-Hispanic; SD, Standard Deviation; USC, Usual Source of Care.

significantly more likely to have a child with a limitation but did not differ by child insurance status (Table 5).

Sensitivity Analyses

Although unmet need in year 1 was a strong predictor of unmet need in year 2, including it in the model did not significantly affect other effect estimates. When families interviewed during the recession (2007–2008) were removed from the analysis, private insurance and a consistent, appropriate USC for children appeared to be protective against unmet need due to cost or insurance (reducing the odds by ~42% and 32%, respectively, in both models); those effects were no longer statistically significant when recession years were included in the analysis.

DISCUSSION

We estimate that nearly 10% of US families did not get needed care over the study period. Our results demonstrate that (1) US families respond strongly to the costs of health care by altering their utilization, (2) there are apparent protective factors that should be seen as policy levers for reducing the occurrence of unmet need, and (3) there are particularly vulnerable subpopulations at high risk of delaying or forgoing care.

We are the first to show that objective absolute and relative family financial burden, independent of health insurance, are significant barriers to needed care for US families with children, confirming what many have alluded to over the past several decades.^{21,22}

These findings are likely a product of the current health care climate, in which health care costs have continued to rise without a similar rise in family incomes, state and federal budgets crises threaten funding for public insurance and other social welfare programs, and health insurance coverage fails to protect many of the insured against substantial financial risk.

Our results show that having private insurance may protect some families against unmet need; however, public insurance appears to confer less protection for families. One explanation as to why publicly insured families are experiencing unmet need may be related to doctors refusing to accept publicly insured patients.^{23–25} Of the families in our sample who

TABLE 2 Distribution of Income and Financial Burden by Occurrence of Delayed or Forgone Care Among US Families

	Total	Delayed or Forgone Care?			P Value
		Yes, Due to Cost or Insurance	Yes, Due to Any Other Reason	No Delayed or Forgone Care	
Income, US\$	32 083.53 [24 564.55]	22 213.16 [17 621.66]	35 715.73 [26 761.99]	32 554.33 [24 660.7]	<.0001
Absolute financial burden, US\$					
Untransformed/ raw burden	1482.79 [2288.36]	1521.49 [2061.10]	1719.21 [2285.71]	1470.94 [2299.59]	.1013
Natural log of burden	6.27 [1.92]	6.47 [1.76]	6.64 [1.54]	6.24 [1.94]	<.0001
Relative financial burden, %					
Untransformed/ raw burden	8.81 [63.04]	12.99 [44.14]	9.76 [37.38]	8.50 [64.83]	.0180
Natural log of burden	1.46 [1.01]	1.82 [1.14]	1.58 [0.95]	1.43 [1.00]	<.0001

Weighted means and their standard errors (in brackets) are presented. Values for income and absolute financial burden are expressed in 2006 US dollars. Values for relative financial burden are expressed as percentages. Natural log transformed values = LN(Untransformed/Raw Burden + 1). Source: 2001–2008 MEPS.

TABLE 3 Multinomial Logistic Regression Modeling the Odds of Delayed or Forgone Care, by Reason, Predicted by Absolute Financial Burden

	Delayed or Forgone Care Due to Cost or Insurance		Delayed or Forgone Care Due to Any Other Reason	
	OR	95% CI	OR	95% CI
Financial burden				
Absolute burden ^a	1.34	1.13–1.58	1.14	0.92–1.40
Absolute burden squared ^a	0.99	0.97–1.00	1.00	0.98–1.02
Need factors				
Childhood activity limitation				
Ongoing	1.81	1.37–2.39	1.97	1.44–2.70
Resolved	1.61	1.16–2.25	1.69	1.13–2.54
None	1.00	Reference	1.00	Reference
Enabling factors				
Child insurance				
Private	0.77	0.53–1.14	1.31	0.60–2.85
Public	0.97	0.67–1.40	0.90	0.43–1.87
Partial	1.24	0.81–1.90	0.97	0.37–2.53
None	1.00	Reference	1.00	Reference
Parent insurance				
Private	0.56	0.41–0.75	0.94	0.55–1.59
Public	0.77	0.54–1.11	1.63	0.86–3.08
Partial	1.33	0.99–1.80	1.06	0.57–1.94
None	1.00	Reference	1.00	Reference
Insurance concordance				
Concordant	0.73	0.54–0.97	0.98	0.64–1.48
Discordant	1.00	Reference	1.00	Reference
Child USC				
Consistent, appropriate	0.86	0.68–1.09	1.16	0.73–1.83
Inconsistent/inappropriate	1.00	Reference	1.00	Reference
Parent USC				
Consistent, appropriate	0.99	0.77–1.27	0.92	0.60–1.41
Inconsistent/inappropriate	1.00	Reference	1.00	Reference
USC concordance				
Concordant	0.92	0.70–1.19	1.10	0.72–1.68
Discordant	1.00	Reference	1.00	Reference
Family income as % of FPL				
<100%	3.37	2.16–5.26	1.16	0.71–1.89
100%–199%	2.71	1.85–3.96	1.17	0.79–1.73
200%–399%	2.05	1.52–2.77	0.86	0.64–1.16
≥400%	1.00	Reference	1.00	Reference
Change in income				
Decrease >10%	1.50	1.18–1.90	0.80	0.61–1.04
No change	1.00	Reference	1.00	Reference
Increase >10%	1.05	0.82–1.34	0.83	0.63–1.09

