Access to Health Care for Young Adults With Disabling Chronic Conditions

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Objective: To assess health insurance status and health care access of young adults with disabilities attributable to a chronic condition.

Design and Setting: We analyzed data from the National Health Interview Survey from 1999 to 2002. We present bivariate analysis and multiple logistic regression of reported health care access barriers in the United States stratified by health insurance status.

Participants: The study population included 1109 survey respondents with and 22,481 without disabling chronic conditions, aged 19 to 29 years.

Main Outcome Measures: Delayed or unmet health needs owing to cost, no contact with a health professional in the prior year, and no usual source of care.

Results: Thirty-five percent of respondents with and 15% without disabling chronic conditions reported an unmet health care need owing to cost (P<.001). Uninsurance rates for young adults with and without disabling chronic conditions were similar (26% vs 28%, respectively), and uninsurance was significantly associated with unmet health care needs. More than two thirds of uninsured respondents with a disabling chronic condition reported an unmet health need and 45% reported no usual source of care. After adjusting for sociodemographic factors, uninsured young adults with disabling chronic conditions had 8 times greater odds of reporting unmet health care needs and 6 times greater odds of having no usual source of care relative to insured respondents with disabling chronic conditions.

Conclusions: Despite increasing attention to issues of health care transition for young adults with disabling chronic conditions, this study suggests that uninsurance is as common among these young adults as non-disabled peers and is significantly associated with health care access barriers in this population.


METHODS

DATA SOURCE

We analyzed responses from young adults aged 19 to 29 years who were participating in the National Health Interview Survey (NHIS) from 1999 to 2002. The NHIS is an ongoing, cross-sectional, national household survey sponsored by the National Center for Health Statistics. The purpose of the survey is to collect information about the health and health service use of the civilian noninstitutionalized population in the United States. The sampling plan
uses a multistage area probability design to yield nationally representative estimates.

The NHIS consists of a group of surveys designed to collect data on households and individuals. Data for the respondents in this study were drawn from the Person-Level file (containing sociodemographic and basic health information for each member of a household collected directly from individuals or from other adult members if the individual is unable to answer) and the Sample Adult file (containing additional health-related data obtained from 1 randomly selected adult in each household). Information in the Sample Adult file is based on self-report unless the respondent is incapable of providing the information. We calculated a response rate of 72.4% for all adults selected for the Sample Adult questionnaire during the 4 years studied.14

**DEFINITION OF DISABLING CHRONIC CONDITION**

Young adults with disabling chronic conditions were identified by questions asking if physical, mental, or emotional problems resulted in limitation or inability to work, difficulty walking without special equipment, or limitations in activities of daily living (bathing, dressing, getting in/out of bed or a chair, using the toilet, eating, or getting around the home), instrumental activities of daily living (household chores, doing necessary business, shopping, or getting around), or any other activity. Chronic conditions were those that are not cured once acquired or that have been present for at least 3 months. Conditions related to pregnancy were not considered chronic. Young adults without disability reported none of the activity limitations. These young adults may or may not have chronic conditions. We excluded 86 participants whose limitations could not be attributed to a chronic condition.

**DESCRIPTION OF VARIABLES**

**Health Care Access Variables**

The dependent variables were responses to questions about unmet health needs, health professional contact, and usual source of health care. Participants were asked if they delayed or missed needed medical care or failed to fill a prescription in the last year because of cost. They were also asked when they last talked with a health professional about their health and if there was a place necessary to meet health needs, health professional contact, and usual source of care other than the emergency department.

**Health Insurance Coverage and Sociodemographic Characteristics**

We used survey data to identify health insurance coverage at the time of the interview. The uninsured had no coverage through private health insurance, Medicare, Medicaid, State Children’s Health Insurance Plan, or other public programs. Young adults with unknown coverage status (n = 159) were excluded from analyses. We used NHIS-recolored variations of survey items to ascertain participants’ educational attainment, marital status, household income, and major activity in the week prior to the survey. Household income was provided as a ratio of income to the US Census Bureau’s poverty threshold for the survey year after considering overall family size.31 The 20% of young adults in the study who did not provide household income data were excluded from multivariate analyses.

