

## **Children with Medical Complexity: Challenges and Opportunities for Human Factors/Ergonomics**

### **Chair**

Hanna Barton, M.S., University of Wisconsin-Madison

### **Panelists**

Ryan Coller, M.D. MPH, University of Wisconsin-Madison

Sara Finesilver, Parent of a Child with Medical Complexity

Christopher Lunsford, MD, Duke University

Rupa S. Valdez, Ph.D., University of Virginia

Nicole E. Werner, Ph.D., University of Wisconsin-Madison

### **ABSTRACT**

For vulnerable patient populations, such as children with medical complexity (CMC), the patient journey is fraught with challenges. By providing a range of perspectives including clinicians, a family caregiver, and Human Factors/Ergonomics (HF/E) experts, the present panel will describe the unique opportunities for HF/E to design jointly optimized systems for CMC and their family caregivers, including an explication of some of the specific challenges and complexities related to studying the work of and designing systems for this population. We will also highlight the ways in which HF/E could help in the design of solutions to improve outcomes for families.

### **SUMMARY**

Healthcare delivery continues to increasingly focus on the management of chronic illness, which occurs not as an episodic response to an acute illness, but as a longitudinal process often referred to as the patient journey (Carayon, Wooldridge, Hoonakker, Hundt, & Kelly, 2020). The patient journey is characterized by a shift of the burden of care from professional healthcare providers to informal, family and friend, caregivers (Werner, Tong, Borkenhagen, & Holden, 2019). The patient journey perspective also requires that the home be included as a healthcare setting (Holden, Schubert, & Mickelson, 2015).

As a result of these changes, the field of Human Factors and Ergonomics (HF/E) has begun to broaden its scope to consider the activities performed by patients and their informal caregivers as a type of healthcare work (Holden, Cornet, & Valdez, 2020), and to examine the home as a healthcare delivery work system (Werner, Jolliff, Casper, Martell, & Ponto, 2018).

For vulnerable patient populations, such as children with medical complexity (CMC), the patient journey is fraught with challenges. An example of a child with medical complexity is a child born very premature and who has quadriplegic cerebral palsy, which requires

parents to manage seizures, feeding and breathing tubes, 12 different medications, and coordination across 8 specialists. CMC are 1% of the pediatric population, but they account for 30% of child health spending (Berry et al., 2014; Cohen et al., 2012).

Family caregivers of the more than one million CMC in the U.S. (Coller et al., 2015) are tasked with delivering care at home at levels typically performed by trained health professionals, such as complicated symptom management (e.g. respiratory failure, severe pain, relentless vomiting, intractable seizures) or sophisticated medical device operation (e.g. ventilators, feeding pumps). Yet, caregivers report insufficient knowledge, skills, and confidence to deliver this care at home (Fleming, 2004; Nelson et al., 2016; Wang & Barnard, 2004). As a result, family caregivers experience an imbalance between the demands required to provide care to their child and the support they receive to provide this care. This imbalance has been associated with higher healthcare costs through avoidable hospitalization (Coller et al., 2014), missed school, and lost parent employment (Coller et al., 2015; Coller et al., 2017; Coller et al., 2014), as well as broad negative physical, mental, and socioeconomic outcomes (Kuo, Cohen, Agrawal, Berry, & Casey, 2011; Thyen, Kuhlthau, & Perrin, 1999; Thyen, Terres, Yazdgerdi, & Perrin, 1998).

A new focus on the home as a healthcare delivery system and the conceptualization of the healthcare activities of patients and informal caregiver as a type of work has the potential to improve healthcare processes and outcomes for these vulnerable populations. By providing a range of perspectives including clinicians, a family caregiver, and HF/E experts, the present panel will describe the unique opportunities for HF/E to design jointly optimized systems for CMC and their family caregivers, including an explication of some of the specific challenges and complexities faced by clinicians and caregivers as well as research process challenges and opportunities. We will also highlight the ways in which HF/E in particular could help in the design of solutions to improve outcomes for families.