The weighted regression model is also adjusting for child gender; parent gender; child age; parent age; family race/ethnicity; number of adults in the household; number of children (aged <18) in the household; Metropolitan Statistical Area; US region; and survey year. Source: 2001–2008 MEPS. CI, confidence interval; FPL, Federal Poverty Level; OR, odds ratio; USC, Usual Source of Care.

^a Absolute burden was natural log transformed: Natural log transformed absolute burden = LN(Raw absolute burden + 1).

experienced unmet need due to a doctor refusing to accept the family's insurance plan, 88.5% had a publicly insured parent or child (81.8% had a publicly insured child and 61.0% had a publicly insured parent). In fact, Medicaid often provides more comprehensive insurance than private insurance and through the Early and Periodic Screening, Diagnostic and

Treatment benefit, Medicaid is required to provide all needed services to enrolled children aged <21 years.^{26,27} This underscores our findings that privately insured families were significantly more likely than publicly insured families to report unmet need because their insurance would not pay for or cover their care.

Interestingly, families with partial insurance were even more likely to delay or forgo care due to cost or insurance than the uninsured. Underinsurance is an increasing problem in the United States²⁸ and research has shown that children who were underinsured or experienced periods of no insurance were more likely to experience unmet need and to receive lower-quality care compared with those who were continuously and adequately insured.^{29,30}

Despite the detrimental effects of lapses in insurance coverage, we found that insurance may confer additional protection when families have concordant insurance coverage. There is some evidence to suggest that differences in family health insurance patterns leads to poorer access to preventive care and greater unmet need for children³¹; in addition, parent's health care utilization has been shown to be a strong predictor of children's health care use.³² Parents in families with concordant insurance may have better access to health care, facilitating better management of children's health and appropriate utilization of health care services for the entire family.

The protective effect of concordant insurance has important implications for future state and federal policy decisions regarding the eligibility criteria and expansion of coverage because providing increased access only for children may not be sufficient to improve access to needed health care or to reduce burden on the family. Public programs that cover parents and children may lead to more stable coverage for children,^{33–36} and evidence suggests that State Children's Health Insurance Program expansion in coverage reduced the likelihood that a parent will report forgoing needed medical care due to cost and an increased utilization of preventative care,^{37–39} which may in turn lead to positive health outcomes

TABLE 4 Multinomial Logistic Regression Modeling the Odds of Delayed or Forgone Care, by Reason, Predicted by Relative Financial Burden

	Delayed or Forgone Care Due to Cost or Insurance		Delayed or Forgone Care Due to Any Other Reason	
	OR	95% CI	OR	95% CI
Financial burden				
Relative burden ^a	1.85	1.48–2.31	1.39	1.01–1.92
Relative burden squared ^a	0.92	0.87–0.96	0.96	0.89–1.04
Need factors				
Childhood activity limitation				
Ongoing	1.81	1.38–2.38	2.00	1.46–2.74
Resolved	1.61	1.16–2.22	1.71	1.14–2.56
None	1.00	Reference	1.00	Reference
Enabling factors				
Child insurance				
Private	0.79	0.54–1.16	1.31	0.60–2.85
Public	0.95	0.66–1.37	0.86	0.41–1.80
Partial	1.23	0.80–1.88	0.95	0.36–2.50
None	1.00	Reference	1.00	Reference
Parent insurance				
Private	0.57	0.42–0.77	0.96	0.57–1.63
Public	0.77	0.54–1.12	1.64	0.86–3.11
Partial	1.36	1.00–1.83	1.08	0.59–1.98
None	1.00	Reference	1.00	Reference
Insurance concordance				
Concordant	0.72	0.54–0.96	0.96	0.64–1.46
Discordant	1.00	Reference	1.00	Reference
Child USC				
Consistent, appropriate	0.86	0.68–1.08	1.17	0.74–1.86
Inconsistent/inappropriate	1.00	Reference	1.00	Reference
Parent USC				
Consistent, appropriate	0.99	0.78–1.27	0.92	0.60–1.42
Inconsistent/inappropriate	1.00	Reference	1.00	Reference
USC concordance				
Concordant	0.91	0.70–1.19	1.09	0.72–1.67
Discordant	1.00	Reference	1.00	Reference
Family income as % of FPL				
<100%	2.47	1.53–3.97	0.89	0.51–1.55
100%–199%	2.20	1.49–3.24	0.99	0.65–1.49
200%–399%	1.81	1.34–2.45	0.78	0.58–1.07
≥400%	1.00	Reference	1.00	Reference
Change in income				
Decrease >10%	1.52	1.20–1.94	0.81	0.62–1.06
No change	1.00	Reference	1.00	Reference
Increase >10%	1.03	0.81–1.32	0.82	0.63–1.08

