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Causes of Death of Patients in an Institution for the Developmentally Disabled

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ABSTRACT: The causes of death of 53 severely to profoundly developmentally disabled patients who died in an intermediate care facility were reviewed. Respiratory disease, predominantly pneumonia and aspiration, accounted for 72% of deaths. Seven patients died of nonrespiratory causes, and in 8 patients, no cause of death could be determined, even after a complete autopsy or investigation. The median age at death was 20 years. The weights of these patients' organs at autopsy were lower than those for normal individuals of the same age. The lifespan of these severely impaired individuals continues to be significantly shortened, even with improved methods of care.

KEYWORDS: pathology and biology, death, disabled patients, postmortem examinations, medical care facilities

The majority of developmentally disabled individuals with severe degrees of impairment reside in institutions. Although improvements in the care of these patients have increased their life expectancies, these individuals still have markedly shortened life spans when compared with a normal population [*1-15*]. These patients often have associated handicaps, such as quadriparesis or orthopedic deformities, which predispose them to illnesses not commonly seen in the general population. However, because these patients die in an institutional setting, the question of abuse or neglect often arises. This study was designed to review the major causes of death in a small, well-staffed institution for the developmentally disabled and to describe the importance of the forensic science autopsy in these patients.

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Materials and Methods

A survey was done of all patients who died at the Los Lunas Hospital and Training School (LLHTS) in Los Lunas, New Mexico, during the years 1979 through 1986 (8 years). LLHTS is a state-supported institution with an average census of 350 resident clients and approximately 650 support staff. Skilled nursing care is available 24 h a day. LLHTS is an intermediate care facility, whose patients are predominantly profoundly (IQ less than 25) or severely (IQ 25 to 40) retarded. Hospital records, reports of death, and autopsy protocols (where available) were reviewed for each case.

Results

A total of 53 deaths occurred during the given time period, with an average of 7 deaths per year (range 2 to 15). Of the 53 patients who died, 34 (64%) were autopsied. No important differences in causes of death for autopsied and nonautopsied patients were found based on death certificate diagnoses.

The ages at death of these patients were as follows: less than 5 years, 8 patients; 5 to 10 years, 3 patients; 11 to 20 years, 17 patients; 21 to 30 years, 19 patients; 31 to 40 years, 4 patients; and greater than 40 years, 2 patients. A relatively high percentage of patients died before age 5, but the majority of patients (68%) died in the second or third decade. Of the patients, 30 (57%) were female, and 23 were male.

Forty-five patients (85%) were profoundly retarded, seven (13%) were severely retarded, and one (2%) was moderately retarded. The functional abilities of these patients were very limited, reflecting the extent of their brain damage. Spastic quadriparesis was observed in forty-two patients (79%) and hemiparesis in one (2%). Thirty-six patients (68%) had seizures. Only eleven patients (21%) were able to feed themselves.

The causes of developmental disability in the 53 patients included in this study are listed in Table 1. The most common cause of disability in our series was an apparently acquired event. The majority of impairments seemed to result from a perinatal infection, perinatal hypoxia, or a postnatal infection. Various structural central nervous system abnormalities, many of which do not have a defined cause, made up the second most numerous group. A relatively small number of patients had well-defined genetic syndromes. In addition, the cause of the impairment in a small number of patients, even after a complete neuropathologic examination, remained undetermined or unclassified.

Respiratory abnormalities were the most common cause of death in these patients, accounting for 72% of deaths (Table 2). In this category, an acute, often fulminating pneumonia was the most common finding, accounting for 22 (41%) of deaths. Aspiration, with or without pneumonia accounted for 11 (21%) deaths. In acute aspiration, food material or another foreign substance was found in the trachea and mainstem bronchi, extending for variable distances out into the periphery. Chronic aspiration pneumonia was a patchy process, with foci of inflammation centered around small airways. A variety of other respiratory illnesses accounted for the remaining 5 deaths (Table 2).

A relatively small number of patients died from nonrespiratory causes, including cerebral hemorrhage, gastrointestinal hemorrhage, or sepsis.

