American Journal of Epidemiology

Vol. 147, No. 9
Printed in U.S.A.

External Causes of Death among Persons with Developmental Disability: The Effect of Residential Placement

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The authors analyzed death rates from external causes (accidents, injuries, homicides, etc.) for persons with developmental disability in California. There were 520 such deaths during the 1981–1995 study period, based on 733,705 person-years of exposure; this represents all persons who received any services from the state. Compared with the general California population, persons with developmental disability were at lower risk of homicide, suicide, and poisonings (standardized mortality ratios, 0.31–0.68), but higher risk of pedestrian accidents, falls, fires, and, especially, drowning (standardized mortality ratio = 6.22). A major focus of the study was comparisons between different residential settings. Persons in semi-independent living had significantly higher risk than did those in their family home or group homes, with homicides rates being three times higher and pedestrian accidents rates being doubled, while persons in institutions had much lower risks with respect to most causes. Of the 28 deaths due to drug and medication overdoses, 79 percent occurred in supported living or small-group homes. Avoidable deaths could be reduced by making direct care staff more aware of the risks and better trained in acute care, along with improved monitoring of special incidents. *Am J Epidemiol* 1998;147:855–62.

death rate; group homes; mental retardation; residential facilities

Developmental disabilities are those associated with mental retardation, cerebral palsy, epilepsy, or other neurologic conditions related to mental retardation and requiring similar treatment. They generally originate in early childhood and constitute a serious handicap to the individual (1). The prevailing views of residential arrangements for such persons have changed dramatically in the last few decades. It had previously been widely thought that large, state-run facilities were the ideal placement for many persons with mental disabilities, especially for those with serious impairments. More recently, the movement for "normalization" and "full inclusion" (2) has led many advocates to argue for the closure of all state institutions in favor of small-group homes ("community care"). Several states have already closed their institutions, and in the United States as a whole, the institutionalized population has been reduced by 60 percent between 1967 and 1991 (3).

Although quality of care in institutions and in community settings has been widely debated, the results have been rather inconclusive (4–6). One widely accepted proxy measure for quality of medical care is mortality. Although several earlier studies compared mortality rates in institutions and the community (7–10), none simultaneously controlled for the known risk factors such as age and mobility. We recently compared community and institutional mortality after controlling for risk factors. During 1980–1992, risk-adjusted mortality for California adults aged 40 years or over was 72 percent higher in the community (11). A follow-up study for 1993–1994 showed an 82 percent increase (12). Among high-risk children in California in 1980–1992, there was a 25 percent increase in mortality (13). These studies raise the question of causes of death. In particular, are avoidable deaths more common in community care? In a recent New Jersey study of 14 community deaths, nearly half were judged to be avoidable (14). Such deaths are of special interest because they may be reduced as a result of policy intervention.

In this study we focus on one clearly identifiable class of avoidable deaths, namely, those due to external causes (accidents, homicides, etc.). The primary issues are:

Received for publication May 15, 1997, and accepted for publication October 25, 1997.

Abbreviations: CDER, Client Development Evaluation Report; ICD-9, *International Classification of Diseases*, Ninth Revision; SMR, standardized mortality ratio.

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1. For external causes of death, such as drownings, pedestrian accidents, homicides, etc., how do mortality rates in the general population compare with those among people with developmental disabilities?
2. After adjustment for risk factors, such as age, male gender, and aggressive behavior, what are the relative mortality rates for external causes among persons living in different residential settings: parents' homes, group homes, institutions, etc.?
3. How do mortality rates for the specific means of externally caused deaths, such as drownings and homicides, vary among persons in different residential settings?

MATERIALS AND METHODS

The instrument

The source of the study data was the Client Development Evaluation Report (CDER) (15). A CDER is completed annually, and additionally on moving to a different placement, for all persons receiving any services from the California Department of Developmental Services. There are many types of services, including speech, behavioral, and physical therapies; board and care; transportation; day programs; and respite services for families. The CDER includes a 66-item Evaluation Element grouped into six domains of adaptive skills and behavior. These are motor and self-care skills, along with social, emotional, cognitive, and communication domains. The instrument is filled out by the caregiver most familiar with the client, most frequently the case worker. The reliability of the CDER has been investigated elsewhere and considered satisfactory (16–19).