The weighted regression model is also adjusting for: child gender, parent gender, child age, parent age, family race/ethnicity, number of adults in the household, number of children (aged <18) in the household, Metropolitan Statistical Area, US region, and survey year. Source: 2001–2008 MEPS. CI, confidence interval; FPL, Federal Poverty Level; OR, odds ratio; USC, Usual Source of Care.

^a Relative burden was natural log transformed: Natural log transformed relative burden = LN(Raw relative burden + 1)

for both the parent and their family. However, it is important to note that the recession (2007–2008) appears to have diminished and eliminated altogether the protective effects of concordant insurance and having a USC, respectively. As such, future policies should seriously consider how the economic climate affects families and their health care decisions.

Families of children with activity limitations were more likely to delay or forgo care. As Fig 1 displays, these families' response to the cost of health care is noticeably more dramatic, with an increased probability of unmet need at just \$0.42 for families of children with ongoing limitations, compared with \$11.72 for families of children without limitations, underscoring that

the families in need of care are the most vulnerable to going without care. Previous work has demonstrated that families of children with activity limitations have higher absolute and relative family-level financial burden, primarily due to spillover.⁹ This large disparity may reflect families who, because of the threat of high expenditures, consistently delay or forgo care in an effort to contain health care costs. Although there are several suggested mechanisms through which family spillover may occur, our results suggest that the rationing of care in response to high financial burden may be a plausible explanation as to why these families have worse health and well-being for all family members.

In addition to disparities by childhood activity limitations, we also discovered significant income-related disparities in unmet need. Persistent income disparities may be indicative of deficiencies in current support systems that seek to address the needs of families with children. Although public insurance, income transfer, and early intervention programs are in place, families still have substantial OOP expenditures for health care.^{9,19} Low-income populations are particularly responsive to OOP costs,¹⁸ and cost sharing among this group does not necessarily generate cost savings for public insurance programs.¹⁸ Additionally, children in middle-income families are more likely to experience periods of uninsurance,¹⁷ and these families may be more susceptible to being underinsured because their incomes may be too high to qualify for public assistance but too low to protect against high relative burden. Families who experienced decreases in their income were also more likely to delay or forgo health care, indicating that changes to income may result in subsequent rationing of health care. It is clear from

FIGURE 1

Predicted probability of delayed or forgone care by financial burden and activity limitation status: the relationship between financial burden and the predicted probability of delayed or forgone care due to cost or insurance-related reasons. The models in Tables 3 and 4 were used to calculate the average predicted probability of experiencing delayed or forgone care due to cost or insurance-related reasons (y-axis) as a function of financial burden (x-axis) while controlling for all other covariates included in the final models. A, This relationship with absolute financial burden. B, This relationship with relative financial burden. In both panels, the solid top line (black) represents the predicted probabilities for families of a child with an ongoing activity limitation, the dashed middle line (black) represents the predicted probabilities for families of a child with a resolved activity limitation and the solid bottom line (gray) represents the predicted probabilities for families of children without any activity limitations. The vertical dotted line corresponds to the mean value of financial burden. The 95th percentile of the financial burden measure was used as the x-axis maximum in both panels. The table included to the right of each graph displays the values of financial burden for families of children with and without activity limitations that correspond to the predicted probability of delayed or forgone care due to cost or insurance, by increments of 0.01. Source: 2001–2008 MEPS.

