

Key Discussion Themes

Overview of the COVID-19 and CMC ECHO

The COVID-19 & CMC ECHO, a partnership between the American Academy of Pediatrics and Boston University, leveraged video conferencing technology to increase participant knowledge, capacity, comfort and competence in caring for children with medical complexity and their families during the COVID-19 pandemic. The program used the ECHO tele-mentoring platform to connect interprofessional participants with experts in infectious disease, emergency preparedness, public health, primary care, mental/behavioral health, palliative care, subspecialty care, and family-centered care.

Between May 2020 and June 2021, the COVID-19 and CMC ECHO covered 28 topics. **Themes from ECHO discussions are outlined below.**

Theme 1: Family/Caregiver Needs

CHALLENGES

- Existing challenges **accessing respite and home care services** were significantly exacerbated during the pandemic
- Families/caregivers felt anxious about bringing **outside care** into their homes
- **Health-related services and therapies** that were typically provided in schools were no longer available
- Families/caregivers felt concerned about **access to supplies/personal protective equipment** and about disruptions in the supply chain
- **Widely varying policies** related to family/caregiver presence in hospitals
- A need for **accurate scientific information from trusted entities** about the pandemic itself, potential therapies, timelines for vaccines, masking and strategies for risk prevention

Theme 2: Mental Health and Well-being of Families/Caregivers and Health Care Professionals

CHALLENGES

- Significant **burnout** experienced by families/caregivers and health care professionals
- Increase of behavioral/mental health needs among families/caregivers during the pandemic, but there was a **lack of behavioral health integration** into primary care, and **lack of available behavioral/mental health professionals**
- High levels of **anxiety** and **social isolation** during the pandemic for many CMC and their families/caregivers
- Tension between **safety needs** of the child(ren) with medical complexity and **socialization needs** of siblings

Theme 3: Telehealth Strategies for CMC

CHALLENGES

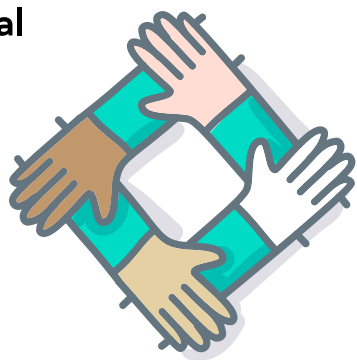
- Issues with **connectivity and access to broadband** for many families/caregivers as an equity concern
- **Payment and financing** concerns related to telehealth in the future
- **Privacy** concerns



Theme 1: Family/Caregiver Needs

PRACTICAL TIPS

- Routinely **refer families/caregivers to state-level family-led organizations** to help navigate and problem-solve around unmet needs
- **Hold conversations** about the COVID-19 vaccine, social distancing, masking, and school planning **with families/caregivers of CMC early on** to address any concerns
- Proactively reach out to families of CMC early in a natural disaster or pandemic to **identify any immediate health-related needs** (medical supplies and medications, electricity in households with durable medical equipment (DME), heat, food, etc.); follow-up on a regular basis to ensure needs are being met
- Determine what **existing natural supports** a family may have access to, like family and friends, and encourage families to use them to help



PRACTICE IMPROVEMENT OPPORTUNITIES

- **Families/caregivers should be active partners in decision-making processes**; mutual trust and respect is key for strong partnerships
- Interdisciplinary team can help identify ways to desensitize **children to new sensory experiences** such as mask wearing
- **Palliative care strategies can help health care professionals build their communication toolbox** to improve communication with families/caregivers
- **Partner with local durable medical equipment, home nursing and suppliers to problem solve**, build processes and create consistent messages for families about access, shortages and delivery times
- **Create consistent messaging** about hospital emergency department, urgent care access, and COVID-19 testing processes
- Work with local hospitals to **create family presence policies that balance infection control concerns with the specialized needs of CMC** and which follow the Americans with Disabilities Act; view families/caregivers as vital partners at the bedside in their child's care
- **Utilize shared decision-making** among families/caregivers, health care professionals, schools, and others within the system of care for CMC to carefully balance family needs versus risk of COVID-19

Theme 2: Mental Health and Well-being of Families/Caregivers and Health Care Professionals

PRACTICAL TIPS

- **Incorporate routines for CMC and their families/caregivers and for health care professionals to address anxiety and stress** caused by the pandemic. Do not wait until things normalize to make new schedules. Examples include routines/schedules related to exercise, nutrition, sleep, and connecting with friends/family/co-workers virtually for peer-support.
- **Utilize trauma-informed strategies to improve mental health**, such as cultivating individual and team relationships, communicating openly, empowering others, showing empathy, showing respect, and understanding that people can grow and improve
- **Acknowledge the stress, fear and confusion around the pandemic**, and assume positive intent with others when communicating

PRACTICE IMPROVEMENT OPPORTUNITIES

- **Palliative care communication techniques** that emphasize honesty and trust, self-compassion, safety, sensitivity, connection, preparedness and other palliative care grounding principles can be used to address mental health concerns and family well-being
- Having **social networks and peer supports** are important for mental health and well-being
- Consider a **team-based approach** to assist with burnout and traumatic stress

Theme 3: Telehealth Strategies for CMC

PRACTICAL TIPS

- **Carefully consider when in-person versus telehealth visits are appropriate** (i.e. medical appropriateness, financial considerations, bandwidth/connectivity issues, equipment availability, privacy concerns)
- **Utilize emerging tools** for families and health care professionals to optimize telehealth visits



PRACTICE IMPROVEMENT OPPORTUNITIES

- Telehealth allows for more **inter-professional collaboration and care coordination** between family/caregiver, primary care physician, specialists, schools, home care nurses, social services/community supports, therapists, and other health care professionals
- Telehealth has the potential to **improve patient/family experience** through lower transportation costs, less time out of work, more convenience for families/caregivers, more relaxing environment, and physically less demanding for CMC and their families/caregivers
- Potential for a **hybrid of in-person and telehealth visits** moving forward to reduce burden and increase access to care while maintaining quality
- Incorporate **professional development** to help health care professionals become more comfortable with utilizing telehealth with patients