Mortality

In California, it is legally required that all deaths be reported to the county authorities, who forward the information to the state Department of Health Services. Mortality information for this study was obtained from computer tapes created annually by the Department. We then identified the deceased persons on these tapes who were also listed in the developmental disabilities database. The tapes provide cause of death information in the form of *International Classification of Diseases*, Ninth Revision (ICD-9) codes (20). From these, we focused on ICD-9 codes E800-E999, the "external" causes such as homicides, accidents, injuries, and poisonings. Data on injury death rates in the general California population were based on tables supplied by the California Department of Health Services.

Variables used in the study

Variables previously established to be important predictors of mortality included age, gender, and level of motor skills (11). As in the previous study (11), a motor skills scale was constructed from five CDER items: rolling and sitting, hand use, arm use, crawling and standing, and ambulation. Each item was originally scored on a scale of between four and nine levels, but was transformed to a three-point scale: high = 2; medium = 1; low = 0. When summed, this resulted in a scale of 0–10, which was recoded as good (score, 10), fair (score, 6–9), poor (score, 1–5), and none (score, 0).

Variables that may be predictive of externally caused deaths were also considered: aggression, severity of self-injurious behavior, tendency to run away, and hyperactivity. On the CDER, these items were coded as 4-to 6-point scales, but were collapsed here into binary or three-point scales on the basis of their mortality rates. Also included in the study was severity of mental retardation (21, 22), which is a potential factor in externally caused deaths. The coding was mild, moderate, severe, profound, and suspected, with the last three being combined in this study as they are elsewhere (23). "Suspected" is a California category for individuals whose retardation has not formally been assessed, and previous work has indicated that this group should be classed with the severe and/or the profound groups.

Residential placement information was obtained from the Client Master File, a state data file linked to the CDER records. Placements were grouped into five categories: live in own home, semi-independent living, community care, institutions, and others. Parent/relative homes were counted as own home. In semi-independent living, one or more persons with developmental disability live in a separate residence, with periodic visits by staff who provide various services. Community care includes both small-group homes and larger board-and-care facilities serving seven or more people, although the small-group home is the predominant model in California. These are generally privately owned and operated. Institutions, now called developmental centers in California, are state operated. The institutions have been depopulated in recent years, and almost all of the remaining residents have serious behavioral or medical conditions. One consequence of the depopulation is that an increasing proportion of group-home residents also have such conditions. The final residence category consisted of all other types, including skilled nursing facilities, intermediate care facilities, and penal institutions. These groups were too small to permit separate analyses.

The sample

Our base population consisted of all persons with developmental disabilities who received services from the Department of Developmental Services at any time during the 15-year period, January 1981 to December 1995. All persons in the study had been referred to one of the 21 regional centers that contract with the state to provide services to individuals in their area.

Exposure time

A basic feature of the study was the construction of various mortality rates, computed by dividing the number of deaths by the exposure time, or time at risk. For each individual, exposure times were taken as the intervals between the time of a CDER evaluation and that of the next evaluation (or death, or end of the study period, if either of these came first).

Intervals longer than 3 years were truncated at 3 years to eliminate the unacceptable, very long intervals. Such intervals occasionally occurred, for example, when an individual left the California system. Because an individual's covariates, such as age and behavioral variables, may change over time, we associated each interval with the covariates from the individual's CDER evaluation at the start of that interval. Only externally caused deaths were considered, with other deaths being treated in effect as censoring events.

From this set of more than 1,000,000 intervals, we retained only those for which 1) the subject's age was between 15 and 59 years inclusive, and 2) the subject had good or fair mobility and was not tube fed. The excluded groups—children, the elderly, and those with seriously reduced mobility or need for tube feeding—were likely to have a different pattern of externally caused deaths and would require separate study. After these groups were excluded, there were 520 externally caused deaths from a total of 733,706 person-years of exposure, for an overall rate of 70.9 (per 100,000 person-years).

