

No-fault compensation for ventilator-dependent children: a reasonable settlement value for lifetime attendant care

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Abstract: Severe neurological outcomes sustained in childhood often result in lifetime health care needs that are beyond the financial means of most families. When severe neurological deficits are alleged to have resulted from professional negligence, relief may be sought through litigation; however, the American tort system often yields inconsistent results or no compensation for patients. We sought to identify a reasonable, objective, and data-based monetary range for a no-fault compensation system with high- and low-financial limits for those with severe neurological deficits. Based on documented life expectancies and attendant care cost studies, the data analysis indicates a no-fault settlement payment ranging from US\$479,712.24 to \$3,098,504.16, reasonably ensures care and services for life.

Keywords: cost of health care, health law, health regulation, long-term care, medical malpractice

Introduction

Severe neurological impairments affect many facets of daily life. In some cases, a breathing machine (ie, mechanical ventilator support) is required for life. Medical technologies, such as mechanical ventilation, have substantially increased survival and life expectancy rates for even the most severely neurologically impaired individuals.¹ Longer survival made possible by mechanical ventilator support necessitates life-care planning to account for comprehensive lifelong medical support needs.

When the severely neurologically impaired individual is a ventilator-dependent child, and such deficits are alleged to have resulted from professional negligence, life-care planning through a medical malpractice settlement may be a preferable option to consider compared to protracted litigation with an uncertain expense and outcome. A 2013 study, found that more than half of families with a ventilator-dependent child reported unmet needs for care, namely an unmet need for skilled nursing care.² Unsurprisingly, financial difficulties were significantly related to an unmet need for care of ventilator-dependent children.² West's Jury Verdicts and Reporters from the four most populous states – California,³ Texas,⁴ Florida,⁵ and New York⁶ – show that the range of verdicts for medical malpractice cases involving ventilator dependence are egregiously disparate. In California, cases have ranged from US\$0 defense verdicts to \$23,900,000 plaintiff verdicts, \$0 to \$33,346,000 in New York, \$0 to \$28,300,000 in Texas, and \$0 to \$20,000,000 in Florida. For the ventilator-dependent plaintiffs who receive a jury verdict, on average, 54 cents of every dollar of compensation awarded is spent on litigation fees and costs.⁷ Regard-

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less of a jury's determination to award the low of \$0 to the high of \$33,346,000, this small but expensive cohort of ventilator-dependent children will still necessitate care. We undertook an analysis of available data to objectively identify a reasonable range of compensation for a fair, no-fault life-care plan approach to avoid the shortcomings noted above of the current American medical malpractice liability system to provide children with severe neurological injuries care for life, without burdening patients and health care providers with years of protracted and costly litigation, and subject to the inconsistent determinations of the current jury system.

Materials and methods

Literature search

We undertook a literature search focused primarily on two factors having paramount influence in determining reasonable compensation for ventilator-dependent children: life expectancy and attendant care costs. Average life expectancies of ventilator-dependent individuals and hours of attendant care provided to such individuals were calculated based upon collective data from existing survival studies. The literature review supports a range that, when combined, provides an objective data-based justification for high and low lifetime dollar amounts to support children with severe neurological damage for life.

All studies we reviewed regarding life expectancy dealt specifically with populations of ventilator-dependent persons. Ventilator dependence was defined as, "any type of mechanical ventilation to sustain daily respiration for at least part of the day".⁸ Literature searches were conducted through Google Scholar and PubMed. A search of "ventilator-dependent children, life expectancy" resulted in 1,580 articles through Google Scholar and four results through PubMed. Due to the relatively low amount of relevant life expectancy studies for ventilator-dependent children, an additional, broader search was conducted for "ventilator-dependent, life expectancy," which resulted in 20,300 articles from Google Scholar and ten from PubMed. After sorting and eliminating by title and abstract, those articles that did not address ventilator-dependent populations or expressly did not include minors; seven of the ten PubMed articles were reviewed and 15 non-repetitive Google Scholar articles were reviewed. Of the 22 articles reviewed, seven were particularly salient to determining life expectancy in ventilator-dependent children.