## THE CLINICAL PERSPECTIVE

### Exploring the home as a complex work system

*Ryan Coller, University of Wisconsin-Madison*

Family caregivers of the more than one million CMC in the US (Coller et al., 2015) are tasked with performing complex medical procedures conventionally performed by trained healthcare professionals – such as operating advanced medical devices (e.g., ventilators, IV pumps) or treating critical symptoms (e.g., severe pain, respiratory distress, persistent vomiting, intractable seizures, etc.). Imbalances between caregiving demands and supports likely has direct health consequences for children and families, including potentially avoidable hospitalization (Coller et al., 2014), missed school, and lost parent employment (Coller et al., 2015; Coller et al., 2017; Desai, Durkin, Jacob-Files, & Mangione-Smith, 2016). In addition, families are often isolated from other caregivers and their care team (Raina et al., 2005), and report important gaps in knowledge, skills, and confidence to provide this care at home (Fleming, 2004; B. B. Nelson et al., 2016; Wang & Barnard, 2004). As a result, both CMC and their caregivers can suffer broad physical health, mental health, and socioeconomic consequences (Kuo et al., 2011; Thyen et al., 1999; Thyen et al., 1998), including early death (Blackburn & Epel, 2012; Cohen et al., 2016) from caregiving stress.

Guided by the Systems Engineering for Patient Safety (SEIPS) 2.0 work system model, we evaluated parent perspectives on the home context's impact on CMC caregiving. We hypothesized that family caregivers would describe how the home context itself (i.e., the physical space, the caregiving roles and routines taking place within the home, the tools and technology used, and the interface between the home and other environments) directly influences caregiving processes and outcomes.

We sought to uncover key themes related to the physical environment, caregiving roles, and key health outcomes.

We conducted 30 in-home contextual inquiry-inspired interviews in which family caregivers walked the researcher through a typical day providing care to the CMC. Participants were recruited from our single academic institutional pediatric complex care program. Family caregivers completed a questionnaire to obtain patient and family characteristics. In-home interviews were audio-recorded and transcribed. We used an inductive thematic analysis strategy. Themes were organized and analyzed using the Social Cognitive Theory (SCT).

Our results revealed 6 key themes and 13 sub-themes. These key themes centered on: (1) physical environment of the home, (2) pursuing family stability, (3) adaptation, improvisation, error-proofing, (4) caregiver confidence, knowledge, skill, and resources, (5) child health and well-being, and (6) financial well-being. In addition to the challenges of the physical environment of their homes (e.g., stairs, multi-level homes), many parents commented on the challenges of caregiving related to external environments (e.g., school, traveling to visit family members) and bringing resources into the home (e.g., paid and unpaid caregivers). Parents described the processes by which they organize and manage resources and how they communicate information between care providers (e.g., home nursing, clinical specialists, family members, and school). Some parents addressed the strains of caregiving in the home environment on their families including strain on finances, relationships, and working outside the home.

### An interdisciplinary approach to understanding self-management practices of families in the home

*Christopher Lunsford, Duke University*

Self-management of chronic and complex pediatric conditions is challenging for families to perform and for researchers to study. To address these challenges, our research team has taken an interdisciplinary approach to understanding self-management practices in the home and community as a way to determine how best to support these families through clinical practice (Valdez, Lunsford, Bae, Letzkus, & Keim-Malpass, 2020). At the University of Virginia and Duke University, I have worked to support families as they interact with a myriad of medical services, funding support mechanisms, and social support systems. Clinically, my treatment paradigm for children with disabilities is always focused on function and quality of life while utilizing patient-centered outcomes and framework tools, such as the

International Classification of Functioning, Disability, and Health (ICF) (World Health Organization, 2001).

