



How do we Improve Systems of Care for Children with Medical Complexity?

Days at Home

Introduction

Children with medical complexity (CMC) have higher rates of hospitalization and health care utilization than the average child. **Days at home (DAH)**, or days without healthcare visits, is a promising patient-centered outcome measure of health service use and care coordination. The objective of this project arm is to understand the perspectives of caregivers of CMC, specifically:

“What makes a good day at home for CMC?”

Methods

- One-on-one semi-structured interviews via Zoom
- Population: **17 English-speaking parents of CMC who live in NC**
- Purposive sampling via collaboration with community partner organizations
- Interviews transcribed and coded in NVivo

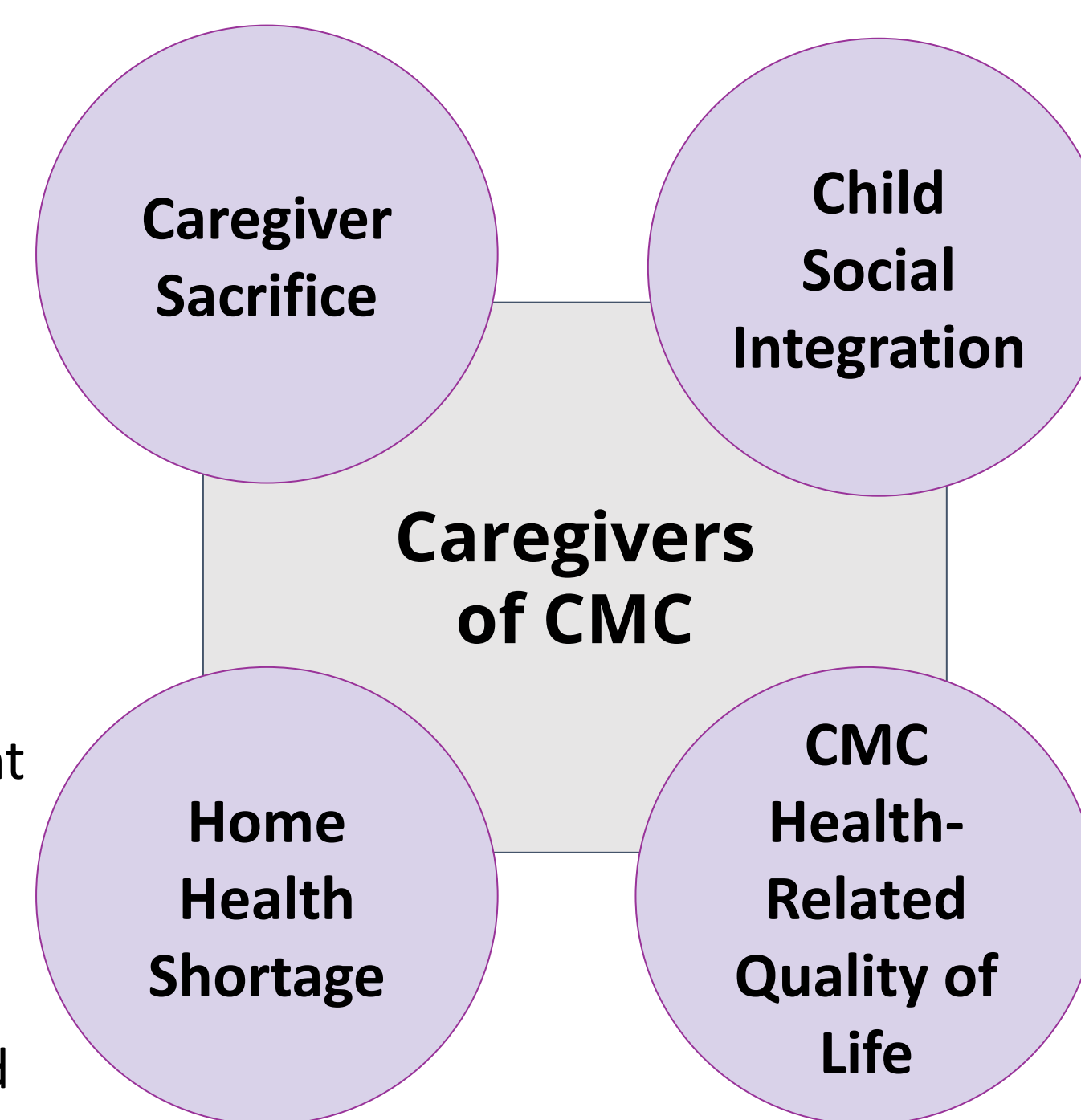
Select Findings and Major Themes

“Because of the nature of my son’s medical condition, there has to be an element of flexibility in cases of, there are always emergencies with regards to him so again, his medical condition doesn’t allow us to be employed.”

“My son is still breathing. I don’t have a choice but to keep going. Simple as that. Mental health, physical health, medical health is now on a dangerous decline.”

“We have no nurses. We have never had a night nurse. We have no care. We have no respite. I have never used respite hours in all of these years. So we have no help”

“We have a CAPC case manager that is assigned to us who writes referrals to a list, an endless list, of nursing agencies. We either don’t get a response or we get a response, unfortunately we have no nurses to staff your case.”



“She has a lot of friends actually, but she’s not able to develop that closeness or that bond with them where she could go and be at their home for extended periods of time, right?”

