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Predictors of Mortality in Children with Severe Mental Retardation: The Effect of Placement

David Strauss, PhD, Richard K. Eyman, PhD, and Herbert J. Grossman, MD

ABSTRACT

Objectives. This study was undertaken to assess the predictors of mortality in severely disabled children with mental retardation, and to compare risk-adjusted mortality rates for those living in institutions with rates for those living in the community.

Methods. Statistical analysis was performed on a set of 24 469 person-years, derived from a population of all children with severe mental retardation and a fragile medical condition who are registered with the California Department of Developmental Services. Variables included age, several measures of mobility, the presence or absence of tube feeding, the level of retardation, and certain adaptive skills.

Results. Reduced mobility and the use of tube feeding were associated with a large increase in mortality risk. Own home residence and community care facilities have an estimated 25% higher risk-adjusted odds on mortality than institutions and health facilities.

Conclusions. The differential mortality in the placements points to a possible effect of quality of care. One consequence of the current trend toward deinstitutionalization may be an increased mortality rate in children with severe developmental disability. (*Am J Public Health.* 1996; 86:1422–1429)

Introduction

Numerous studies of people with mental retardation have shown that immobility, in combination with either feeding and toileting difficulties or severe cerebral palsy, is associated with higher mortality.[1–9] Those in a persistent vegetative state, which includes immobility, are subject to an especially high mortality rate.[10] However, although all these studies have identified mobility and other risk factors as important in predicting survival, no study to date has attempted to compare mortality rates in different residential placements while controlling for such risk factors simultaneously. In a previous study that controlled for ambulation alone, similar mortality rates in institutions versus the community had been reported.[11]

Our interest in comparative mortality among different placements derives from studies that report problems with the delivery of medical care to people with developmental disabilities in community settings (primarily their own homes and small group homes).[12–23] For example, difficulties noted in a survey of physicians in Maine included the poor quality of medical records, problems communicating with multiple caregivers, the maladaptive behavior of patients in the office, and potential liability issues.[17] A New Jersey study of the causes of 14 deaths in the community judged that nearly half the deaths were preventable.[21] Such studies raise the question of whether mortality rates in the community are greater than those in facilities such as state institutions, which have the resources to provide a higher level of medical care. This would have implications for the current trend toward deinstitutionalization, which has resulted in a 60% reduction in the number of clients residing in large institutions in the United States since 1967.[24]

This paper addresses three questions: (1) Based on a large number of potential candidates culled from previous research, what are the most sensitive predictors of mortality? (2) Does residential placement make a difference in mortality after these risk factors are controlled? (3) If there is such a difference, is it the same for the most medically disabled individuals (at highest risk) compared with those who have fewer disabilities?

Methods and Materials

Data Source

The subjects were children with severe developmental disabilities who had received services from the California Department of Developmental Services between January 1, 1980, and December 31, 1992. All were referred to one of the 21 regional centers contracted by the state to provide services to clients in their geographic areas. The regional centers, which are privately owned corporations, coordinate all services including the choice of residential placement.

The data source was the Client Development Evaluation Report.[25] This report is completed once a year, and additionally on moving to a new placement, for anyone receiving services from the Department of Developmental Ser-

David Strauss is with the Department of Statistics and Richard K. Eyman is with the School of Education, University of California, Riverside. Herbert J. Grossman is with the University of Michigan Medical Center, Ann Arbor.

Requests for reprints should be sent to David Strauss, PhD, Department of Statistics, University of California, Riverside, CA 92521.

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Editor's Note. See related editorial by Durkin (p 1359) in this issue.

vices. Consisting of a 100-item Diagnostic Element and a 66-item adaptive behavior Evaluation Element, it provides demographic, health, and behavioral data. Information is collected by case workers or psychiatric technicians who have been trained in the use of the instrument, and evaluations are based on personal observations, supplemented where appropriate with interviews with parents.

