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Invited Commentary

Commentary on "Causes of death among people with myelomeningocele: A multi-institutional 47-year retrospective study" by Szymanski et al.

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At first glance, a retrospective report of the cause and manner of death in a cohort of individuals with myelomeningocele may seem dark, actuarial, or both, but the real world need for an understanding of the mortality risks of this disorder cannot be ignored. While preparing this commentary, a parent of a healthy five-year-old girl with myelomeningocele asked me if the fact that she had survived a tumultuous infancy meant that she could be expected to live to "a typical life expectancy?" The challenge of answering this question for patients and their families is quite real.

In this report, Szymanski et al. add to the existing literature on this topic, primarily consisting of single center reports of long-term outcomes [1]. Their approach is to use a large convenience sample of known deaths reported to 16 centers in the USA and Canada, representing a broad sample of multidisciplinary spina bifida clinics. In each case, the cause and manner of death were identified if known. The 293 patients were grouped by those who had been treated for hydrocephalus (shunt or endoscopy, 89%) and those not treated for hydrocephalus. In the shunted population, the leading cause of death was neurologic, but the leading manner of death was infectious in both shunted and unshunted patients. The authors rightly point out that the shunt was not necessarily the direct cause of death (i.e., by shunt malfunction or infection), but its presence is an indicator that the patient's care was more complex. It is fair to say that this complexity of care likely increases the possibility of a lethal comorbidity, such as pulmonary or urologic infections. With a median age at death of 19 years, but with 12% of deaths occurring in infancy, it can be said that early death is infrequent in this population, but not zero. Surviving infancy is indeed a somewhat predictive achievement in this diagnosis.

Much remains to be learned in this area. Fully one quarter of these patients had no clear cause or manner of death identified, especially for those who died outside of the hospital setting. The lack of detail in death certificate data makes it difficult to identify causes of sudden death, such as acute shunt failure, sudden unexpected death in epilepsy, or latex anaphylaxis. Future efforts in this area should strive to fill in these knowledge gaps and build on the data presented in this excellent work.

1. Szymanski KM, Adams CM, Alkawaldeh MY, et al. Causes of death among people with myelomeningocele: A multi-institutional 47-year retrospective study. J Pediatr Rehab Med. 2023;16(4). doi: 10.3233/PRM-220086.