“He lives... a very isolated life unfortunately and because we’re unable to leave the home we have no social network so we don’t have individuals that we know who... offer help or time for him to enjoy having someone read to him or just a new face.”

“She would have seizures so serious where she would be catatonic for days, nonresponsive, not eating, no human bodily functions happening, I mean it was crazy. And once she was talking, she was very delayed to start talking”

“She just needs time to, she’ll even wake up and shower and eat breakfast but she’ll be right back down, laying down you know, and I don’t push her.”

Conclusion

- CMC and their families face numerous barriers to good days at home, including intensive caregiving workload; lack of health system, community, and governmental supports; barriers to social integration and education; and significant financial strain.
- Numerous opportunities exist to better these conditions through improvements in care coordination and system supports.

Next Steps

- Thematic analysis ongoing, manuscript in progress
- **Scoping literature review** in progress: “How is days at home used as an outcome measure across populations/conditions?”

Discharge Process from Hospital to Home

Introduction

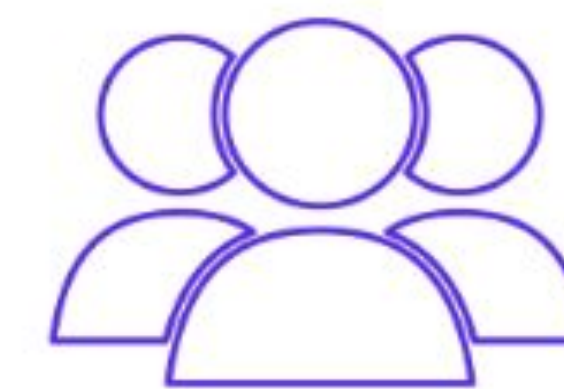
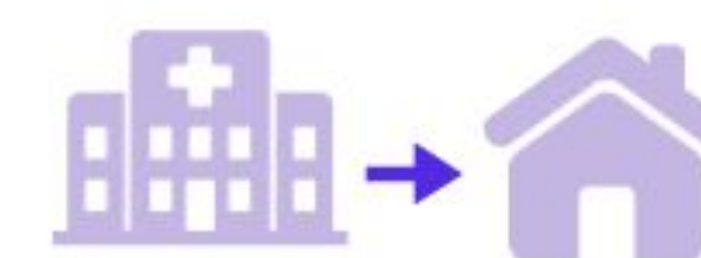
Hospital-to-home transition interventions have been widely adopted by health systems. However, children with complex health care needs still experience gaps in this process. Working with Duke Population Health Management Office (PHMO) and UNC Health Alliance, we aim to:

Understand transitional care management in context of broader health care systems

Characterize granular workflow processes and barriers to transitional care management

Methods (In Progress)

Implementing **human-centered design** and a **plan-do-study-act cycle**, we are in collaboration transitional care management teams:



Current state process mapping of transitional care practices and organization

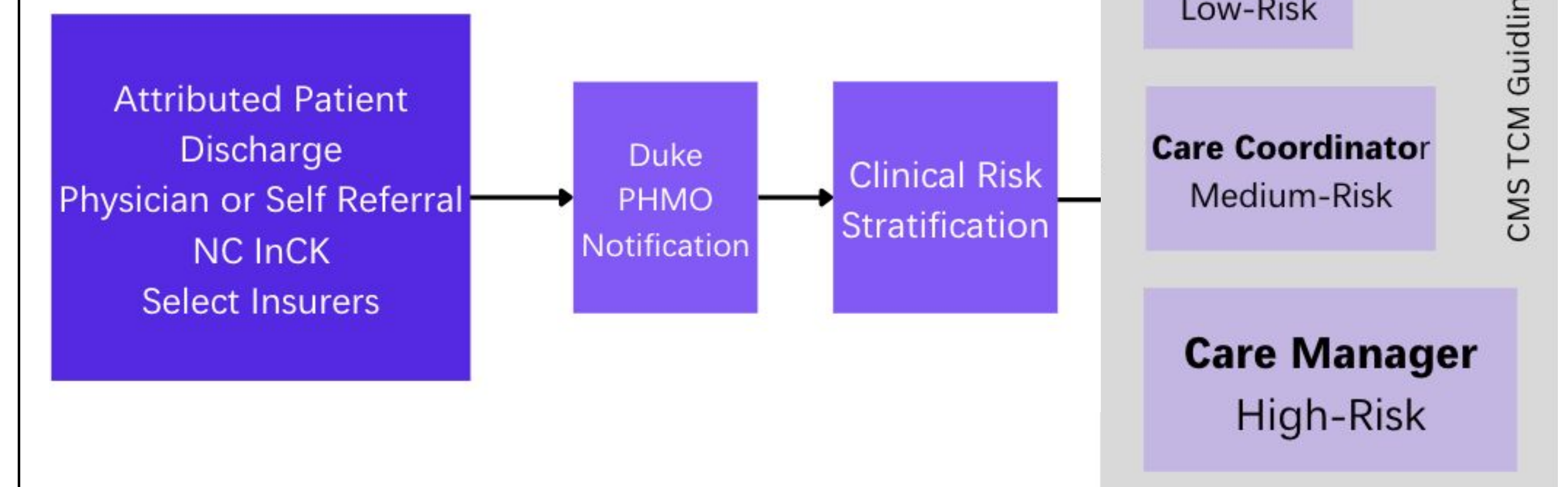
Semi-structured interviews with transitional care managers (N=8)

Rapid qualitative analysis of interviews & **journey mapping** of key workflow stages

Co-design adaptations to workflow with transitional care management staff

Results and Preliminary Findings

- **Current state process map of Duke transitional care practices**



- **Emerging themes from 5 semi-structured interviews:**

Difficult to gain consent to refer patients to external resources

Lack of available resources for patients that address social needs

Use of standardized workflows to confirm medication and appointments.

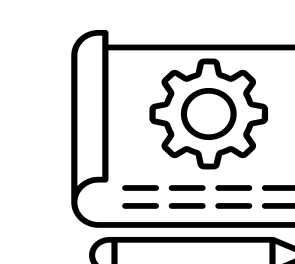
The transitional care workflow is the same for all patients, and **there is no workflow specifically catered to the pediatric population**

“We’re just trying to make sure all of jigsaw pieces are fitting together and that the patient has everything they need.” – A Transitional Care Manager

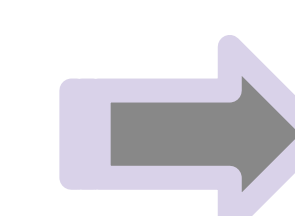
Next Steps



Conducting **final interviews** and continuing with **rapid qualitative analysis**



Potential **prototype** solutions encompassing **pediatric-specific training, alternative EHR documentation methods, and a revised consent form procedure.**



These insights will directly underpin an upcoming **clinical trial** designed to compare H2H care transition interventions between Duke Health and UNC Health.