The interrater reliability of the evaluation report items employed has been investigated elsewhere[26,27] and in recent unpublished work. As assessed by Cohen's kappa, reliability exceeded .8 for the motor skills variables and .7 for all the variables used in the analysis here, with the exception of interaction with peers (κ = .60). The concurrent validity of the report's adaptive skills items, relative to a shortened version of the American Association on Mental Retardation's Adaptive Behavior Scale, has been judged satisfactory, with correlations between the factor scores ranging from .50 to .88.[28,29] In addition, the Department of Developmental Services periodically evaluates the report's information since that is what is used to reimburse service providers.

Mortality information was obtained from department sources, supplemented by annual computer tapes issued by the California Bureau of Vital Statistics.

Sample

As in Eyman et al.,[1,2] the focus of this study was on the severely disabled, medically fragile younger clients. Mortality for this group is much higher than that for the more ambulatory, robust children, and the causes of death patterns are very different. In addition, this target group included virtually all children with profound and severe mental retardation known to regional centers throughout the state; hence, there is no issue of selection bias.

An operational definition of severely disabled and fragile for this study was based on four variables reported in the Client Development Evaluation Report:

1. *Crawling or standing:* cannot pull to a standing position.
2. *Ambulation:* does not walk.
3. *Eating:* does not feed self, must be fed completely.
4. *Toileting:* not toilet trained or habit trained.

These are referred to collectively here as Condition A. Of the more than 150 000 clients known to the department and represented by at least one evaluation report, some 11 000 were children with one or more evaluation reports meeting Condition A.

TABLE 1—California Children with Severe Mental Retardation and a Fragile Medical Condition (n = 7241), by Age at First Person-Year Contributed to Analysis

Age at First Person-Year	%
2 y	51.1
3 y	10.9
4 y	7.2
5 y	5.0
6 y	4.0
7 y	3.7
8 y	2.8
9 y	2.8
10 y	2.6
11 y	2.6
12 y	2.5
13 y	2.5
14 y	2.4

TABLE 2—California Children with Severe Mental Retardation and a Fragile Medical Condition (n = 7241), by Number of Person-Years Contributed to Analysis

No. Person-Years Contributed	% Children Contributing that Number of Person-Years
1 y	30.1
2 y	20.4
3 y	13.5
4 y	9.1
5 y	7.2
6 y	5.5
7 y	4.5
8 y	3.5
9 y	2.7
10 y	2.1
11 y	1.2
12 y	0.3

A distinctive feature of the study was that the unit of analysis was not an individual person but instead a *person-year.* A year was taken to be the interval between two birthdays. To avoid bias, a given person-year was included in the sample only if it was complete: roughly speaking, this meant that (1) during that time the child met Condition A, (2) the child's age was between 2 and 14 years, inclusively, and (3) there was evidence that the child was in the system from the beginning of the year and either died or was still in the system at the end. (More complete details are available from the first author.) Such a procedure was necessary to exclude time intervals for which the individual was not known to be in the system throughout. An example may clarify the procedure: Suppose a child entered the system at age 4 years 6 months and stayed in Condition A throughout until death at age 7 years 4 months. Three person-years would be contributed: the complete year between the fifth and sixth birthdays, the complete year between the sixth and seventh birthdays, and the year beginning at the seventh birthday. The incomplete year preceding the fifth birthday would not be included.

The procedure yielded a set of 24 469 person-years, arising from 7241 children; not all of the 11 000 children who had one or more evaluation reports meeting Condition A contributed a complete person-year. Tables 1 and 2 classify the subjects by age at first contributed person-year and by the number of years contributed. The first contributed person-year was at age 2 for about half the children. The majority of the children contributed only 1 or 2 person-years, although a maximum number of 12 was possible. In all, there were 1330 deaths in the 24 469 person-years, for an overall annual mortality rate of 5.44%.

Description of Variables

Table 3 gives the percentages of client years and the mortality rates for a number of variables in the evaluation reports. The first eight of these were ultimately selected for use in our modeling.