Several cases had medicolegal implications. Two patients died of accidental drowning, one in an institutional swimming pool and one in a bathtub after a seizure. Another patient died of plugging of a tracheostomy tube, which had been a recurrent problem. One patient was institutionalized as a result of cerebral injuries secondary to a motor vehicle accident at age sixteen.

The case in which the autopsy was most important was that of a 19-year-old girl who died after an episode of flu-like symptoms. At autopsy, she was found to have a small bowel perforation resulting in peritonitis and sepsis. There was a laceration at the vaginal introitus, and vaginal smears were positive for sperm. The relationship between sexual abuse and her

TABLE 1—*Etiology of retardation.*

Causes of Disability	Number of Patients
Acquired	24
Intrauterine insult	3
Perinatal infection/hypoxia	7
Postnatal infection/trauma	9
Trauma—motor vehicle accident	1
Subacute Sclerosing panencephalitis (Dawson)	2
Kernicterus	2
Structural central nervous system abnormalities	16
Meningomyelocele	3
Dandy-Walker Syndrome	1
Tuberous sclerosis	1
Miscellaneous	
Porencephaly	1
Hydrocephalus	2
Microcephaly	5
Cortical disorganization	1
Lissencephaly	1
Cerebellar degeneration	1
Genetic syndromes	9
Down's Syndrome	1
Menke's Snydrome	1
Rothmund-Thomson Syndrome	1
Niemann-Pick disease	1
Glycogen storage disease, type unknown	1
Lipofuscinosis	1
Urea cycle defect	1
Phenylketonuria	1
Chromosome abnormality $10q^-$	1
Unclassified	4

TABLE 2—*Causes of death.*

	Number of Patients
Total respiratory	38
Pneumonia	22
Aspiration	
without pneumonia	4
with pneumonia	7
Bronchiolitis	1
Respiratory failure	2
Mucus plugging of tracheostomy	1
Asthma	1
Nonrespiratory	7
Cerebral hemorrhage	2
Gastrointestinal hemorrhage	1
Accidental drowning	2
Necrotizing fasciitis with sepsis	1
Sepsis as a result of bowel perforation	1
No specific cause determined	8

small bowel perforation was not clear, therefore the manner of death was signed out as undetermined. Because of these findings, which would not have been discovered without a meticulous autopsy, there was an investigation of the staff and the institution, and steps were taken to assure a similar event would not reoccur.

No morphologic cause of death was found in eight patients, even after a complete autopsy or investigation. Death in these cases was usually considered to be a consequence of the underlying illness, that is, severe developmental disability which caused respiratory arrest, cardiac arrhythmias, or some other mechanism that could not be determined morphologically. No obvious relationship was apparent between the etiology of developmental disability and the cause of death.

Severely retarded individuals were commonly small for age, as shown in Table 3. These patients had correspondingly small organs that were histologically unremarkable. The lung weights were not included, since they were highly variable depending on the extent of pulmonary disease. As might be expected, brain weights were also highly variable, depending on the amount of structural damage and parenchymal loss.

Discussion

The medicolegal autopsy in severely mentally retarded patients dying in an institution can answer many questions for the family as well as the caretakers. The most important questions concern the etiology of the patient's disability and the cause of his or her death.

A large number of developmental, hereditary, or acquired insults to the nervous system can result in mental retardation. In the case of many retarded individuals, detailed medical records from perinatal and early infancy periods are not available. Expensive or invasive diagnostic studies may not have been performed during life. Thus, a detailed postmortem examination may be essential in establishing a diagnosis. Most important is a thorough neuropathologic examination. Examination of other organs, such as liver, spleen, or bone marrow, may be important in cases of inherited metabolic diseases. Establishing or confirming

TABLE 3—*Height, weight, and organ weights of developmentally disabled patients compared with normals* [16].[a]