Neither Google Scholar nor PubMed searches resulted in any information regarding rates of pay for home health

care nurses and aides. A standard Google search for "rates of pay, home health-care" resulted in 6,960,000 hits, with the vast majority found to be unhelpful. Whereas the Bureau of Labor Statistics (BLS) is a useful resource for determining self-managed care, most nursing and home health care agencies are not forthcoming with their salary documentation. Therefore, we were required to pull agency information from the limited reports to state legislatures available to the public. Rates of pay for self-managed care were taken from the BLS and increased by 15% to show variation and to account for withholding and other deductions. Institutional or agency managed-care rates were taken from the legislative report of the Florida Agency for Health Care Administration, the Healthcare Financial Management Association, and from Prince et al,¹⁷ inflated to 2015 dollars using the BLS wage inflation formula (nominal wages₁/consumer price index in year 1) × consumer price index in year 2.^{9,10}

Results

Life expectancy

A severe neurological injury resulting in ventilator dependence can drastically reduce the injured party's life expectancy.¹¹ DeVivo and Ivie¹¹ published one of the earliest survival studies of ventilator-dependent persons with spinal cord injuries (SCIs) by age. In their 19-year study conducted on 435 persons who sustained traumatic SCIs resulting in ventilator dependence, participants were divided into 5-year intervals beginning at age 5 years and finishing at age 80 years. Those subsamples were further delineated by life expectancies for "Day One Admits", "Year One Survivors", and "Year Two Survivors". All persons remained ventilator-dependent at the time of discharge or died prior to discharge while still ventilator-dependent. At age 5, Day One Admits had the lowest life expectancy at just 8 years, an 89% life expectancy reduction.¹¹ Year One and Two Survivors fared much better than their Day One counterparts, with life expectancies of 26.8 years (62% reduction) and 35.8 years (51% reduction), respectively.¹¹

A similar study in the UK viewed three groups of ventilator-dependent patients aged between 0–30, 31–45, and 45 plus years for 24 years.¹² Cases were excluded if ventilation lasted fewer than 5 days, and all the patients were personally known by at least one of the study's authors. Of the 262 patients having invasive ventilator support, 55 patients remained ventilated upon discharge. This study found that ventilator-dependent patients in the 0–30 years age group had a mean life expectancy of 18.4 years from the time

of ventilation, gaining nominal (<1 month) additional life expectancy after the first year of ventilation.¹²

One of the lengthiest studies reviewed was performed by Gilgoff and Gilgoff,¹³ which tracked the progress of 39 children, all of whom were ventilator-dependent by their sixth birthday. Of the 39 children, 16 required ventilation due to SCIs: 14 C2 injuries, one C3 injury, and one C4,5 injury. The remaining 23 children had severe neuromuscular diseases, including spinal muscular atrophy, nemaline (rod) myopathy, polio, congenital muscular dystrophy, demyelinating neuropathy, mitochondrial myopathy, and myotubular myopathy. Four of the 16 SCI children died during the study, and of these, the average age at the time of ventilation was 4 years 1 month, and the average lifespan was 10 years 7 months post-injury. For the entire study, the survival rate was 71% at 10 years.¹³

Several additional studies have attempted to quantify the life expectancy of ventilator-dependent persons with neurological injuries, but have purposefully excluded children.^{8,14} Two such studies were conducted, one by the National Spinal Cord Injury Statistical Center at the University of Alabama-Birmingham and the other by Shavelle et al.⁸ Both studies involved patient populations wherein the youngest participants were, on average, 20 years of age at the time of injury. The National Spinal Cord Injury Statistical Center found that 20-year-old individuals at the time of injury had a life expectancy of just 19.2 years from the time of ventilation.¹⁴ Similarly, Shavelle et al.⁸ found that 20-year-old individuals >3 years post-injury had a life expectancy of 21.9 years from the time of ventilation. These findings demonstrate that while previous studies involved smaller populations due to the relatively low number of ventilator-dependent persons, the statistical data are nonetheless sound. Even with a population >70 times DeVivo and Ivie's¹¹ initial study, the average life expectancy of a severely injured, ventilator-dependent individual remains <40 years.

In spite of medical advances, a more recent 2012 study found "no meaningful reduction" in mortality rates since the late-1980s for those with severe neurological injury and ventilator dependence, widening the gap in life expectancies between the general population and those persons with ventilator dependence.^{15,16} Therefore, the current understanding of the life expectancy data for ventilator-dependent children remains relatively unchanged from the published range of 8 to ~36 years (Table 1).