**STATISTICAL ANALYSES**

Sociodemographic and insurance characteristics for 1101 young adults with and 22,481 without disabling chronic conditions are presented in Table 1. Bivariate analyses show the relationship between unmet health care needs and insurance status for young adults with and without disabling chronic conditions (Table 2). We used statistical weights provided by the NHIS to present population estimates, percentages, and standard errors reflecting United States population totals in the text and tables. Multivariate analyses are presented to estimate the odds of reporting unmet health care needs for the 885 young adults with and 17,903 without disabling chronic conditions who provided complete information, stratified by insurance status and adjusting for the sociodemographic variables (Table 3). To account for the complex sampling design employed in the NHIS, final analyses were conducted using SUDAAN statistical software (Research Triangle Institute, Research Triangle Park, NC).14 The study protocol was approved.
RESULTS

DISABLING CHRONIC CONDITIONS AND UNINSURANCE

Among young adults participating in the NHIS from 1999 to 2002, 4.7% had a disabling chronic condition. Of this group, 64% reported a work limitation or inability to work. The chronic conditions most frequently leading to disability included musculoskeletal problems (33%), emotional problems including depression and anxiety (18%), and lung problems including asthma (12%).

Compared with peers without disability, young adults with disabling chronic conditions were poorer, reported lower educational attainment, and were less likely to be working (Table 1). Uninsurance rates were not significantly different for young adults with and without disabling chronic conditions (26% and 28%, respectively); however, young adults with disabling chronic conditions were more likely to have Medicaid and less likely to be privately insured.

UNMET HEALTH CARE NEEDS/HEALTH CARE ACCESS

Uninsured young adults with disabling chronic conditions were 4 times more likely than insured young adults with disability to report unmet health care needs and no usual source of health care, and 2 times more likely to have no health professional contact in the last year (Table 2). Over two thirds of young adults with disabling chronic conditions either delayed or missed needed care owing to the high cost and 45% identified no usual source of care.

After controlling for sociodemographic characteristics, uninsured young adults with disabling chronic conditions had 8 times higher odds of delaying or missing needed care owing to cost and 6 times the odds of having no usual source of health care relative to insured peers. The odds of delaying or failing to get medical care owing to cost were more than 20-fold greater for uninsured young adults with disabling chronic conditions than for insured young adults without disability.

COMMENT

In this study, we demonstrated that uninsured is common among young adults with disabling chronic conditions and that it is significantly associated with barriers to health care access. Five percent of young adults reported that they had a disabling chronic condition, corresponding to an estimated 2 million young adults nationally. The estimates from this study are similar to those

Table 2. Unmet Health Care Needs of Young Adults With and Without Limitations by Insurance Status*

<table>
<thead>
<tr>
<th>Disability /Insurance Status</th>
<th>Unmet Health Care Needs</th>
<th>AOR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Delayed Medical Care Owing to Cost</td>
<td>Did Not Get Medical Care Owing to Cost</td>
</tr>
<tr>
<td>Disabled/uninsured</td>
<td>8.40 (5.59-12.63)</td>
<td>7.92 (5.17-12.14)</td>
</tr>
<tr>
<td>Disabled/insured</td>
<td>[1.58 (1.22-2.05)]</td>
<td>1.92 (1.46-2.51)</td>
</tr>
<tr>
<td>No disability/uninsured</td>
<td>0.32 (0.24-0.42)</td>
<td>0.28 (0.21-0.39)</td>
</tr>
<tr>
<td>No disability/insured</td>
<td>[1.58 (1.22-2.05)]</td>
<td>1.92 (1.46-2.51)</td>
</tr>
</tbody>
</table>

Abbreviations: AOR, adjusted odds ratio; CI, confidence interval.
*Also adjusted for sex, race/ethnicity, age (19-24 years or 25-29 years), marital status, major activity in the prior week, household income, and educational attainment. Data Source: National Center for Health Statistics, National Health Interview Survey 1999 to 2002.
†Reference.