Statistical methods

We compared cause-specific mortality rates in our sample with those in the general California population. We adjusted for age and gender by reporting standardized mortality ratios (SMRs) for each cause (24). Each SMR was computed as $(d/E\{D\})$, where d is the actual number of deaths in our sample and $E\{D\}$ is the expected number of deaths in our sample based on the age- and gender-specific mortality rates for the California population. Confidence intervals for the SMRs were computed using standard methods (24).

For comparison of risks across residence groups, it was necessary to adjust for risk covariates. Statistical modeling rather than standardization was needed because of the very large number of combinations of covariate values. As is customary when modeling risk rates based on occurrence/exposure data with covariates, we used Poisson regression (25). According to this, if there are d_i deaths and n_i person-years of exposure for covariate value x_i, then d_i follows a Poisson distribution with mean $\exp(\beta' x_i)$. Here β is a vector of unknown regression coefficients to be estimated.

The Poisson regression was carried out using SAS (26). The five residence types were coded with four dummy variables, each representing a contrast with community care. The latter was used as referent because it was one of the largest groups and because we were interested in comparing it with other residence groups. The other covariates (aggression, self-injurious behavior, etc.) were also coded using dummy variables to contrast the milder levels against the most severe group. The age variable was coded into nine age groups: 15–19, 20–24,..., 55–59 years. It was found that a single linear term in age sufficed, in that the model indicated a significant linear increase in risk with age, but quadratic and cubic terms did not make significant contributions. After age, gender, and residence variables were forced into the model, stepwise regression was used to select further variables. The significance levels for entry and removal were both 0.05. Goodness-of-fit was assessed using the Hosmer-Lemeshow test (27), which is most commonly used for the logistic model, but can be shown to apply also to the case of Poisson regression.

For comparison of cause-specific rates in different types of residence while adjusting for the covariates, observed numbers of deaths by cause and residence were compared with expected numbers based on mortality rates in the entire sample. Expected numbers were computed in three stages: 1) The Poisson regression model was used to compute the expected number of deaths for each covariate pattern, with all placement variables set to their means. This, in effect, adjusts the covariate-specific risks to an "average" placement; 2) For each residence type, these expected numbers were summed over all the exposure times to give an expected total number of deaths on the basis of rates in the whole sample; and 3) each total was then partitioned among the causes in the same proportions as in the whole sample. It can be shown that the ratios of observed and expected numbers in each residence type are SMRs.

RESULTS

Table 1 gives raw data, stratified by type of residence, on the major variables considered here. As the person-year exposure data indicate, the most common placement was one's own home, followed by community care, institutions, and semi-independent living. Because we have included only data on persons with fair or good motor abilities, many of the more medically impaired persons have been excluded. As noted, the latter are relatively more likely to live in institutions than in the community. Table 1 does show the much higher proportion of serious aggressive or self-injurious behavior in the institutions, along with high proportions of severe or profound mental retardation. As would be expected, persons placed in supported or semi-independent living situations tend to be those who are relatively high functioning and have fewer behavioral problems. Table 1 also shows that the highest externally caused mortality rate occurs in semi-independent living and the lowest occurs in one's own home. These, however, are crude rates unadjusted for effects of other factors.

Table 2 shows mortality rates due to various categories of injury in the general California population

TABLE 1. Raw data by residence and selected variables for persons with developmental disability who received services in California, 1981–1995