As the aggregate hours of attendant care required by ventilator-dependent children typically represent the most significant item in lifetime health care costs, the life expectancy data are a critical step in determining the cost

Table 1 Average life expectancy of persons with ventilator dependence

| Study | Age (in years at time of injury) | Life expectancy (in years post-injury) | Population |
|-----------------------------------|----------------------------------|---|------------|
| DeVivo and Ivie ¹¹ | 5 | 8.0 (day 1) 26.8 (year 1) 35.8 (year 2) | 435 |
| Watt et al ¹² | 0–30 | 18.4 | 293 |
| Gilgoff and Gilgoff ¹³ | <6 | N/A (71% survival) | 39 |
| NSCISC ¹⁴ | 20 | 19.2 | 30,532 |
| Shavelle et al ⁸ | 20 | 21.9 | 319 |

Abbreviations: NSCISC, National Spinal Cord Injury Statistical Center; N/A, not available.

Table 2 Average costs per hour of care

| Level of care | RN (US\$) | LPN (US\$) | CNA (US\$) | HHA (US\$) |
|-------------------------------|---------------------|---------------------|---------------------|---------------------|
| BLS (self) | 32.04 ¹⁹ | 20.43 ²¹ | 12.06 ²² | 10.28 ²³ |
| BLS (15% inflation) | 36.85 | 23.49 | 13.87 | 11.82 |
| AHCA (agency) ²⁴ | 43.85 | 31.34 | 18.45 | N/A |
| Prince (agency) ¹⁷ | 58.61 | 43.19 | 21.59 | N/A |
| HFMA (agency) ²⁵ | 59.67 | N/A | N/A | N/A |

Abbreviations: RN, registered nurse; LPN, licensed practical nurse; CNA, certified nursing assistant; HHA, home health aide; BLS, Bureau of Labor Statistics; AHCA, Agency for Health Care Administration; HFMA, Healthcare Financial Management Association; N/A, not available.

of medical care and thereby reasonable compensation for ventilator-dependent children.

Attendant care cost

Historically, ventilator-dependent persons have been viewed as chronic patients entirely reliant upon health care professionals for treatment.^{17,18} In recent years, however, health care professionals and academics increasingly endorse self-managed care over the less autonomous, more costly agency-provided care.^{17,19} In a self-managed system, costs for health care services can be reduced to fair market value. According to the BLS, patients can hire a registered nurse (RN) for an average of \$32.04/hour,²⁰ or a licensed practical nurse (LPN) or licensed vocational nurse for \$20.43/hour.²¹ Certified nursing assistants (CNAs) earn an average of \$12.06/hour²² under a self-managed system, while home health aides earn an average of \$10.28/hour.²³

By contrast, costs for care provided through agencies are typically markedly higher (Table 2). In a 2015 report to the Florida Legislature, Agency for Health Care Administration submitted figures from over 200 institutions detailing their pay for RN, LPN, and CNA levels of care (figures for home health aides were not reported, as this position generally requires no certification).²⁴ On average, reported hourly wages were \$43.85 for RNs, \$31.34 for LPNs, and \$18.45

Table 3 Yearly and lifetime attendant care costs

| Level of care | Self-managed care (h/day) ¹⁸ | Agency-managed care (h/day) ¹⁸ | Yearly range of costs (US\$) (self) | Yearly range of costs (US\$) (agency) | Lifetime range of costs (US\$) (8–36 years) (self) | Lifetime range of costs (US\$) (8–36 years) (agency) |
|-----------------------------------|---|---|-------------------------------------|---------------------------------------|--|--|
| Skilled nursing (RN/LPN) | 1.5 | 1.6 | 11,185.43–20,175.38 | 18,302.56–34,847.28 | 89,483.44–726,313.68 | 146,420.48–1,254,502.08 |
| Personal care assistant (CNA/HHA) | 13.0 | 6.5 | 48,778.60–65,813.15 | 43,772.63–51,222.28 | 390,228.80–2,369,273.40 | 350,181.04–1,844,002.08 |
| Unpaid care | 4.3 | 7.7 | 0 | 0 | 0 | 0 |
| Total | 18.8 | 15.8 | 59,964.03–85,988.53 | 62,075.19–86,069.56 | 479,712.24–3,095,587.08 | 496,601.52–3,098,504.16 |

