Absence of Health Insurance Is Associated with Decreased Life Expectancy in Patients with Cystic Fibrosis

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Life expectancy for individuals with cystic fibrosis (CF) has increased dramatically in the last 30 yr, but it is unclear whether the improved survival has applied equally to individuals with different health insurance status. We developed a retrospective inception cohort of all 189 patients with CF born 1/1/55 to 12/31/70 who had at least one hospitalization at a university referral center. The median survival for patients with CF who were without health insurance was 6.1 yr compared with 20.5 yr for those with Medicaid and 20.5 yr for those with private insurance. Using multivariate Cox regression, health insurance and increased socioeconomic status were independently associated with longer survival. The adjusted relative risk of death was greater for the absence of health insurance than for factors previously shown to predict mortality in individuals with CF (female sex and presentation with meconium ileus). In summary, the absence of health insurance was associated with increased mortality rate in children with CF and was a stronger predictor of mortality than variables previously shown to be associated with mortality for CF. If increasing numbers of children with CF lose health insurance coverage, our results suggest that their life expectancy will decrease dramatically. Curtis JR, Burke W, Kassner AW, Aitken ML. Absence of health insurance is associated with decreased life expectancy in patients with cystic fibrosis. AM J RESPIR CRIT CARE MED 1997;155:1921–1924.

Cystic fibrosis (CF) is one of the most common genetic diseases, occurring in approximately 1 in 2500 births, and causes progressive loss of lung function and premature death. The life expectancy of individuals with CF has increased steadily from 1960, when the median survival was 2 yr, to 1994, when the median survival was 28 yr (1). Much of this improvement is attributed to (*1*) the establishment of specialized CF centers staffed by multidisciplinary teams, (*2*) improved antibiotic therapy with increased activity against the multidrug-resistant organisms which commonly colonize and infect persons with CF, and (*3*) improved nutritional support (2–4). However, with these therapeutic advances and the increased median survival, there has been an increase in the interpatient variability for survival (1). It is not clear whether the marked improvements in health and survival of the past three decades have applied equally to children with and without health insurance or to children from lower as well as upper income families. We speculated that the increased median survival of individuals with CF depends in large part on adequate access to health care and, therefore, that those without health insurance would have decreased survival time independent of socioeconomic status (SES). The hypothesis of this study is that absence of health insurance is associated with decreased survival time even after controlling for SES.

Factors associated with decreased survival time for individuals with CF include specific gene mutations (5–7), female sex (8, 9), exocrine pancreatic insufficiency (10, 11), early colonization with *Pseudomonas aeruginosa*, *Pseudomonas cepacia*, and *Staphylococcus aureus* (12), presentation with meconium ileus or respiratory disease (8, 9), and decreased functional status (13). In a British study, decreased social class was associated with decreased survival from CF (14). Decreased SES has been shown to increase morbidity and mortality in a number of other diseases including cardiovascular disease (15–17), cancer (18, 19), and respiratory diseases (20). The absence of health insurance has been shown to convey increased mortality in the general population (21) as well as in patients with breast cancer (22), even after controlling for SES. There is increased mortality from AIDS-related *Pneumocystis carinii* pneumonia among patients without health insurance (23) and this increase in mortality seems to be due to decreased access to expensive diagnostic procedures (24). The role of health insurance status in survival with CF has not been previously reported.

METHODS

Subjects and Data Collection

All individuals with CF who were born between January 1, 1955 and December 31, 1970 and had at least one hospitalization at the Children's Hospital and Medical Center were identified by ICD-9 discharge diagnosis code. The Children's Hospital and Medical Center

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houses the CF Foundation–sponsored CF Center for a four-state region (Washington, Alaska, Montana, and Idaho), accepting referrals independent of ability to pay. The diagnosis of CF was based on a sweat chloride test of 60 mEq or greater and clinical features consistent with CF (recurrent pulmonary infections and/or pancreatic insufficiency documented in the medical record). We identified 190 patients with a hospital discharge diagnosis of CF, clinical features consistent with CF, and a documented positive sweat chloride test. One patient was excluded because of an additional severe genetic disease.

Each subject's inpatient and outpatient medical records were abstracted with a standardized data collection form. Parental occupation was recorded from the registration records in the medical chart and scored according to a 1980 revision of the Socioeconomic Index (25). If occupations were recorded for both parents, the highest of the two scores was used. Health insurance information for the entire observation period was obtained from the registration records, and subjects were assigned to one of three groups: no insurance, Medicaid, or private insurance. If subjects' insurance status changed during the observation period, they were assigned to the category to which they belonged for the longest period. There were 28 individuals with a change in insurance status, and exclusion of these individuals did not change the results (data not shown).