*Percentages are based on weighted data to represent the civilian noninstitutionalized population in the United States. Data Source: National Center for Health Statistics, National Health Interview Survey 1999 to 2002.
by the US Census Bureau (5.3% of 15- to 24-year-olds). 17
In studies of children and adults, individuals with disab-
ling chronic conditions have been shown to have higher
health care use than healthy peers or those with chronic
conditions or disability alone. 18,19

Given their presumed greater need for health care ser-
vices, it is troubling that 1 of every 4 young adults with
a disabling chronic condition reported being uninsured.
This proportion was essentially the same as that of
young adults without disability. We would anticipate
that young adults with disabling chronic conditions
would have greater incentive to maintain health insurance
coverage than peers without disability, however, the find-
ings of this study suggest several reasons that these young
adults may have particular difficulty doing so. Young
adults with disabilities were significantly worse off than
peers without disability in terms of poverty, educational
attainment, and employment—all socioeconomic char-
acteristics associated with uninsurance and poor health
care access.2,3,20-26 Most young adults obtain private
insurance through employment-based coverage or depend-
tent coverage as a full-time student. Only 54% of
young adults with disabling chronic conditions were
attending school or working, which may explain why
only 40% of these young adults hold private health
insurance coverage.

Medicaid and other public insurance programs play
an important role in covering children with disabling
chronic conditions, however, these public programs are
frequently much more limited in size and scope for adults.
For example, more stringent adult requirements mean
that about one third of older adolescents who qualify for
Supplemental Security Income as children will lose these
benefits during a redetermination process at age 19.27
Adult applicants for Supplemental Security Income must
demonstrate an inability to work and have a monthly in-
come of no more than $700.28 Because many young adults
with disabling chronic conditions are able to work (in-
cluding 45% of the young adults in this study), meeting
the requirements for Supplemental Security Income ben-
efits as an adult may be particularly difficult.29 State Chil-
dren's Health Insurance Plan may provide coverage for
some young adults with disabling chronic conditions,
however, increasing budget deficits and resultant cut-
backs by some states may further limit the availability of
this coverage.30

Uninsurance was associated with health care access
barriers for all young adults, but particularly for those
with disabling chronic conditions. Uninsured young
adults with disabling chronic conditions had 8 times
greater adjusted odds of reporting unmet health care
needs and 6 times greater odds of having no usual
source of care relative to insured respondents with
disabling chronic conditions. In this population, delayed
or forgone care may represent missed opportunities to
improve functioning, provide preventive services, or
delay disease progression. Nearly half of uninsured
young adults with disabling chronic conditions did not
identify a usual source of health care. Beyond being a nec-
 essary component for transitioning young adults to de-
velopmentally appropriate care, lacking a usual source of
care has been associated with poorer access to pre-
ventive services, longer hospitalizations, and increased
use of emergency departments.31-33

The findings of this study should be considered in light
of several limitations. These analyses rely on self-report
and may be subject to recall or response error. Because the data
are derived from a cross-sectional survey, we are limited
in our ability to conclude that uninsurance resulted in the
reported unmet health care needs. Finally, we would have
preferred to analyze differences in unmet health care needs
among those with different types of health insurance cov-
erage (Medicaid, private, etc), but had insufficient sample
size to support this level of analyses.

CONCLUSION

Five percent of young adults in this study had a disa-
bilitating chronic condition. Despite increasing attention to
issues of health care transition for young adults with disa-
bilitating chronic conditions, the results of this study sug-
gest that uninsurance is as common for young adults with
disabling chronic conditions as for those without disa-
ability. Moreover, the uninsured disproportionately ex-
perience health care access barriers. Improving health in-
surance coverage options and ensuring continuity of
coverage during young adulthood may improve health care
access in this population. Additional research is
needed to identify barriers to maintaining health insur-
ce coverage and the financial and health effects of bar-
riers to health care for young adults with disabling chronic
conditions.

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Announcement

Submissions. The Editors welcome contributions to Picture of the Month. Submissions should describe common problems presenting uncommonly, rather than total zebras. Cases should be of interest to practicing pediatricians, highlighting problems that they are likely to at least occasionally encounter in the office or hospital setting. High-quality clinical images (in either 35-mm slide or electronic format) along with parent or patient permission to use these images must accompany the submission. The entire discussion should comprise no more than 750 words. Articles and photographs accepted for publication will bear the contributor’s name. There is no charge for reproduction and printing of color illustrations. For details regarding electronic submission, please see: http://archpedi.ama-assn.org.