1. *Rolling and Sitting.* This is a 9-point scale, ranging from "Does not lift head when lying on stomach" to "Assumes and maintains sitting position independently." Coders report the highest level of skill attained. As the table shows, the group at highest risk has a relative risk of about six (10.19/1.73), compared with the group at lowest risk. The importance of mobility as a predictor of mortality has been documented.[1,3,10]

On the basis of the mortality rates shown in Table 3 for the rolling-and-sitting variable, this variable was collapsed to a new variable, MOBIL, with four levels as follows:

TABLE 3—Percentages of Person-Years and Mortality Rates for Some Client Development Evaluation Report Variables (n = 24 465 Person-Years)

	Person-Years, %	Mortality Rate, %
Rolling and sitting		
Does not lift head when lying on stomach	26.1	10.19
Lifts head when lying on stomach	22.2	5.37
Lifts head and chest using arm support when lying on stomach	7.1	3.80
Rolls from side to side	9.0	4.26
Rolls from front to back only	6.5	3.42
Rolls from front to back and back to front	14.3	2.40
Maintains sitting position with minimal support for at least 5 minutes	8.4	2.62
Sits without support for at least 5 minutes	3.1	2.89
Assumes and maintains sitting position independently	3.3	1.73
Hand use		
No functional use of hands	45.0	7.85
Has use of hands	55.0	3.46
Crawling		
Does not creep, crawl, or scoot	83.3	6.87
Creep, crawls, or scoots, without the ability to stand	16.7	2.28
Tube feeding		
No feeding tube	23.2	9.48
Has feeding tube	76.8	4.21
Placement		
Own home	66.3	4.78
Community care	14.2	5.35
Health facility	8.9	4.67
Institution	11.1	8.74
Interaction with peers		
Does not have interaction with peers	65.2	6.66
Has interaction with peers	34.8	3.15
Auditory perception		
Does not react, demonstrates startle, or turns head or eyes to sound source	48.9	7.30
Responds differently to voices	51.2	3.66
Expressive language		
Does not have expressive language	36.8	8.12
Has expressive language	63.2	3.88
Mental retardation		
Mild	2.4	4.10
Moderate	5.2	3.63
Severe	21.3	4.00
Profound	48.7	6.31
Not/suspected	22.1	5.77
Age, y		
2	15.1	4.68
3	12.7	5.85
4	10.8	5.94
5	9.1	5.85
6	8.0	5.08
7	7.3	4.62
8	6.6	5.78
9	6.1	4.57
10	5.5	5.47
11	5.1	5.51
12	4.8	6.34
13	4.4	6.28
14	4.1	5.46

MOBIL1 = first level of rolling-and-sitting (cannot lift head)

MOBIL2 = second level (lifts head when lying on stomach)

MOBIL3 = levels 3 to 5 (lifts head and chest when lying on stomach, rolls from side to side, or rolls from front to back)

MOBIL4 = levels 6 to 9 (rolls both back to front and front to back, or sits with at most minimal support for at least 5 minutes).

2. *Hand Use.* We used a simple dichotomy of "No functional use of hand" vs "Uses fingers independently."

3. *Crawling and Standing.* According to Condition A, only two groups were included in this study. These are "Does not creep, crawl, or scoot" and "Creeps, crawls, or scoots without the ability to stand." The crawling variable is thus dichotomous.

4. *Tube Feeding.* This is an indicator of whether the subject was tube fed; the evaluation report currently does not distinguish between nasogastric and gastrostomy tube feeding, but gastrostomy feeding is known to account for the great majority of the instances in this population. Tube feeding is associated with a markedly higher mortality risk (9.48% vs 4.21%), with a crude relative risk of 2.25; it was thus an important mortality predictor, as previously noted by Eyman et al.[1,3]

5. *Placement.* Placements were grouped into four categories: own home, community care, health facilities, and institutions. Parents' or relatives' homes were counted as own home. Community care included small homes such as foster care as well as larger board-and-care facilities that serve seven or more people. Health facilities provide intermediate health care. Institutions, now called developmental centers in California, are operated by the state. Table 3 shows that the crude mortality rate for institutions (8.74%) was almost double that of the other placements. Skilled nursing facilities were excluded from this study because of complexities involved with time spent in the facility: children are referred to this placement during a serious illness but return to their former placement when improvement is noted. Nearly all those who remain are chronically ill, with medical conditions that preclude other placement.