The ICF complements our understanding of human factors study and theory. For example, even if I see two children with strikingly similar medical conditions, they may have varying degrees of difficulty with self-management due to the ICF domains of activity and participation being affected by differing social and physical environmental contexts. We need to give every child and her family the best chance of success and I believe this combined approach allows us to understand the broader complexities of everyday life that need to be supported. Based on the findings of our study, we anticipate designing clinic-based resources that allow the clinical team to capture this broader understanding and to connect families of CMCs with the community and other resources they need to support their self-management efforts. In this talk, I will discuss how these frameworks may be conceptualized as complementary and how an analysis that combines both perspectives may serve as a foundation for appropriate clinical intervention.

## **THE FAMILY PERSPECTIVE**

### **The perspective of a parent of a child with medical complexity**

*Sara Att, Madison, Wisconsin*

Caring for my medically fragile child, now teenager, has been the greatest challenge of my life. While there are great rewards the stress at times can feel overwhelming. My daughter was born with a rare genetic disorder and has suffered from multiple strokes resulting in intellectual disabilities, speech delays and use of a wheelchair.

Her history and needs are complex and detailed. My child takes over 20 medications, has multiple tube feeds a day, a highly specialized diet and long list of diagnoses. She has had I am guessing over 50 hospitalizations. I have worked very hard to ensure that this does not define her: she has been to the top of the highest drivable road in Colorado, swam in the ocean and has been on too many roller coaster and water slides to count (I carried her to the top and she screamed with joy the whole way down). She goes to sleep away camp, attends school full-time and is active in our community. Additionally, for the entire time I have been her mom, except for a one year sabbatical, I have had a vibrant career as a full-time faculty member in higher education that provides well for my family and uses my gift and talents.

All of this is possible for two reasons: Because of advocacy (both by me and the clinicians) and shared

caregiving. Through learning how to advocate well (on both sides), communicate effectively, to team around my daughter. I believe her outcomes stay strong and she is kept safe. Through a shared caregiving team including an in home certified nursing assistant, (CNA) a paraprofessional trained to support medically fragile children at school, school nursing services, respite staff, and overnight camps with a nurse and phenomenal clinical complex care team, my daughter's world has not had to get smaller despite her age, increase in physical limitation and exponential increase in care needs; through advocacy, and shared caregiving each day her world and her future as well as and mine and our family's has only gotten bigger.

It is essential to include parents in this critical research. The extensive advocacy I perform, the creation and maintenance of the shared caregiving network for my child, and all the systems and process that entails, along with ensuring consistent and accurate communication between many parties, require that I spend extremely large amounts of effort and many hours of time trying to advocate, manage, coordinate, and communicate care information. I have to do all this while also ensuring that my daughter's care needs are met in both the manner that keeps her medically safe, while letting her grow in independence. This is a stressful process both for me and our family, which at times, has affected my own health, work-life balance and ability to participate in life and the community in ways that I would find meaningful. This is why it is imperative for researchers such as Human Factors experts to study the care that we as parents of children with medical complexity provide and the many systems we have developed to provide that care across many different caregivers. Only then can support tools be developed that actually meet our specific needs.

## **THE HUMAN FACTORS PERSPECTIVE**

### **Macroergonomics Approach to Elucidating the Social Environment of Families of CMCs**

*Rupa Valdez, University of Virginia*

Traditionally in literature focused on caregiving, caregivers are conceptualized as a dyad comprised of a patient and their spouse, or their parent and their adult child (Bidwell et al., 2015; Ferro & Boyle, 2015; Shawler, Edward, Ling, Crawford, & Rayens, 2018). From a systems perspective, however, individuals living with chronic conditions are imbedded within a broader social environment that extends beyond a single informal primary caregiver. My previous work has focused on articulating social environments and ways in which health information is communicated to those comprising the

social environments (Valdez & Brennan, 2015). This research has demonstrated the wide range of support provided by social network members, including those that may not traditionally be conceptualized as caregivers. Given this previous research, and the fact that CMCs and their parents may be embedded in broader social environment, our current research, funded by the National Institute of Nursing Research, focuses on articulating these social environments and understanding the ways in which they are leveraged for self-management. We are seeking to understand this latter point both from the perspective of parents of CMC and from the perspective of their social network members. Unlike previous research, we layer a work system framework over a social network framework to understand barriers and facilitators to self-management as well as to understand how self-management tasks are distributed across network members (Valdez et al., 2020).