Statistical Analysis

The outcome of interest was survival time from birth. The predictor variables were sex, presentation with meconium ileus (yes or no), parental socioeconomic index (continuous variable ranging from 0 to 100) (25), and health insurance (using the three categories described above with private insurance as the reference category). Age at diagnosis of CF was an additional predictor used to examine the impact of time to diagnosis on survival. Comparisons of survival for different strata of the predictor variables were plotted using Kaplan–Meier estimates (26). A cox proportional-hazards model was constructed to determine independent predictors of survival using time-fixed covariates (27). Our goal was to examine the association between health insurance and survival while controlling for SES and the clinical variables previously shown to predict survival. Consequently, sex, presentation with meonium ileus, and SES were forced into the Cox proportional-hazards model before health insurance was entered. The assumption of a constant risk ratio over time was tested and found to be valid for the variables modeled. To exclude the possibility of a cohort effect, year of birth was entered as a predictor variable alternatively as a continuous variable and a dichotomous variable for birth year pre- and post-1960.

RESULTS

One hundred eighty-nine patients with a discharge diagnosis of CF were born between January 1, 1955 and December 31, 1970. Follow-up was complete through December 1991, with 2251 person-years of observation and a median follow-up of 10.4 yr. Fifty-one percent of the subjects were female. The median age at diagnosis was 0.5 yr (mean, 1.8 yr). The median survival for all subjects was 17 yr. The majority of subjects had private insurance (65%), 10% had Medicaid, and 25% had no insurance for the majority of their observation period. There was no difference in median follow-up in the three health insurance groups.

During the study period, 94 of the 189 patients died (50%). Kaplan–Meier survival estimates, stratified for health insurance status, are shown in Figure 1. The median survival for individuals without insurance was 6.1 yr compared with 20.5 yr for those with private insurance and those with Medicaid. The unadjusted relative risk of death for those without insurance compared with those with private insurance was 2.4 (95% confidence intervals [CI]: 1.6, 3.8).

The results of the Cox proportional-hazards analysis of factors associated with mortality among all 189 patients are shown in Table 1. Absence of insurance was associated with an increased risk of mortality compared with private insurance (relative risk, 2.1; 95% CI: 1.3, 3.4; $p < 0.005$) even after controlling for the other variables in the model, including Socioeconomic Index. There was no difference in mortality for those with Medicaid compared with those with private insurance (relative risk, 1.0; 95% CI: 0.4, 2.1). Increasing Socioeconomic Index was associated with decreasing mortality rate. We found a trend toward increased risk of death for female patients and those presenting with meconium ileus, although the association did not achieve statistical significance.

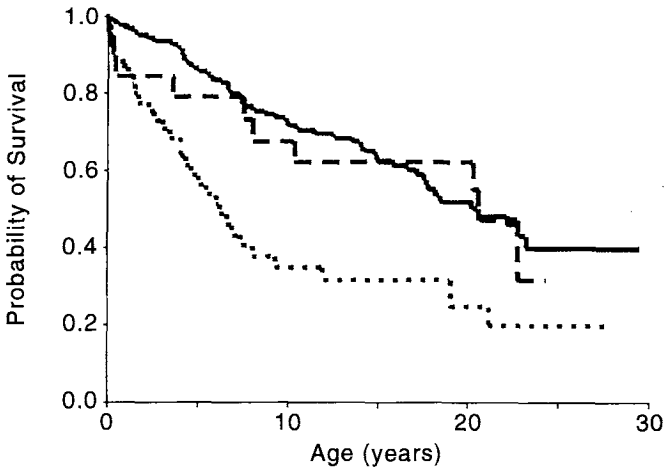

Figure 1. Kaplan-Meier estimates of survival time for patients with CF according to insurance status. *Solid line* represents private insurance, *dashed line* represents Medicaid, and *dotted line* represents no insurance.

Age at diagnosis was added to the Cox regression model to control, in part, for severity of illness at presentation. There was a trend toward decreased survival for younger age at diagnosis, although the association was not statistically significant (relative risk, 0.92/yr; CI: 0.84, 1.0; $p = 0.07$). Addition of age at diagnosis did not change the association between survival and either health insurance or SES (data not shown). In addition, we controlled for year of birth to exclude the possibility that the association between insurance and survival occurred because children without insurance were more likely to be born earlier in the study period (cohort effect). The association between insurance status and survival time did not change after controlling for birth year.