In addition, all the remaining variables from the 66-item Evaluative Element of the report were screened for mortality prediction. The following three variables emerged as having some predictive value; all showed the expected rise in mortality rates with increasing disability.

6. *Interaction with Peers.* This 4-point scale was dichotomized according to whether the child entered into social

interactions. Once again, the main contrast in mortality rates was between the lowest level of the scale and the other three levels. The rate for the former (6.66%) was more than double the rate for the latter.

7. *Auditory Perception.* This is a 7-point scale that was ultimately dichotomized according to whether the child appeared to distinguish voices from other sounds. Again, the relative mortality at the lower level was more than double that at the higher level.

8. *Expressive Language.* This is a 7-point scale, dichotomized according to whether the child expresses words. The relative risk for this variable also exceeded 2.

Two other variables that were eventually excluded from the multivariate modeling nevertheless deserve comment:

1. *Mental Retardation Level.*[30] Categories are mild (IQ between 50–55 and 70–75), moderate (between 35–40 and 50–55), severe (between 20–25 and 35–40), and profound (less than 20–25). California uses an additional category, suspected mental retardation, for those whose level of disability has not been established. It might be expected that the level of retardation would be an important mortality predictor; as Table 3 suggests and some preliminary modeling confirmed, however, the variable contributed rather little when the others were taken into account.

2. *Age.* Table 2 shows the decline in frequencies (proportion of person-years) with age. This is owing partly to mortality but mostly to the children whose condition improved enough for them to graduate out of Condition A. As Table 3 shows, the age-specific mortality rate is fairly constant: there was no hint here of the usual decline with age. This suggests that for those who remain in a fragile condition, survival prospects do not improve over time.

TABLE 4—Logistic Regression Model for Mortality Probability, Based on 24 465 Person-Years

Variable	df	Odds Ratio[a]	95% Confidence Interval
Intercept	1	0.01**	
TF & MOBIL1[b]	1	4.02**	3.12, 5.19
TF & MOBIL2, 3, 4[c]	1	2.64**	2.08, 3.35
Not TF & MOBIL1[d]	1	2.76**	2.17, 3.51
Not TF & MOBIL2[e]	1	1.80**	1.42, 2.28
Not TF & MOBIL3[f]	1	1.40**	1.11, 1.78
Hand use	1	1.19*	1.03, 1.38
Crawling	1	1.36*	1.07, 1.71
Interaction with peers	1	1.29**	1.10, 1.50
Auditory perception	1	1.21**	1.06, 1.39
Expressive language	1	1.23**	1.08, 1.40
Community care[g]	1	1.09[NS]	0.92, 1.29
Health facility[g]	1	0.81[NS]	0.65, 1.01
Institution[g]	1	0.81*	0.70, 0.94

[a]Odds ratios refer to odds on dying in a given year for each designated variable relative to those children in the reference category.
[b]Binary variable contrasting those tube fed and unable to lift their heads when lying on their stomachs (i.e., MOBIL1) with the reference group. The reference group consists of those not tube fed and at the highest of the four mobility levels, MOBIL4 (i.e., with full rolling ability; see text for complete definition).
[c]Contrasts those tube fed but able to lift their heads when lying on their stomachs (i.e., MOBIL2, MOBIL3, or MOBIL4) with the reference group.
[d]Contrasts those not tube fed and MOBIL1 with the reference group.
[e]Contrasts those not tube fed and MOBIL2 with the reference group.
[f]Contrasts those not tube fed and MOBIL3 with the reference group.
[g]Contrasts with own home as reference group.
$^*P < .05$; $^{**}P < .01$. NS = not significant.