In this talk, I will explain the rationale behind our methodology, which may be classified as a hybrid macroergonomics approach (Valdez & Zayas-Caban, 2015). Such an approach may be defined as one that layers an explicit macroergonomics framework over a framework drawn from another discipline. In this study, the secondary framework is the Convoy model, drawn from the nursing literature, and used to elucidate and affect-based, ego-centric social network (Antonucci & Akiyama, 1987). I will present initial findings drawn from 30 families, and their networks in addition to design and methodological implications that arise from this work.

### **Participatory design of a mobile application to support family caregivers of children with medical complexity who require enteral care**

Nicole E. Werner, University of Wisconsin-Madison

Most CMC require the use of medical devices, such as tracheostomies and enteral feeding, yet device complications are common and have been associated with frequent emergency department visits or hospitalizations (Berry et al., 2011; Nackers et al., 2019). Our research found that device complications account for 17% of overall hospitalizations and 30% of overall emergency department (ED) visits for children in our pediatric complex care program (Nackers et al., 2019).

Enteral tubes - tubes into the stomach or intestines to allow feeding, medications and hydration - are a model device for research to improve CMC outcomes. Enteral tubes are common, used by over 80% of CMC in our clinical program, and account for the majority of device-complication ED visits and hospitalizations (Nackers et al., 2019). Although they provide life-sustaining treatment, enteral tubes can cause caregiver burden,

anxiety, social isolation, stigma, family discord, and financial shocks, among others (Lim et al., 2018; K. E. Nelson et al., 2015). Enteral tube complications can result in infections, bleeding, and inadequate nutrition, hydration, or medication administration, any of which can lead to health services use, health declines, or death (Lim et al., 2018; Nelson et al., 2015).

To address these challenges and support families in providing enteral care in the home, we conducted a participatory design process with family caregivers of CMC both as part of the research team and as members of the design team to design a mobile application (app), @HOME. In this talk, I will describe the participatory design process and resulting app. I will also discuss the unique challenges and strengths we experienced in engaging in this process with families of CMC.

### **REFERENCES**

- Antonucci, T. C., & Akiyama, H. (1987). Social Networks in Adult Life and a Preliminary Examination of the Convoy Model. *Journal of Gerontology*, 42(5), 519-527.
- Berry, J. G., Agrawal, R., Kuo, D. Z., Cohen, E., Risko, W., Hall, M., . . . Srivastava, R. (2011). Characteristics of hospitalizations for patients who use a structured clinical care program for children with medical complexity. *J Pediatr*, 159(2), 284-290. doi:10.1016/j.jpeds.2011.02.002
- Berry, J. G., Hall, M., Neff, J., Goodman, D., Cohen, E., Agrawal, R., . . . Feudtner, C. (2014). Children with medical complexity and Medicaid: spending and cost savings. *Health Aff (Millwood)*, 33(12), 2199-2206. doi:10.1377/hlthaff.2014.0828
- Bidwell, J. T., Vellone, E., Lyons, K. S., D'Agostino, F., Riegel, B., Juárez-Vela, R., Hiatt, S. O., Alvaro, R., & Lee, C. S. (2015). Determinants of Heart Failure Self-Care Maintenance and Management in Patients and Caregivers: A Dyadic Analysis. *Research in nursing & health*, 38(5), 392-402. <https://doi.org/10.1002/nur.21675>
- Blackburn, E. H., & Epel, E. S. (2012). Telomeres and adversity: Too toxic to ignore. *Nature*, 490(7419), 169-171. doi:10.1038/490169a
- Carayon, P., Wooldridge, A., Hoonakker, P., Hundt, A. S., & Kelly, M. M. (2020). SEIPS 3.0: Human-centered design of the patient journey for patient safety. *Applied ergonomics*, 84, 103033. <https://doi.org/10.1016/j.apergo.2019.103033>
- Cohen, E., Berry, J. G., Camacho, X., Anderson, G., Wodchis, W., & Guttman, A. (2012). Patterns and costs of health care use of children with medical complexity. *Pediatrics*, 130(6), e1463-1470. doi:10.1542/peds.2012-0175
- Cohen, E., Horvath-Puho, E., Ray, J. G., Pedersen, L., Adler, N., Ording, A. G., . . . Toft Sorensen, H. (2016). Association Between the Birth of an Infant With Major Congenital Anomalies and Subsequent Risk of Mortality in Their Mothers. *JAMA*, 316(23), 2515-2524. doi:10.1001/jama.2016.18425
- Coller, R. J., Lerner, C. F., Eickhoff, J. C., Klitzner, T. S., Sklansky, D. J., Ehlenbach, M., & Chung, P. J. (2015). Medical Complexity among Children with Special Health Care Needs: A Two-Dimensional View. *Health Serv Res*. doi:10.1111/1475-6773.12416