Abbreviations: RN, registered nurse; LPN, licensed practical nurse; CNA, certified nursing assistant; HHA, home health aide.

for CNAs.²⁴ Nationally, Healthcare Financial Management Association documented the “total all-in” hourly cost of an agency RN to be \$59.67.²⁵ For illustrative purposes, we include costs calculated by Prince et al¹⁷ based upon a study involving 71 ventilator-dependent persons with high quadriplegia (C1–C4). Based on actual hours reported and charges billed for the subject population, and adjusted for inflation to 2015 dollars, hourly rates averaged \$58.61 for RNs, \$43.19 for LPNs, and \$21.59 for CNAs.¹⁷

Hours of attendant care

Using data from their study involving 71 persons, Prince et al¹⁷ also calculated the average number of hours of attendant care required by ventilator-dependent persons at least 1 year post-injury, in both self-managed and agency-directed systems. On average, those persons who had self-managed care had a comparable amount of care by skilled nurses (1.5 h/day for managed vs 1.6 h/day for agency); a significantly higher amount of paid non-skilled nursing care (13 h/day vs 6.5 h/day); and significantly less unpaid care from a spouse, family member, or other caregiver (4.3 h/day vs 7.7 h/day).¹⁷ Although no studies have demonstrated significant disparity in life expectancy rates, they have shown that all persons with ventilator dependence, especially children, benefit from plans of care in which they participate.^{17,19} Self-selected and self-directed care leads to a higher sense of self-worth and fewer hospitalizations.¹⁹

When the costs of attendant care are combined with the life expectancy range of 8–36 years, lifetime attendant care costs range from \$479,712.24 to \$3,098,504.16 (Table 3).

Contributory/collateral sources

Contributory/collateral sources are defined as compensation from a source independent of the parties settling and are beyond the scope of this article.²⁶ Many of these sources are fully or partially funded, such as lifelong medical care for all Americans through the Affordable Care Act²⁷ and care for

categorically needy children through Medicaid and the Children’s Health Insurance Program.²⁸ Another example, involving children, is the Individuals with Disabilities Education Act, through which ventilator-dependent children are eligible for a range of “related services” concomitant to their right to public education.²⁹ To determine eligibility and services, the school system must evaluate each child with a disability and develop an individualized education plan created by a team of teachers, administrators, health care providers, experts, and the parents or guardians.²⁹ The Supreme Court of the United States has determined that if continuous “one-on-one nursing service” is required to keep a ventilator-dependent child with high quadriplegia in school, then it is the school district’s responsibility to provide that service.³⁰ Collateral sources can offer important supplementary care and services to ventilator-dependent children at little or no out-of-pocket cost to parents or guardians.

Discussion

We aim to objectively outline the necessary costs to reasonably care for the most severely neurologically impaired children regardless of cause. We do not propose a complete replacement of the medical tort liability by no-fault compensation programs. Though there is much academic debate ongoing about the efficacy and practicality of implementing replacements for tort law, there are tangible examples of no-fault compensation programs already in place that successfully care for patients with the greatest needs. Examples would be, Florida’s Birth-Related Neurological Injury Compensation Association³¹ and Virginia’s Birth-Related Neurological Injury Compensation Program (Birth-Injury Program).³² Both programs utilized enabling legislation to create funds, paid into by health care providers and facilities, which provide compensation to eligible claimants for life and have had long-term success in meeting the life needs of claimants.³³ Both programs have stringent medical and procedural eligibility standards, along with restrictions on

qualifying claimants' remedies at tort.³³ Due to their no-fault nature, both the Neurological Injury Compensation Association and the Birth-Injury Program have reduced physician risk of being reported to the National Practitioner Data Bank, and reduced all practitioner premiums by mitigating "truly catastrophic claims".³⁴ Creating a program through legislation is preferable for implementation and uniformity; however, a national legislative mandate may have the widest impact given the varied approaches used by each state. Some states such as Florida have had success with contractual agreements with patients regarding mandatory mediation agreements, but establishing a no-fault program through contract would be challenging.³⁵

If one were to follow Florida's Neurological Injury Compensation Association program model, then after establishment by the legislature, annual assessments of participating and nonparticipating physicians, and hospitals would need to be collected.³³ Participating physicians would typically be neurosurgeons and orthopedic spinal surgeons, and the savings on premiums from removing the high damage claims may sufficiently fund a significant portion of the no-fault program. Nonparticipating physicians may also pay a negligible amount, which would benefit the medical community and health care consumers in the aggregate. As another option, purchasers of health insurance could provide a modest payment, supplemental to the practitioners and providers, further dispersing costs.