Age, years	Height, cm	Weight, kg	Heart, g	Liver, g	Kidney, g	Brain, g
2-4	82 (15)[b]	9.0 (2.2)	46 (16)	346 (75)	32 (10)	511 (380)
(n = 5)	(70-104)	(6.3-11.3)	(30-65)	(245-440)	(20-50)	(220-1010)
Normal	87-111	12.2-19.4	58-100	350-600	36-52	950-1200
12-15	123	24.6	125	730	64	942
(n = 3)	(117-132)	(18.2-36.7)	(110-140)	(650-800)	(40-95)	(380-1395)
Normal	139-168	31.8-54.8	120-240	800-1270	62-100	1230-1340
16-19	109 (57)	28 (16.4)	194 (104)	642 (550)	68 (20)	911 (394)
(n = 5)	(99-175)	(14.5-56.2)	(110-350)	(320-1500)	(35-90)	(400-1345)
Normal	161-170	51.4-62.0	200-280	930-1560	92-135	1260-1400
20-29	142 (14)	36.0 (13.5)	198 (58)	1088 (415)	92 (26)	1038 (313)
(n = 16)	(112-165)	(18-67)	(100-280)	(565-1775)	(60-170)	(650-1775)
Normal	165-170	56-68	265-315	1370-1580	120-145	1250-1400
>30	148 (14)	44.7 (10.6)	260 (50)	1262 (355)	98 (28)	922 (113)
n = 4	(135-168)	(35-58)	(200-310)	(940-2010)	(70-140)	(775-1050)
Normal	165-170	58-72	270-340	1370-1600	120-145	1240-1390

[a]One child who was autopsied was less than 1 year of age, and is excluded from this table. No patients between the ages of 5 and 11 years of age were autopsied.

[b]Values are given a mean (SD) and (range).

such a diagnosis can be very important to the patient's family, who may be concerned for the health of future generations. Similarly, detection of a congenital malformation can alleviate concerns, sometimes medicolegal, about the role of birth trauma or hypoxia in the etiology of retardation.

Many studies over the past 40 years have shown increased mortality in developmentally disabled patients when compared with normal individuals [*1-15*]. The mortality rate increases with increasing severity of mental impairment [*3,4,8,9,12*]. Improved care has resulted in improved survival rates for less severely impaired individuals [*4,6,8,15*]; however, the life span of the severely or profoundly impaired patient remains significantly decreased, averaging less than 20 years [*4,8,15*]. Indeed, a recent study has shown an increase in the mortality rate in patients who were hospitalized in 1980 compared to those admitted in 1970 [*17*].

Throughout the years, mortality from respiratory causes has been found to be the most important cause of death in developmentally disabled patients [*1-3,5-9,12-15,18,19*]. The percentage of deaths as a result of respiratory illnesses seems to have increased somewhat over the years. On the other hand, fatalities from other diseases, most notably tuberculosis, are declining [*3,6,7,15*]. With many disabled children now living to adulthood, some different diseases are becoming increasingly important as causes of death. For example, atherosclerotic disease (resulting in myocardial infarction and cerebrovascular accidents) and malignant diseases are becoming more common [*9,10,13-15,20*]. In addition, dementia is being seen more frequently in aging impaired persons, especially in those with Down's Syndrome [*21*]. Although patients with Down's Syndrome are commonly less severely impaired than those with other syndromes, they are susceptible to a spectrum of associated illnesses, including congenital heart disease and leukemia [*11,14*]. Epilepsy, which was once a common cause of death in impaired patients, usually can be controlled with anticonvulsant medications [*15,20*]. However, these medications themselves may contribute to aspiration, which can be lethal [*20,22*]. A significant percentage of patients in a recent study had anticonvulsant levels above the therapeutic range, which may result in other forms of toxicity [*22*]. Feeding gastrostomies placed in severely disabled patients to improve their nutritional status can also exacerbate respiratory problems [*23*].

The weights of organs at autopsy in these severely disabled patients are markedly less than those of normal persons of the same age. These findings are important in the pathological examination of developmentally disabled individuals, in that their organ weights should be compared with a similar population, rather than with normal adults.

Equally, or perhaps more important are the "negative" findings in the autopsy of a mentally retarded individual. Because these patients reside in institutions, often state-funded, their deaths may be accompanied by the suspicion of neglect or abuse. Documentation that proper care was given is very important to family members. Indeed, sexual abuse was documented in one of our cases. This would probably have remained unnoticed had not a careful autopsy been performed.

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