

When Families of Children With Medical Complexity Are Left to Their Own [Medical] Devices

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Families of children with medical complexity do not have it easy. Among multiple other challenges, they have to juggle numerous subspecialist appointments, insurance issues, and the socio-emotional impact of being on call 24/7/365.

And the equipment! There is often so much equipment - supplies, machines, and other devices. What happens once the medical supply company drops off all of the equipment, and the family is left (often without adequate home health support) to deal with all of this? We see these families at intermittent intervals, but do we really know what is happening in the home?

This week in *Pediatrics*, we are early releasing a fascinating paper by Hanna Barton and her colleagues in pediatrics and engineering at the University of Wisconsin that describes families' experiences with medical devices ([10.1542/peds.2020-019513](https://doi.org/10.1542/peds.2020-019513)).

The authors conducted a qualitative study in which they made home visits to 30 families with children who are medically complex. The parents were asked to physically walk through the typical daily tasks that were required to care for their child. The investigators used an interview guide for these home visits, recorded the visits, and then analyzed the transcripts for barriers to medical device use and the workarounds that families used to bypass these barriers.

There were 4 major themes regarding barriers: 1) quantity/type of devices were not adequate for what the child really needed, 2) devices were often not designed to be used where they needed to be used, 3) the use of some devices was disruptive, and 4) the device did not fit the user.

Parents described multiple workarounds. For instance, parents would wash and re-use single use items, such as suction catheters, for as long as possible. Some parents physically modified devices so that they could be used, would better fit the child, or were less disruptive. Some parents stopped using devices that were too disruptive.

This was such an enlightening paper to read. You will be impressed with the ingenuity of parents, while at the time feel alarmed or shocked at some of the workarounds that parents were forced to use.

Please read this paper! Even if you don't have many patients who are medically complex in your practice, the insights in this paper will change your approach to families when you prescribe a device as mundane as a multi-

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dose inhaler and a spacer device.

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