Health Care for Adults With Cerebral Palsy and Spina Bifida—Must It Be so Difficult?

For children with cerebral palsy and spina bifida (CP/SB), their complex medical needs are often coordinated through a medical home or multidisciplinary clinic setting. In these settings, a care team works to coordinate appointments, follow up on missed appointments, and facilitate communication with and between medical providers and patients. This care coordination is often done through many methods and contact points. Despite this, children with CP/SB may still have unexpected or potentially preventable hospitalizations (PPHs) for urinary tract infection (UTI), pneumonia, pressure wounds, and other illnesses. However, through these medical homes and multidisciplinary clinics, these types of hospital admissions are reduced.1

In this issue of Mayo Clinic Proceedings, Mahmoudi et al2 retrospectively reviewed claims from a large private insurance database, finding that adults with CP/SB have a significantly greater risk of PPH for respiratory illnesses or UTI compared with adults without disability. Specifically, for adults with CP/SB, there is an 85% greater chance of a PPH for chronic obstructive pulmonary disease, more than 300% greater chance of a PPH for pneumonia, and more than 600% greater chance of a PPH for UTI compared with adults without disability.2 The odds of a PPH were more than 4 times greater in adults with CP/SB than in those without disability.2 Whereas adults with CP/SB were significantly more likely to have office visits with a medical provider and significantly more likely to have diabetes, cholesterol, and bone density screening, they were less likely to have well visits. In both cohorts, being screened for diabetes or needing physical or occupational therapy increased the odds of a PPH, whereas annual wellness visits were protective.

This study is striking in the fact that even with private insurance, individuals with CP/SB have fewer well visits and greater risk of PPH than peers. However, what is also striking is that adults with CP/SB had greater number of medical comorbidities, greater number of clinical office visits, and greater number of preventive health screening tests than peers without disability. It is not clear whether the greater number of clinic visits for adults with CP/SB is due to care for the conditions that resulted in the PPH. It is also possible that some clinical office visits may have been used for scheduling screening tests, resulting in the increased number of screening tests that was seen in adults with CP/SB, despite fewer wellness visits. Combining visits (ie, ordering preventive screening tests while being seen for another medical concern) can reduce health care provider visits and thereby reduce the burden and cost of attending multiple medical appointments for adults with CP/SB. The impact of increased number of medical visits and hospitalizations in disrupting activities and creating a greater financial burden is significantly greater in adults with CP/SB than in peers.3 Missed work, missed personal events, and missed time with family are all significant consequences. Thus, for some, reduced well visits may have been intentional to decrease medical clinic visit burden. However, these well visits may have facilitated identification of early symptoms of conditions that resulted in hospitalization.

Furthermore, Mahmoudi et al2 indicate that there is inequity in health care for adults with CP/SB, resulting in a greater number of PPHs. This inequity in health care is likely to be multifactorial. Primary care providers report lack of comfort with caring for adults with pediatric-onset disorders.4 A greater number of adults with pediatric-onset disorders have public insurance,3 which is generally deemed an unfavorable payer compared with private insurance and may not be...
accepted at the medical provider they wish to see or who is nearest to them. Providers may not have time to address all medical needs of a complex patient in one visit, resulting in unmet health care needs. In contradistinction, some providers may feel obligated to address all medical issues even though time allotted for the appointment is much too short, resulting in inadvertent mismanagement due to not being able to thoroughly address each issue. In a managed care setting, providers can be penalized for ordering too many tests, too many consults, or too many clinic visits, even if this is due to having patients of greater medical complexity for which all of these are necessary for the patient’s health care. Last, many adults with pediatric-onset disorders are not prepared to do their own care coordination as this may have been done through care teams and their parents when they were pediatric patients. This dramatic change in the paradigm of care experienced as a child with CP/SB to that as an adult with CP/SB contributes to gaps in care as the individual tries to navigate the adult health care system with less support than they had as a child.

This study by Mahmoudi et al highlights the result of inequities in health care for adults with CP/SB. The underlying contributors to these health care inequities are complex. Some contributors to inequity in health care for adults with CP/SB include identifying providers willing or able to take on new patients with multiple medical comorbidities, access to providers familiar or comfortable with treating adults with pediatric-onset disabilities, and, for some adults, their desire to avoid medical facilities because of poor experiences with the medical system as a child. This study suggests that access to well visits for adults with CP/SB may be a barrier, even when having the same or similar insurance as adults without disabilities. For an equitable medical system, more medical touchpoints for individuals who have a greater number of medical needs/comorbidities, like individuals with CP/SB, are needed. However, these medical touchpoints must be delivered in an efficient, convenient, and coordinated manner to facilitate access. Telemedicine and telerehabilitation can improve health care interactions while also having potential to reduce missed time from work/school or the need to arrange transportation or childcare. Contact with care providers through medical apps and online medical portals facilitates asynchronous communication, thus reducing time wasted with “phone tag” or making a medical appointment for a question that could be resolved in a different way. Screening tests performed at home reduce the burden of arranging an appointment, traveling to a medical facility, and time needed to wait to have the test performed. For those with a greater medical care burden, it is imperative that we deliver the right care to the right person at the right time.

Furthermore, it begs the question as to why health care delivery models are so strikingly different between children and adults, especially for those with complex medical needs. It is entirely wrong to think that children with complex medical needs who were successfully managed through a care team would not need or benefit from this similar model of care as adults. Yet, this is how the medical system in the United States frequently functions. Childhood medical comorbidities do not disappear when children mature and transition to adult care. For children with CP, mild respiratory difficulties that may be overlooked contribute to the dramatic respiratory morbidity seen in adults. Medical needs and complexity of individuals increase with age, not decrease. In this study by Mahmoudi et al, the significantly greater number of PPHs in adults with CP/SB indicates that health care needs of these individuals are not being met. As a physician who cares for children with CP/SB, I have seen the challenges my transitioning adult patients have had with accessing adult health care, becoming responsible for coordinating their care, and not feeling heard or seen in the adult health care setting. As a parent of an adolescent with CP, I worry that my soon-to-be adult daughter will struggle to meaningfully access and navigate adult health care, will not receive appropriate preventive health care, and will feel invisible and unheard when interacting with health care
providers, even with the support of a medically savvy family. Changes in the relationship between adults with complex pediatric-onset disorders and health care delivery must occur to improve their access to health care, to reduce the burden of health care these adults experience, and to reduce the unacceptable number of PPHs.

POTENTIAL COMPETING INTERESTS
The author reports no competing interests.

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