- Coller, R. J., Nelson, B. B., Klitzner, T. S., Saenz, A. A., Shekelle, P. G., Lerner, C. F., & Chung, P. J. (2017). Strategies to Reduce Hospitalizations of Children with Medical Complexity through Complex Care: Expert Perspectives. *Acad Pediatr*. doi:10.1016/j.acap.2017.01.006
- Coller, R. J., Nelson, B. B., Sklansky, D. J., Saenz, A. A., Klitzner, T. S., Lerner, C. F., & Chung, P. J. (2014). Preventing Hospitalizations in Children With Medical Complexity: A Systematic Review. *Pediatrics*, *134*(6), e1628-e1647. doi:10.1542/peds.2014-1956
- Desai, A. D., Durkin, L. K., Jacob-Files, E. A., & Mangione-Smith, R. (2016). Caregiver Perceptions of Hospital to Home Transitions According to Medical Complexity: A Qualitative Study. *Acad Pediatr*, *16*(2), 136-144. doi:10.1016/j.acap.2015.08.003
- Ferro, M. A., & Boyle, M. H. (2015). The impact of chronic physical illness, maternal depressive symptoms, family functioning, and self-esteem on symptoms of anxiety and depression in children. *Journal of Abnormal Child Psychology*, *43*(1), 177-187. <https://doi.org/10.1007/s10802-014-9893-6>
- Fleming, J. W. (2004). *Home health care for children who are technology dependent*. New York, New York: Springer Pub Co.
- Holden, R. J., Cornet, V. P., & Valdez, R. S. (2020). Patient ergonomics: 10-year mapping review of patient-centered human factors. *Applied ergonomics*, *82*, 102972.
- Holden, R. J., Schubert, C. C., & Mickelson, R. S. (2015). The patient work system: an analysis of self-care performance barriers among elderly heart failure patients and their informal caregivers. *Applied ergonomics*, *47*, 133-150.
- Kuo, D. Z., Cohen, E., Agrawal, R., Berry, J. G., & Casey, P. H. (2011). A national profile of caregiver challenges among more medically complex children with special health care needs. *Arch Pediatr Adolesc Med*, *165*(11), 1020-1026. doi:10.1001/archpediatrics.2011.172
- Lim, M. L., Yong, B. Y. P., Mar, M. Q. M., Ang, S. Y., Chan, M. M., Lam, M., . . . Lopez, V. (2018). Caring for patients on home enteral nutrition: Reported complications by home carers and perspectives of community nurses. *J Clin Nurs*, *27*(13-14), 2825-2835. doi:10.1111/jocn.14347
- Nackers, A., Ehlenbach, M., Kelly, M. M., Werner, N., Warner, G., & Coller, R. J. (2019). Encounters From Device Complications Among Children With Medical Complexity. *Hosp Pediatr*, *9*(1), 6-15. doi:10.1542/hpeds.2018-0103
- Nelson, B. B., Coller, R. J., Saenz, A. A., Chung, P. J., Kaplan, A., Lerner, C. F., & Klitzner, T. S. (2016). How Avoidable are Hospitalizations for Children With Medical Complexity? Understanding Parent Perspectives. *Acad Pediatr*. doi:10.1016/j.acap.2016.04.009
- Nelson, K. E., Lacombe-Duncan, A., Cohen, E., Nicholas, D. B., Rosella, L. C., Guttman, A., & Mahant, S. (2015). Family Experiences With Feeding Tubes in Neurologic Impairment: A Systematic Review. *Pediatrics*, *136*(1), e140-151. doi:10.1542/peds.2014-4162
- Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., . . . Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, *115*(6), E626-E636. doi:10.1542/peds.2004-1689
- Shawler, C., Edward, J., Ling, J., Crawford, T. N., & Rayens, M. K. (2018). Impact of Mother-Daughter Relationship on Hypertension Self-management and Quality of Life: Testing Dyadic Dynamics Using the Actor-Partner Interdependence Model. *The Journal of cardiovascular nursing*, *33*(3), 232-238. <https://doi.org/10.1097/JCN.0000000000000448>
- Thyen, U., Kuhlthau, K., & Perrin, J. M. (1999). Employment, child care, and mental health of mothers caring for children assisted by technology. *Pediatrics*, *103*(6 Pt 1), 1235-1242. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/10353935> <http://pediatrics.aappublications.org/content/pediatrics/103/6/1235.full.pdf>
- Thyen, U., Terres, N. M., Yazdgerdi, S. R., & Perrin, J. M. (1998). Impact of long-term care of children assisted by technology on maternal health. *J Dev Behav Pediatr*, *19*(4), 273-282. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9717137>
- Valdez, R. S. & Brennan, P.F. (2015). Exploring patients' health information communication practices with social network members as a foundation for consumer health IT design. *Int J Med Inform* *84*(5), 363-374.
- Valdez, R. S., Lunsford, C., Bae, J., Letzkus, L. C., & Keim-Malpess, J. (2020). Self-Management Characterization for Families of Children With Medical Complexity and Their Social Networks: Protocol for a Qualitative Assessment. *JMIR research protocols*, *9*(1), e14810. <https://doi.org/10.2196/14810>
- Valdez, R. S. & Zayas-Caban, T. (2015). Developing hybrid macroergonomic methodologies: a systems foundation for consumer health IT design. *19th Triennial Congress of the International Ergonomics Association*, Melbourne, Australia.
- Wang, K. W., & Barnard, A. (2004). Technology-dependent children and their families: a review. *J Adv Nurs*, *45*(1), 36-46. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/14675299> <http://onlinelibrary.wiley.com/store/10.1046/j.1365-2648.2003.02858.x/asset/j.1365-2648.2003.02858.x.pdf?v=1&t=iqy24dvi&s=73ad6529047721b5a53c9ea187727e7f7dd2837>
- Werner, N. E., Jolliff, A. F., Casper, G., Martell, T., & Ponto, K. (2018). Home is where the head is: a distributed cognition account of personal health information management in the home among those with chronic illness. *Ergonomics*, *61*(8), 1065-1078.
- Werner, N. E., Tong, M., Borkenhagen, A., & Holden, R. J. (2019). Performance-shaping factors affecting older adults' hospital-to-home transition success: a systems approach. *The Gerontologist*, *59*(2), 303-314.
- World Health Organization. (2001). *International classification of functioning, disability and health: ICF*. Geneva: World Health Organization.