TABLE 5 Distribution of Select Need and Enabling Factors by Reason for Delayed or Forgone Care Among US Families

	Total	Any Delayed or Forgone Care?									
		Yes, Due to Cost or Insurance					Yes, Due to Any Other Reason				
		Could Not Afford Care	Insurance Company Would Not Cover/Pay	Doctor Refused Family Insurance	Problems Getting to Doctor	Could Not Get Time Off Work	Don't Know Where To Go	Was Refused Services	Did Not Have Time/Took Too Long	Other	
Unweighted <i>n</i>	14 138	673	179	22	38	14	18	43	68	345	
%		4.8	1.3	0.2	0.3	0.1	0.1	0.3	0.5	2.4	
Weighted <i>n</i>	15 909 213	676 920	225 527	19 194	43 401	17 992	20 343	46 611	87 668	428 712	
%		4.3	1.4	0.1	0.3	0.1	0.1	0.3	0.6	2.7	
Need factors, %											
Childhood activity limitation		****	****	**	****	NS	**	NS	NS	****	
Ongoing	7.8	12.7	15.4	25.1	28.9	16.8	21.3	10.9	8.6	14.0	
Resolved	5.2	7.5	13.8	7.0	15.2	0.0	0.0	9.8	9.6	6.6	
None	87.0	79.8	70.8	68.0	55.9	83.2	78.7	79.3	81.9	79.4	
Select enabling factors, %											
Child insurance		****	NS	****	***	NS	NS	****	NS	NS	
Private	64.6	33.2	64.2	18.2	55.3	72.2	54.9	34.0	72.3	71.5	
Public	26.4	46.1	29.3	81.8	28.8	24.4	37.2	53.0	24.1	22.3	
Partial	4.2	11.1	5.2	0.0	15.9	0.0	6.5	0.0	3.6	3.0	
None	4.8	9.6	1.4	0.0	0.0	3.4	1.3	13.0	0.0	3.2	
Parent insurance		****	*	****	*	NS	NS	**	*	NS	
Private	70.0	37.2	72.9	25.5	66.7	80.6	54.9	37.0	70.0	75.1	
Public	11.6	14.4	16.2	61.0	23.8	3.1	25.1	28.2	19.5	11.1	
Partial	6.5	20.5	5.6	11.1	9.4	0.0	13.9	10.6	7.4	5.4	
None	11.9	27.9	5.3	2.4	0.0	16.3	6.0	24.2	3.2	8.5	
Family income as % of FPL		****	NS	****	NS	NS	NS	***	NS	**	
<100%	14.2	26.5	13.7	59.9	22.7	7.4	23.8	34.6	15.4	11.3	
100%–199%	19.4	31.3	17.2	15.4	20.2	27.3	30.9	18.4	14.9	17.5	
200%–399%	34.7	33.0	39.2	13.5	38.9	33.2	28.7	35.1	29.4	31.7	
≥400%	31.7	9.2	29.9	11.2	18.2	32.1	16.6	11.9	40.4	39.5	

Weighted column percentages are displayed. Percentages may not sum to 100 due to rounding. These groups are NOT mutually exclusive. They include any endorsement of each reason for any of the 4 original questions by either the reference parent or the reference child. Source: 2001–2008 MEPS. NS, not statistically significant, $P \geq 0.1$.

* $P < .1$.

** $P < .05$.

*** $P < .01$.

**** $P < .001$.

***** $P < .0001$.

prior studies and our findings that additional assistance is needed across the income spectrum to alleviate extreme financial losses and burden, thus reducing the occurrence of unmet need.

There are clear short- and long-term implications when families are faced with unmet need. In the short-term, families who ration their health care may be more likely to use health care inappropriately, such as seeking preventive care in the emergency department,¹⁸ or may be more likely to develop symptoms or conditions which deteriorate and result in illnesses that are often more expensive to treat.^{40–42} Long-term individual and societal costs of unmet need may include adverse health outcomes, loss of time at school or work, and avoidable long-term expenditures.^{43,44}

Data on childhood limitation status, OOP expenditures, and unmet need are based solely on household reports.

However, the MEPS verifies reported expenditures with medical provider records, limiting this concern. This study examined children's activity limitations, as opposed to diagnosed health conditions. Using a non-categorical measure of child activity limitation likely reduces the impact of confounders associated with obtaining a medical diagnosis, such as socioeconomic status, race/ethnicity, and health insurance status. Additionally, we used gross annual family-level income before adjustment, as opposed to net annual income, which may not be an accurate reflection of the liquid income available to these families. However, the use of gross income should result in conservative estimates for the effect of financial burden. In utilizing outcome data from the parent-child dyad, rather than the entire family, we are likely underestimating the overall prevalence of unmet need among families with children, and this

underestimation may contribute to conservative estimates of various effects. Finally, our USC concordance measure only reflects whether the dyad shared the same type of place and does not capture whether the actual place of care is concordant.

CONCLUSIONS

Children and their families are delaying or forgoing needed care because of health care–related financial burden. As a first step, policymakers should look to limit patient cost sharing and provide comprehensive, continuous coverage to families as a unit to prevent unmet need, keeping in mind those families who are most vulnerable to experiencing unmet need. Understanding these barriers to needed care is critical for designing effective interventions, reducing inequities, and ultimately improving the long-term health of US families with children.

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