Statistical Analysis

It may seem at first sight that a cohort survival analysis, such as a Cox regression,[31] should be used here. In fact, however, a cohort perspective would be somewhat inappropriate for a number of reasons. First, our observations do not yield survival times in any natural way: subjects were observed only from 1980 through 1992 (giving rise to left censoring as well as to the usual right censoring) and may have moved in and out of the "severely disabled" state (Condition A). Second, special rules were required to determine when the subject was actually in the system and thus at risk. And third, because the study focused on the effect of the predictor variables (mobility, etc., plus residence) on the *hazard rate*[32] rather than on the duration of survival times, an analysis of hazards was sufficient.

Instead, it was convenient to model the hazards directly in terms of the predictor variables using logistic regression.[33] Note that had this actually been a cohort study, the logistic regression approach here would have been a version of discrete survival analysis.[34–36] The units of the analysis were the 24 469 person-years (reduced to 24 465 because four subjects contained missing values on one or more variables). This logistic modeling of person-year data is closely related to Poisson regression.[37] Note that, just as in Poisson regression, no assumption is made regarding the independence of the several person-years contributed by a single individual; technically, the individual's contribution to the likelihood function is the product over the person-years of the *conditional* survival probabilities, the conditioning events being that he or she is alive at the start of the year.

In general, the baseline hazard function (i.e., the mortality probability corresponding to a reference covariate pattern as a function of age or other "time" variable) depends on both the subject's age and the calendar year. In this instance, however, the hazard analysis showed that

1. there were no discernible trends in the age-specific baseline hazard rates,
2. when the age range (2 to 14) was partitioned into age groups, there were no significant differences among the age group–specific baseline hazard rates,
3. there was no evidence of interactions (effect modification) between age groups and other major predictors, and
4. no substantial temporal dependencies (i.e., effects associated with the calendar year) were observed.

In view of this, age and calendar were excluded from the analysis; this implies a constant baseline hazard function.

All covariates used in the models considered were binary. The rolling-and-sitting variable, which had been reduced to four categories as described above, was coded with three binary variables: MOBIL1, MOBIL2, and MOBIL3; these are contrasts of the first three categories

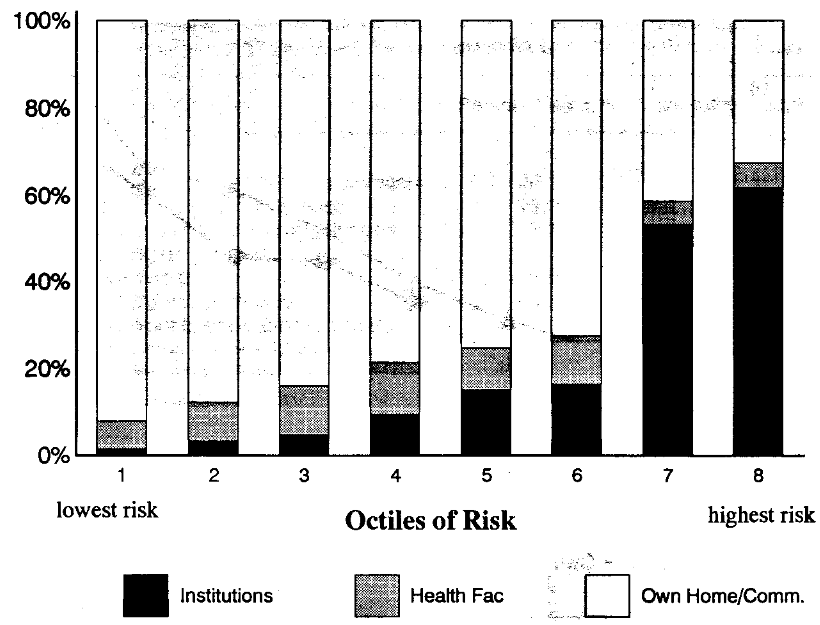

FIGURE 1—Eight ordered mortality risk groups, by residential placement: data are based on 24 465 person-years, derived from 7241 California children with severe mental retardation.

against the fourth. In this way, odds ratios (ORs) and related quantities were easily obtained.[33] For residence, binary contrasts for each of community care, health facilities, and institutions were defined. Own home was taken as the reference group because it was the largest.

