

Beyond growth: gastrostomy feeding in children with cerebral palsy

Children with cerebral palsy (CP) frequently grow poorly, compared with their typically-developing peers. Moreover, as children with CP age, their growth diverges further and further from that of typical children. The reasons for poor growth are multi-factorial and include nutritional, hormonal, physical, and neurological causes. Nevertheless, it appears that much of the poor growth is related to acute and chronic malnutrition at various points across the lifespan. The malnutrition is largely due to inefficient and dysfunctional feeding. While remediable to some extent, this dysfunctional feeding often cannot be overcome. Consequently, in children with (usually severe) CP, malnutrition is often treated by bypassing the dysfunctional oral feeding through the use of a gastrostomy.

The decision to place a gastrostomy is made largely because of poor growth. 'Poor' or sub-normal growth is equated with poor health. Poor growth is determined by careful measurement (anthropometry) and comparison of the results with appropriate reference standards. The anthropometric assessment of children with CP has been difficult, historically, because of difficulty in acquiring reliable measurements (particularly for height or length) and having appropriate reference data for comparison. While the problem of reliable measurement has been overcome through the use of alternative measures (e.g. upper arm length, lower leg length, and skinfold thicknesses) the problem of reference standards remains. One must question the appropriateness of general population standards for a group of non-ambulatory, severely-impaired children. The fundamental clinical question, of course, is: how small (or thin) is too small?

An important feature of most growth charts is that they are intended to be descriptive of a population, and not necessarily prescriptive for health.¹ The growth charts help clinicians determine the body size of an individual child, compared with the reference norms. This is usually described in terms of the child's growth centile (50th centile being 'average') or in standard deviation scores (z-score) from the mean. However, a child at the 10th centile (for any measure) is not necessarily less healthy than a child at the 50th centile, although clearly smaller. While clinicians may consider the 50th centile weight for a particular height as being 'ideal', in fact it is simply average for the population. The 'ideal' is defined by the average. However, no data exist linking this statistical 'ideal' to any marker of health. Similarly, while clinicians may consider the 3rd centile minimally adequate, true thresholds of nutritional adequacy as they relate to health have not been determined.

While the differences in growth between children with CP and the general population have long been recognized and well-described, relatively little work has been done to evaluate the impact of these differences on health.² In this issue

of DMCN, Sullivan and colleagues report on a prospective longitudinal trial of gastrostomy feeding in a cohort of children with severe CP. This study improves on older studies by enrolling a relatively large number in a prospective trial. They used reliable anthropometric measures as their primary outcome measure. Most importantly, the authors went beyond growth as the sole outcome and included indicators of health. While one could argue that their specific indicator of health (reported hospitalizations) is of untested validity/reliability, the important point is that they attempted to measure health more directly. Despite the relatively short-term nature of this study (one year follow up) the authors demonstrated statistically significant and clinically important improvements in weight, length, and skinfold thicknesses, coupled with improvements in health and parental worry about health. Moreover, this study also focused closely on adverse events associated with the gastrostomy feedings, finding predominantly minor side effects.

Much important work remains before the evidence will direct clinical practice. Longer-term studies are needed. In addition, the relationships between body size, composition, and health need to be investigated more closely. Such studies might lend themselves to randomization (e.g. to two different levels of nutritional adequacy). One could then compare clinical benefit, on growth and health, versus potential adverse events, such as vomiting, aspiration, pneumonia, and death. Physical growth is an important and convenient proxy for health, but currently there are limited data available about desirable limits.

The report by Sullivan et al. is a major contribution to the body of scientific knowledge. This area of research is fundamental to the care of children with CP. Furthermore, the report illustrates that the tools and background knowledge exist to devise and conduct informed clinical trials that will change our practice. However, we must utilize outcome measures that go beyond physical growth and evaluate physical functioning, general health, and health-related quality of life. By going beyond growth we have the opportunity to truly change clinical practice and improve the lives of children with cerebral palsy.

Richard Stevenson

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References

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