	Semi-Independent	Community care	Own Home	Institutionalized	Other	All
Externally caused deaths	61	180	196	50	33	520
Exposure (person-years)	61,845	216,202	348,902	67,289	39,467	733,706
Crude mortality rate (per 100,000 person-years)	98.6	83.3	56.2	74.3	83.6	70.9
Age group (%)						
15–29	40	44	66	40	41	54
30–44	48	40	28	47	41	35
45–59	12	17	6	13	18	11
Gender (%)						
Female	51	43	45	36	46	44
Male	49	57	55	64	54	56
Motor skills (%)						
Good	14	20	15	39	53	21
Fair	86	80	85	61	47	79
Aggression (%)						
Has had one or more violent episodes causing minor or serious injury within the previous year	5	19	7	55	22	15
Resorts to verbal abuse or threats, but has not caused physical injuries	21	28	18	15	23	21
Episodes of displaying anger are undetected or rare and appropriate to the situation	74	53	76	30	55	64
Severity of self-injurious behavior (%)						
At least once a year	2	10	3	37	15	9
No injury or no such behavior exists	98	90	97	63	85	91
Running or wandering away (%)						
At least once a year	6	18	9	59	23	17
Less than once a year, or not at all	94	82	91	41	77	83
Hyperactivity (%)						
Is hyperactive, except when given individual attention, or always	1	8	3	24	10	7
Controlled hyperactivity	8	23	12	31	20	17
No hyperactivity	91	70	85	45	70	76
Level of mental retardation (%)						
Mild	68	31	42	9	15	37
Moderate	9	32	31	9	16	27
Severe/profound/other	23	36	26	82	69	36

TABLE 2. Mortality rates from injuries, by cause, for the general California population and for persons with developmental disabilities, 1981–1995

Cause	Raw injury death rates per 100,000 person-years		SMR‡	95% confidence interval
	California*	Dev. dis. pop.†		
Homicide	56	8.04	0.36	0.27–0.46
Suicide	13	4.36	0.31	0.21–0.43
Poisoning	4	3.95	0.68	0.46–0.98
Falls	3	6.13	4.03	2.94–5.39
Pedestrian	3	8.04	2.85	2.17–3.68
Drowning	2	11.26	6.22	4.84–7.85
Fire	1	4.19	5.02	3.11–7.67

* Source: California Department of Health and Welfare, 1995.

† Dev. dis. pop., developmentally disabled population, based on 733,706 person-years.

‡ Standardized mortality ratio (SMR) with standardization for age and gender, comparing the developmentally disabled population to the California general population.

and in our sample. The SMRs compare the two rates after adjustment for age and gender differences. Persons with developmental disability were at lower risk than the general population for homicide, suicide, and poisoning, but at substantially higher risk for deaths by falls, pedestrian accidents involving automobiles, fires, and drowning.

Table 3 shows the results of the Poisson regression analysis of risk. Risk of externally caused death increases slowly with age. Perhaps not surprisingly, male gender is associated with a substantial 54 percent increase in risk. Other factors that increase risk are aggressive behavior (those with high aggression are at about twice the risk of those at the low level of aggression), and tendency to run away (48 percent increase). All of these effects are statistically significant ($p < 0.01$).

One focus of the study was the risk-adjusted comparisons of the types of residence against the referent group, community care. Residence in one's own home was associated with a slightly lower level of risk (87 percent), but the difference was not statistically significant. Semi-independent living was associated with a significant increase in risk. Institutions were at a significantly lower level of risk than community care ($p < 0.01$), with the risk ratio being estimated at 58 percent. Equivalently, community care was associated with a 72 percent increase in risk compared with institutions ($1/0.58 = 1.72$).

The Poisson model allowed us to test for possible time trends in the rates of external deaths, either overall or specifically for some residence types. We examined this by introducing dummy variables for three 5-year periods and also by fitting linear and quadratic cubic terms in time. No discernable or statistically significant trends were observed. The same result was observed when we examined for time trends separately within each residence type.

Figure 1 shows SMRs by cause in the four major residence groups. As explained in Materials and Methods, the ratios compare the actual numbers of deaths to the expected numbers based on the entire sample. In this way, adjustment is made for interplacement differences in both exposure time and risk factors.

Figure 1 shows that persons in semi-independent living had the highest risk for most causes, including drowning, homicide, and pedestrian accidents. The comparison of semi-independent living and parents' home is noteworthy: Residents in semi-independent living were at several times the risk of homicide, fatal pedestrian accidents, and medication overdoses. Community home residence was associated with lower risks than own homes for homicide and suicide but much higher risks of death due to inhalation or suffocation as well as medication overdoses. Finally, institutions had much the lowest risks with respect to most causes. The exceptions were deaths due to inhalations and suffocation and deaths due to falls. The reasons for the high rate of fatal falls are not clear (and were not clarified by inspection of the detailed ICD-9 codes); in particular, most California institutions are