Model building and diagnostic analyses were carried out using standard procedures,[33] including stepwise logistic regression and likelihood ratio testing for groups of two-way and higher interactions. An overall test of the model presented in Table 4 showed no evidence of lack of fit (Hosmer and Lemeshow test,[38] $\chi^2 = 3.5, df = 8; P = .9$).

To compare mortality rates for the different placements within strata that are homogeneous with respect to risk, the "multivariate confounder score" procedure of Miettinen was adapted.[39] The logistic regression equation defined by Table 4, but with all placement variables set to zero, was used to generate a predicted probability of death for each person-year. These probabilities were estimates of risk, adjusted for placement effects. They were then used to rank order all the 24 465 person-years from highest to lowest risk. Next, the person-years were partitioned into eight homogeneous "risk octiles," with the boundaries chosen to produce an equal number of expected deaths in each. This choice resulted in approximately equal variances for the octile-specific mortality rates. Finally, mortality rates were computed and plotted for (1) own home and community care, and (2) health facilities and institutions. The latter rate was directly standardized[40] to adjust for the tendency within each octile for institutions and health facilities to have relatively more person-years with higher risk. (The own home and community group was selected as the standard population because it was the larger of the two.)

Results

The main results are condensed into Table 4, which summarizes a series of logistic regression analyses. Thirteen binary variables were ultimately retained. These fall into three groups: five binary variables for the main effects and interactions of rolling and sitting (MOBIL) and use of tube feeding (TF), five for other predictors, and the last three for contrasts between the residence types.

The joint relationship of tube feeding and rolling and sitting to mortality is expressed in Table 4 by five contrasts against a reference group. The reference group consists of person-years for subjects at lowest risk—that is, those not tube fed and having the highest level of mobility (MOBIL4, indicating at least full rolling ability and in some cases the ability to sit). The first variable (TF & MOBIL1) contrasts those who are tube fed and unable to lift their heads when lying on their stomachs with the reference group. The odds ratio of 4.02 indicates that the former group has about four times higher odds of dying in a given year than the reference group, other variables held constant. This odds ratio may be interpreted as being roughly equal to the relative risk for the two groups.[40] Those who are tube fed but possess more mobility (TF & MOBIL2, 3, 4) had 2.64 times the mortality odds of the reference group; this ratio was substantially the same for subjects at all three of the higher levels of the rolling-and-sitting scale.

For those not tube fed, the odds ratio was 2.76 for those who could not lift their heads (not TF & MOBIL1); this declined to 1.80 for those who could lift their heads but no more (not TF & MOBIL2), and to 1.40 for those at the next level (not TF & MOBIL3). This last group still had significantly higher risk than the reference group. The hand use variable was significant; those who had no functional use of their hands had an estimated odds ratio of 1.19 compared with those who had some hand use. Table 4 shows that those who could not creep, crawl, or scoot had nearly 40% higher mortality odds than those who could, again underscoring the importance of mobility to survival. The three adaptive variables, interaction with peers, auditory perception, and expressive language, also contributed appreciably to the prediction; the absence of any of these skills was accompanied by a 20% to 30% increase in odds on mortality.

The final three rows of the table refer to the placement variables, a major focus of the study. The own home group was used as the reference. The community care variable contrasted the mortality of community care with that of own home. Although the odds ratio (1.09) is in the direction of a higher mortality rate than for own home, it is not significantly different from 1. Both of the other two contrasts, those of health facilities and institutions with own home, are in the direction of a *reduced* mortality risk. Compared with own home, the odds ratios for both of these placements, .81, correspond to a 19% reduction in mortality odds. Equivalently, own home is associated with a 23% *increase* in mortality odds, relative to either health facilities or institutions. Thus, the apparently superior mortality rate of own home over institutions observed in Table 3 is actually reversed when the confounding variables are controlled. It may be noted that when own home and community care are combined and the logistic analysis is recomputed, the odds on mortality for the combined group exceed those for institutions and health facilities by 25%.