DISCUSSION

We have shown the absence of health insurance and decreased SES are independently associated with increased mortality rate in patients with CF. The magnitude of increased risk of mortality was larger for the absence of health insurance than it was for the previously demonstrated risk factors that we examined, and we found no difference between mortality rates for those with private insurance and those with Medicaid. Previous research has shown that the absence of health insurance decreases access to health care among children with chronic conditions (28), and the disparity in access to health care between uninsured and insured is greater for the chronically ill than for those with acute medical conditions (29). Absence of insurance has also been shown to have a negative impact on the health status of the general population (21, 30, 31). In the context of this previous research, our findings suggest that absence of health insurance decreases access to health care and results in a decrease in life expectancy for children with CF.

TABLE 1

RESULTS OF COX PROPORTIONAL-HAZARDS ANALYSIS OF TIME FROM BIRTH TO DEATH AMONG 189 INDIVIDUALS WITH CYSTIC FIBROSIS

Variable	Relative Risk	95% Confidence Intervals	p Value
Insurance status			0.009
Medicaid (compared with private insurance)	1.0	0.4, 2.1	0.9
No insurance (compared with private insurance)	2.1	1.3, 3.4	0.005
Socioeconomic status (per unit of Socioeconomic Index; range 0–100)	0.98	0.97, 0.99	0.04
Female sex (yes = 1, no = 0)	1.5	0.97, 2.3	0.07
Meconium ileus at presentation (yes = 1, no = 0)	1.6	0.95, 2.7	0.08

Since increasing numbers of children are losing private insurance every year (32), there are unavoidable policy implications of our findings. Currently, about half of all Medicaid enrollees are children, and Medicaid finances health care for one in every four children in the United States (28). In addition, children have fared poorly in battles over budget allocations for social welfare programs in the past (33). A recent review outlines the impact on children of curtailing Medicaid funding (28). If our findings are found to be generalizable to children with other chronic childhood illnesses, a decrease in the number of children eligible for health insurance may have an impact on life expectancy well beyond the CF population.

We did not control for markers for severity of illness after initial diagnosis of CF because our primary interest was assessing the impact of health insurance status. We speculated that absence of health insurance would change the mortality rate by decreasing access to health care and consequently, over time, increasing severity of illness. Therefore, controlling for severity of illness after initial diagnosis could be expected to confound and disguise the impact of health insurance. In a secondary analysis, we examined the role of age of diagnosis on survival. While earlier diagnosis was associated with a trend toward increased mortality rate, age of diagnosis did not affect the association of health insurance or SES with survival. Age of diagnosis might be confounded by access to health care, since those with greater access would tend to be diagnosed earlier. In addition, age of diagnosis is confounded by severity of illness, since patients with more severe disease are diagnosed earlier. Some data have suggested that early diagnosis of CF through newborn screening results in better nutritional status, fewer hospitalizations, and fewer respiratory tract infections among the screened children (34). However, long-term benefits of newborn screening, such as improved pulmonary function and survival, have not been documented. In our study, the lack of effect of age at diagnosis on the association between health insurance status and mortality suggests that the largest impact of health insurance is through access to health services after the initial diagnosis of CF.

There are several limitations of this study. First, we assigned all patients to one of three health insurance categories according to the category in which they spent the most time. In fact, health insurance status may change several times over the course of a lifetime. However, excluding individuals with a change in health insurance status did not change the results. A second limitation is that we used a single measure of SES, the socioeconomic index (27). While the socioeconomic index attempts to account for education and income in its scaling, it is not a direct measure of these two components of SES. It is possible that direct information about the education or income of patients' parents could have weakened the association between health insurance status and mortality rate. However, of the three components of SES, occupation is often the most reliable (35). Finally, our method of selecting subjects could result in bias if some patients were never hospitalized at the university referral center *because* they had no insurance. While it is difficult to disprove this possibility, it is our experience that prior to the introduction in the late 1980s of home-therapy programs for intravenous antibiotics virtually all children with CF living in this region were hospitalized at this referral center at some time in the course of their illness. In addition, since the university-affiliated children's hospital accepts all patients regardless of ability to pay, it seems less likely that a substantial number of uninsured patients requiring hospitalization would not be seen at this hospital. Nonetheless, the potential for ascertainment bias remains an important limitation of this study.

Our findings suggest that individuals with CF have a markedly decreased life expectancy if they have no health insurance. We did not demonstrate a significant difference in survival between individuals with private insurance and those with Medicaid. The implications of these findings are that an increase in the proportion of children with CF who are without health insurance can be expected to lead to a decrease in their life expectancy.

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