In creating a non-adversarial remedy there must be constraints on discretion of the assignment of damages and like parties must be treated alike.³⁶ These steps reduce the tort phenomenon where the aggregate creates the appearance of equity, while in actuality most claimants are significantly undercompensated and others are significantly overcompensated.³⁶ Metrics for qualification must be determined to effectively compensate the narrow but expensive cohort of ventilator-dependent children. Criteria could include an age restriction, neurological devastation, ventilator dependence, a complete injury, and an American Spinal Injury Association "A classification".¹ Additionally, such a no-fault program would not put an undue burden on health care facilities, as it would not require that every facility, such as rural or underfunded hospitals, conform to a national standard, and may instead reduce the burden of malpractice premiums, while caring for some of their most vulnerable patients.

The challenges to implementing a no-fault program for ventilator-dependent children are mainly administrative: enacting enabling legislation by either citizen initiative or through the traditional legislative process, ensuring that

hospitals and medical centers conform to either the new laws or programs, and combating fears from the public and plaintiff's bar that physicians will be able to commit malpractice and face no meaningful consequence through no-fault program. Most states, legislators, and lobbying groups are not prepared for a massive overhaul of the traditional tort system and critics of no-fault programs view their implementation as a failure to utilize the adversarial system to influence providers and deter adverse incidents.³⁷ However, examples from no-fault compensation programs both in the US and abroad have proven those fears to be unfounded.^{33,38} In New Zealand, where the entire medical liability system has been replaced by no-fault compensation programs through the Accident Compensation Corporation, the accountability function of the New Zealand tort system has been replaced by the establishment of the Health and Disability Commissioner with the directive to promote patients' rights and to act as a "gatekeeper" to disciplinary hearings.³⁸ Similarly, in Virginia, the Board of Medicine and the Department of Health are required to review all claims submitted to the program to determine if any disciplinary action should be taken against the provider or the facility.³³ While states may not be fully prepared for a complete shift, such as what has occurred in New Zealand, it is clear from the success of programs in Virginia and Florida that states are prepared to slowly and incrementally implement no-fault programs to benefit their most vulnerable populations.

Conclusion

To combat the uncertainty, high costs, and time associated with medical malpractice litigation in the US, legal and medical experts have advocated for a no-fault system to ensure needed care for ventilator-dependent children. Existing life-expectancy data for ventilator-dependent children and published wage data can be used to identify a reasonable range for lifetime attendant care costs from \$479,712.24 to \$3,098,504.16, with a median of \$1,789,108.20. Such calculations can be updated as new data (eg, cost of wages) become available and further accomplished using annuities and other financial planning options that allow present dollars to continue growing to provide financial security in future years. Further, we would note the less costly option of self-managed care for selected patients be considered, because that enables compensation dollars to cover more hours of attendant care per day over a longer period of time, while also providing the emotional and physical benefits of autonomy. Life expectancy and attendant care costs are the largest variables to consider in determining the reasonable and

fair compensation amount for a ventilator-dependent child. Collateral sources exist at varying levels to address many remaining costs of caring for ventilator-dependent children for life. The compensation, as derived from this data, when used in conjunction with an annuity or structured settlement through a life-care plan, will allow for a ventilator-dependent child to receive necessary care while not exacerbating the current insurance premium crisis.

Implementing a system that supports ventilator-dependent children begins with an analytical understanding of long-term care costs, as they are one of the most contentious, limiting factors to reaching resolution. Accordingly, a no-fault compensation program using the proposed range of \$479,712.24–\$3,098,504.16 present day value will reduce settlement uncertainty and delays, and may lower malpractice premiums, all while providing care for the most seriously in need, ventilator-dependent children by ensuring that the most costly service for such patients, daily attendant care, continues for life.

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