Table 4 shows that the health facilities–own home comparison is on the borderline of statistical significance (OR = .81; P = 5.6%), while the institution–own home comparison results in the same odds ratio with a P value of 2.4%. For some purposes, we have combined institutions and health facilities since they both represent the higher levels of medical care, have very similar mortality patterns, and are represented by relatively small sample sizes (see Table 3). The contrast of own home and the combined group is significant at the 1% level (all P values quoted are two-tailed). This result goes beyond earlier studies, which have shown that the lower mortality in own home placement can be accounted for by controlling for certain predictor variables.[4,11] In the present study, we also compared mortality in the lower level of care placements (own home and community care) with mortality in the higher level of care placements (health facilities and institutions), controlling for just the two variables of rolling and sitting and tube feeding. This resulted in a set of eight 2 × 2 placement mortality tables, not shown here. Even when only these two variables were controlled, health facilities and institutions showed slightly lower mortality (P = 4.5%, Cochran-Mantel-Haenszel test).

It was of interest to compare mortality rates by placement at different levels of risk. As described above, we partitioned the person-years into eight risk-homogeneous groups or risk octiles. Figure 1 shows the breakdown of the person-years by residential type within the octiles. For clarity and for reasons discussed earlier, own home and community care have been grouped. In this group, the proportions in the octiles decline steadily as the risk increases. As may have been expected, health facilities tend to cater to the higher risk groups, although not to the very highest ones. These highest-risk person-years are concentrated in the institutions, which explains the high (unadjusted) mortality rate for institutions noted previously.

Mortality rates are plotted against octiles of risk in Figure 2. For reasons noted above, health facilities and institutions have been combined. Figure 2 shows, for each octile, the mortality rates for the own home and community group and for the health facility and institution group. The pattern of a lower mortality rate for the latter group appears to be rather consistent across the risk octiles, with no suggestion of a trend.

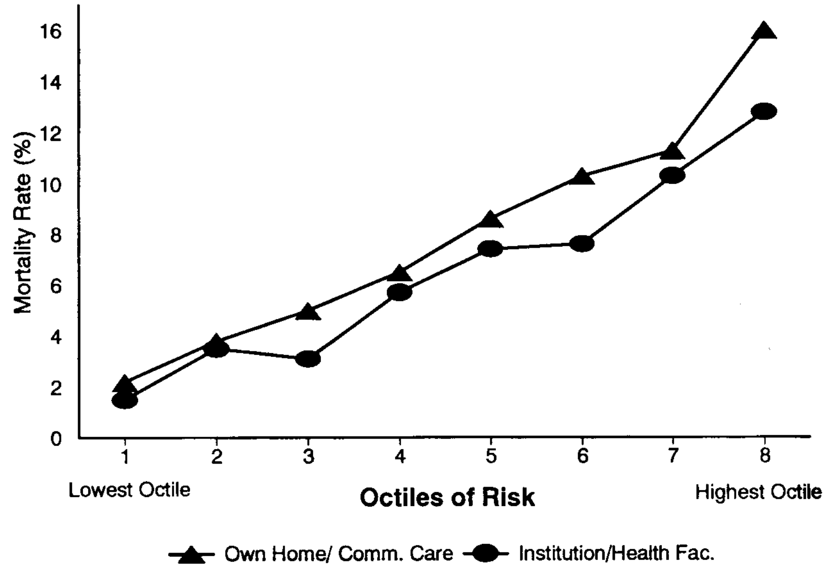

FIGURE 2—Annual mortality rates, by placement, derived from 7241 severely retarded California children.