TABLE 3. Poisson regression model for prediction of externally caused mortality among persons with developmental disability in California, 1981–1995

Variable	df	Risk ratio	95% confidence interval
Age group*	1	1.07	1.02–1.12
Male gender	1	1.54	1.28–1.85
Severity of retardation†			
Moderate	1	0.67	0.43–0.85
Severe/profound	1	0.90	0.73–1.11
Level of aggression‡			
Moderate	1	1.45	1.06–1.75
High	1	1.98	1.56–2.50
Running away	1	1.48	1.19–1.85
Type of residence§			
Semi-independent	1	1.34	1.01–1.81
Own home	1	0.87	0.70–1.07
Institution	1	0.58	0.41–0.81
Other	1	0.95	0.65–1.38

* The nine 5-year age groups (15–19, 20–24, etc.) are modeled with a linear trend. The risk increases by a factor of 1.07 for each 5-year increase in age.

† Contrast with referent group, those with mild mental retardation.

‡ Contrast with those with low level of aggressive behavior.

§ Contrast with community care.

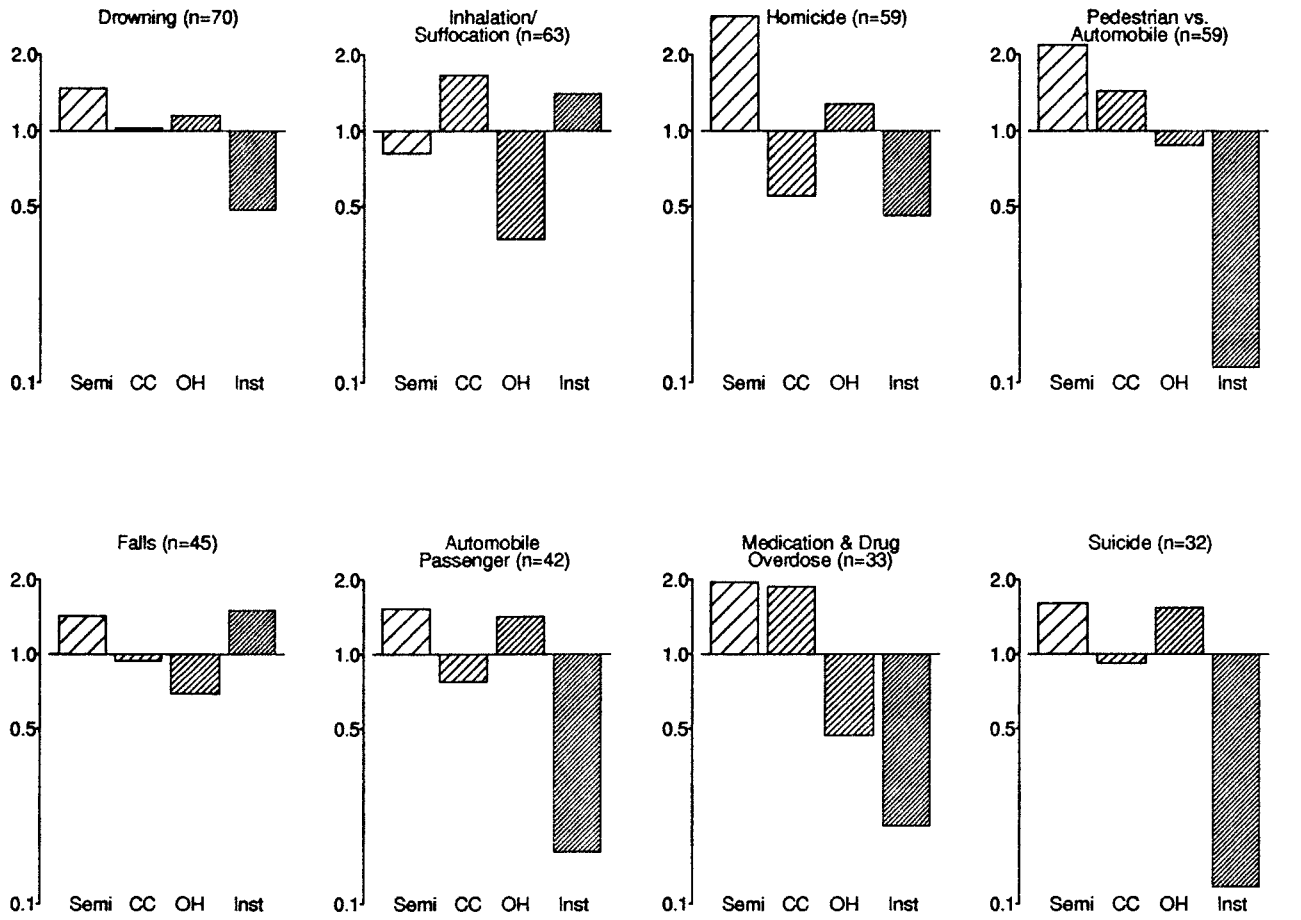

FIGURE 1. Standardized mortality ratios for four residence types, by eight external causes. Subjects are persons with developmental disability who resided in California in 1981–1995. Each number in parentheses is the total number of deaths in the sample due to that cause. The residence types are semi-independent living (Semi), community care (CC), own home (OH), and institution (Inst). The bars show the ratios of actual numbers of deaths to expected numbers, computed on the basis of the entire sample. The computations adjust for differences in exposure time and covariate patterns for each type of residence.

not multistoried, so the residents are not at increased risk of falling down stairs.

A more refined grouping of ICD-9 codes of the externally caused deaths, broken down by residence type, may be obtained from the authors. We note here that 1) the drownings were about equally divided between swimming pool and bathtub incidents, with no clear associations between location of drowning and type of residence; and 2) 22 of the 28 deaths due to overdoses of drugs or medications occurred in group homes or independent living. There were seven deaths due to tranquilizer overdoses (all in group homes) and six due to overdoses of central appetite depressants.

DISCUSSION

To our knowledge, this is the first study to analyze causes of death among persons with developmental disability, after adjustment for potential confounding factors. Externally caused deaths, studied here, are of interest because they serve as a measure of safety or quality of supervision, just as mortality as a whole is a proxy for quality of care.

