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BACKGROUND

- *Days at home (DAH)* = days without healthcare visits
- DAH = proposed patient-centered outcome measure of health service use and care coordination for children with medical complexity (CMC)
- According to perspectives of parents/caregivers of CMC, are DAH inherently good?



OBJECTIVE

- To explore perspectives and experiences of parents/caregivers of CMC on “days at home,” including facilitators of and barriers to **good** days at home

METHODS

- Partnership with the Exceptional Children's Assistance Center (ECAC)
- Purposive sampling of 17 primary parents/caregivers of CMC involved in ECAC
- Virtual (Zoom) semi-structured qualitative 1:1 interview (lasting ~60 minutes)
- Interview transcriptions coded in NVivo 14, using codebook informed by the 10 Domains of Healthy Children (Barnert et al., 2018)

RESULTS

Participant Demographics	%
Average age (y)	42.6 y
White	87%
Spanish/Hispanic/Latine	0%
Female	100%
Christian	67%
Completed graduate/professional school	53%
Employed full-time	40%
Child Demographics	%
Child average age (y)	8.9 y
White	87%
Primary insurance: Medicaid/CHIP	53%
Primary insurance: Private	47%
Has secondary insurance	27%
Family Demographics	%
Single parent Household	33%
Household income less than \$50,000/year	33%
Suburban home community	73%

"a typical day means we don't have any nursing help... the state is supposed to equip us with like, like reliable home nursing so that like I could have a career and like we can sleep at nighttime and all that good stuff but with the nursing shortage that is just like, that's like a sad joke..."	Impact of access to nurses on days at home
"Even with a nurse, it's truly a full-time job because it's just managing therapists, medical equipment, physicians, different things they're changing with his medical condition, dealing with all the vendors and pharmacies and I mean, we have two pharmacies, so it's just, it's really a lot in general."	Impact of organizing outpatient needs while at home
"We just have to be around him and have to take care of him basically every minute of every day. So if I have him for a full day it basically inhibits us from going most places."	Impact of intensive caregiving workload on days at home
"I have burnout super bad, like caregiver burnout I guess is like the title of it... until my aunt really started helping me out a lot more and being here there were days where I literally like, it was, it took everything in me to still do a catheter or to still give her medicine."	Impact of access to caregiving support on days at home

"Last summer we did... all the stuff to get her set up to go to our public preschool for our school district... the school found a nurse and (Name) went to school two days and then the nurse quit... the school couldn't find another nurse for months and then in November we finally agreed to just make her like a homebound student... [later] I asked can we please get her like back in the classroom?... and the school was like no."	Challenges assessing school based services
"When I started her up for kindergarten, the elementary school she's zoned for has playground issues... that they have to fix before she can start school and one of the things they said to me was, well did her daycare ever fix it... I looked at them and I said, well actually yeah... kind of got like some dirty looks from the principal and couple people from the county but I'm like, you know, I've learned in five years what my rights are for her."	Judgement from others
"Basically the child is given a diagnosis and they're like okay, he's going to live [a month] and then they were like okay, here's your child... Like, no, hey do you need this resource? Hey, do you need to talk to somebody?... and then he comes home with oxygen and he comes home with all of these, this medical grade equipment I had never seen [except] in the hospital. Didn't mean I know how to run it... the hospital just wants you out... there's no coordination of care, especially with the complex so then what happens?"	Lack of provider training
"A year ago... an organization called A Kid Again... they try to let families with their children that have life threatening illnesses be able to do different things together as a family and just kind of push illness to the side for the day or whatever. So they had a day at Carowinds...it was just a fun day and being able to connect with other families that had kids with illnesses and g-tubes... being able to go outside and do something that felt normal."	Acute changes & access to enrichment activities

CONCLUSIONS

- Parents/caregivers CMC reported that **DAH are challenging and that not all DAH are inherently 'good.'**
 - DAH are influenced by (1) the caregiver's **support within** the home but also (2) the family's **experiences outside** the home
 - Parents **emphatically recommended greater system-level support** to improve DAH for CMC and their families
- Quantitative measure of DAH as a family-centered outcome should integrate perspectives of parents/caregivers to ensure the measure best reflects their lived experiences.