Discussion

We have identified the functional disabilities that are most predictive of an unfavorable prognosis in a large population of severely disabled and nonambulatory children with mental retardation. All the disabilities are a consequence of devastating neurological deficits. The most important predictors are mobility and the use of a feeding tube. The importance of mobility and tube feeding had been recognized previously,[1–3] but the multivariate analysis performed here resulted in greater refinement of the mobility variables, together with a quantitative assessment of predictive power. For example, Table 3 shows that subjects who are unable to lift their heads are subject to markedly greater risk than those who have this ability. The predictive value of the can/cannot lift head distinction is a new finding that results in substantially improved discrimination.

We have seen that four distinct levels of rolling and sitting are associated with importantly different mortality rates. Other predictors making a contribution are hand use and the abilities to creep, crawl, or scoot; to speak intelligible words; to recognize voices; and to interact with peers. The predictive utility of these variables also had not previously been assessed.

The results of the study can be used in a number of ways. For a given individual with a specific profile of mobility, hand use, tube feeding, and so on, the logistic regression model presented in Table 4 provides an immediate estimate of the annual mortality rate. Table 4 also identifies some major variables that should be considered for stratification (subdivision) of the population of younger persons with mental retardation before one undertakes life table or survival analyses. A further use of the model is to identify combinations of covariate values that are similar with respect to their associated hazard levels; in this way, one can identify a group of subjects who are at similar risk to a target individual and then, for example, construct a life table for that individual. Finally, the variables identified, together with their odds ratios, provide an informal guide to the survival prospects of a given individual.

The differential mortality rates among the various placements is noteworthy. The odds on dying for those in their own home or in small group homes are estimated to be 25% higher than the odds for those in institutions and health facilities, other factors held constant. We have seen that consideration of the crude mortality rates (Table 3), without controlling for any predictors, would incorrectly point to the opposite conclusion. The issue appears to be a case of spurious association resulting from the excess of higher-risk patients in institutions and health facilities.

The analysis here is based on an observational study rather than on a controlled experiment, so its results must be considered tentative. A definitive judgment on whether institutions are "safer" than children's own homes would require a properly randomized experiment, and this would be ethically infeasible. In the absence of such an experiment, it is conceivable that there are confounding factors, not measured here, that somehow favor institutions and health facilities; controlling for these might then change the result. As pointed out by a referee, one way this could happen is through "overcontrolling": if community care resulted in better outcomes for mobility or other functioning than did institutional care, controlling for such factors would introduce a bias against the community placements. However, we are not aware of any evidence of such placement differences. Further, it seems likely that own home placements, for example, vary substantially in quality and quantity of care. To identify the causes of the differences and to measure their relationship to mortality are important tasks for future work.

On the other hand, we have seen that the more variables in the study are statistically controlled, the more the comparison favors placements with a higher level of care. Thus, Table 3 shows institutions and health facilities to have the highest mortality rate when no variables are controlled; when the two major predictors (tube feeding and mobility) are controlled, the comparison slightly favors institutions and health facilities, being in fact marginally significant, and these placements appear substantially better in the fully controlled model of Table 4. We have also seen institutions to be disproportionately represented in the highest risk groups. Variables such as mobility and tube feeding serve as markers for health risk, and if one could control for health risk precisely by including all relevant variables, the comparison might be expected to tilt still further toward the higher-care placements.

One explanation for the difference is that the greater access to medical care, and especially emergency care, in these placements is being expressed in a reduced mortality rate. Further study on the *causes* of deaths, based on examination of medical records, would be helpful here. It would also be of interest to carry out similar studies in states other than California.

Mortality is, of course, only one of a number of outcome measures relevant to the current debate over deinstitutionalization. Other criteria include cost,[41] issues of family cohesion, and the desirability of the least restrictive environment.[42] Nevertheless, the results here raise the possibility that the trend toward deinstitutionalization is accompanied by increased mortality in children with severe developmental disabilities, as in recent years even highly debilitated children have been moved out into the community. Parents, guardians, and others concerned with placement decisions may wish to take this into account. □

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