The developmentally disabled population is recognized to be a group requiring special protection. It is therefore of interest that although its mortality is lower than that of the general population regarding homicide, suicide, and poisoning, it has much higher rates of fatalities due to pedestrian accidents, falls, fires, and, especially, drowning.

It is notable that the sequence of placements according to degree of freedom/supervision, namely, semi-independent living (least supervision), group homes, family homes, and institution (greatest supervision), is the same as the sequence according to mortality rates from external causes. The lower rates of externally caused deaths in institutions compared with the various forms of community living support the findings of

previous studies showing lower mortality overall in institutions (11–13). Perhaps the debate over whether institutions provide better supervision and medical care than does the community should move to a discussion of the costs and benefits of the generally more dependable medical delivery system available in institutions. There seem to be good reasons for states to monitor and improve the quality of care in private group homes. Fortunately, California is currently one of the few states with a tracking systems that could be used for the purpose (28).

This study was restricted to California, and replication in other states or countries would be desirable. In-depth case review would also be valuable. For example, Kastner et al. (14) were able to review the complete medical records for 14 deceased persons who had been living in the community. Using death certificates and other information, we have recently compared 45 California community deaths with a matching set for institutionalized persons (29). The community deaths were much more likely to have been acute or subacute (i.e., with onset a week or less before death) and were judged to be, on average, more avoidable.

The results of this study suggest that avoidable deaths in community care could be reduced by increased awareness of the risks and improved training in emergency procedures, such as cardiopulmonary resuscitation and the Heimlich maneuver. It would also be appropriate for states or local authorities to assess staff competence on a regular basis. Finally, special incidents should be reported promptly and incorporated into a computerized database so that patterns may rapidly be identified.

ACKNOWLEDGMENTS

Supported in part by grants HD21056 and HD22953 from the National Institute of Child Health and Human Development. Provision of data by the California Departments of Developmental Services and Health Services is gratefully acknowledged.

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