

Family Burden and Medical Complexity: Wrestling with the Meaning and Impact of Commonly Used Terms

by Meg Comeau, MHA, Senior Project Director at the Center for Innovation in Social Work & Health, Boston University School of Social Work, and Parent of a Young Adult with a Chronic Condition

I'm currently working on a project¹ that is focused in large part on improving the quality of life for children with medical complexity (CMC) and the well-being of their families. It's exciting work, and I'm privileged to be part of it. In addition to working in the field, I'm also the parent of a young adult who was born with a complex genetic syndrome.

Perhaps because of this dual identity, I have found myself a little uncomfortable with certain terms and concepts that are commonplace and generally accepted within the world of CMC. I'm not sure that families and professionals always understand what these terms can mean from different vantage points.

Two terms in particular could benefit from reexamination.

When researchers seek to measure concepts that influence children's quality of life and the well-being of their family, they often consider measuring "family burden." The concept of family burden generally includes measures of financial hardship, emotional stress, and the health-related impacts of physical caregiving.

But these burdens are not caused by my child or any of my family members. They are not the direct result of my complex caregiving responsibilities. They are the result of deficits

in the systems that surround us; the systems that are supposedly designed to support us.

I'm concerned that these deficits are not recognized as the causes of family burden. My personal experience is that often the child with complex needs is seen as the burden, not the systems that fail to provide adequate insurance coverage, meaningful mental health services, and easy access to high quality community-based supports.

Stigmatizing the child is obviously upsetting (as a parent, a public health professional and a human being) but it's also dangerous. When people with special health care needs and disabilities are perceived as "less than" or "burdensome" (either on their families or on society) they become vulnerable in ways that can be frightening, such as an increased risk of bullying, abuse, or neglect.

A second, related term that I find problematic is "complexity." What do we really mean when we talk about complexity? In my work, I use a definition of medical complexity that is widely acknowledged as a standard in the field. One of its many attractions to me is that it includes "need" for a high level of health care services in addition to receipt of them. Simple utilization data will only tell you what was paid for, not necessarily what was needed by a family.

It certainly can't easily tell us anything about the impact – the burden imposed – of unmet needs or services.

The current definition of medical complexity is typically focused on multiple affected body systems, the need for or use of high levels of health care services, and often the presence of life-sustaining medical technology. This definition has great utility in many contexts. But is it enough? Could we broaden our definition of what constitutes complexity when thinking about sources of family burden and systems-based deficits?

For example, social determinants are appropriately beginning to be included as part of the definition of medical complexity. A relatively straightforward and manageable health care need in a child can become astonishingly complex if that child is homeless, or in foster care. Similarly, families of children who experience significant behavioral or mental health issues encounter systems that are not designed to meet their needs: coverage is scanty, providers are in short supply and there is little integration to help coordinate and improve the quality of their care (not to mention its cost-effectiveness).

It's no wonder that families who experience any combination of these factors often are crushed beneath the burden of system-based deficits.

These types of issues should be factored in when deciding what constitutes complexity and thus eligibility for services.

The lack of high-quality, reliable, affordable services is felt most acutely by children and families, but others—pediatricians, schools and payers—also experience related burdens that hinder their ability to operate at peak performance. This in turn inhibits their ability to serve children and families effectively. It begins to feel like a never-ending cycle in which we're all stuck together.

I encourage those who have the power to influence CMC

research, and to improve the systems that serve these children and their families, to examine their thinking about the terms family burden and complexity.

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We should place responsibility for burden on the system deficits that cause the burdens, not on the child and family, and we should acknowledge the many non-medical factors that contribute to complexity. Having better definitions will allow us to work together to repair the system flaws. Anyone and everyone who loves, is in service to, or has responsibility around the health and well-being of CMC has a role to play.

The views expressed here are my own, and not representative of the CMC CoIIN project or the Maternal and Child Health Bureau.

References

1. Center for Innovation in Social Work & Health, Boston University School of Social Work. *The Collaborative Improvement and Innovation Network (COIIN) to Advance Care for CMC*. <https://ciswh.org/project/CoIIN-CMC>. Retrieved on June 13, 2019.

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CONTACT: The Lucile Packard Foundation for Children's Health, 400 Hamilton Avenue, Suite 340, Palo Alto, CA 94301
cshcn@lpfch.org (650) 497-8365