

Guest Editorial

Children with Medical Complexity (CMC) Offer Challenges and Opportunities for the Healthcare System

This special issue of the *Journal of Pediatric Rehabilitation Medicine* addresses the important and difficult topic of Children with Medical Complexity (CMC). As with many diagnoses in health care that involve co-morbidities, nothing is simple. In the case of CMC we do not have a consensus definition [1]. This lack of a uniform definition makes discussion of quality measures and determining resources needed by patients and caregivers virtually impossible. How do we determine what we need to measure if we do not even know what the entity is that needs to be assessed? How do we know which services need to be coordinated? That said, some themes are important for children who may be CMC. For example, the family and caregivers have a tremendous burden on them with CMC. Yet we do not know whether our rehabilitation services help unburden them or actually add burden. Thus, surveys of patient/family satisfaction are important because we need to make sure they are not under too much stress. We likely also need to be able to gather data remotely and communicate with the child and caregivers using telehealth and other virtual technologies. The article by Cormack et al. starts addressing this major problem and potential ways to deal with it.

These children have so many problems we need to grasp and we may not know the total care they are receiving. For example, how often are they visiting outpatient clinics, what is the variety of these clinics, how often do they go to the Emergency Department and how often are they admitted to the hospital? Is an admission for one or more issues? Without this type of information, we will never know the scope of resources needed, and the cost in time and money to our healthcare system and to employers, etc. For example, in

the article by Kral et al., an association is found between epilepsy and ADHD. The management of these two disparate problems requires the proper expertise and excellent interprofessional approaches in order to achieve the proper coordination of care.

Another important theme that this special issue addresses is predicting future disability. Making reasonable predictions of future impairments and disability will help clinicians and others plan for the needs of these children and their caretakers. For example, one of the articles in this issue describes the use of diffusion tensor imaging (DTI) of brain axons to predict motor function [2]. This knowledge may help us allocate resources properly while helping families modify their home appropriately. In another article, prone hip angle evidently can serve as a proxy for the 42-item Test of Infant Motor Performance (TIMP) in preterm infants [3]. This would be a relatively simple way to gauge motor performance and may indicate occult brain damage. Again, all of this information will help with proper treatment and resource planning for the children and their caretakers. Moreover, this simple hip angle measure may cue us to use more advanced testing such as DTI to more precisely determine future deficits.

In summary, CMC is a complex diagnosis. Our lack of a consensus definition is probably limiting development of quality outcome measures so that we can assess needs and determine whether or not therapeutic measures are helpful. If we do not know what services are needed, then it is hard to coordinate services. At the same time the healthcare system in the United States is highly decentralized, which in itself limits our ability to coordinate services and avoid duplication of ser-

vices. And we also might be missing delivering some services. I think some of these articles in this issue provide a ray of hope. For example, the Cormack et al. article suggests ways in which we might get good information about remote patients/caregivers and possibly provide appropriate interventions using telehealth. The articles by Coker-Bolt et al. and Shehee et al. may give us a handle on prediction of future needs for patients and caregivers. The article by Kral et al. reinforces that there are many levels to the complexity of CMC. CMC is an area ripe for important research. I hope these articles give a hint of what is necessary and what is possible.

Guest Editor

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