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**PARENTAL PERSPECTIVE ON CHANGES IN HEALTH CARE FOLLOWING INTEGRATION TO A COMPLEX CARE PROGRAM**

Louis-Philippe Thibault  
CHU Sainte-Justine  
Maria Marano  
CHU Sainte-Justine  
Lydia Saad  
University of Montreal  
Nathalie Gaucher  
CHU Sainte-Justine  
Karine Couture  
CHU Sainte-Justine  
Marie-Joëlle Doré-Bergeron  
CHU Sainte-Justine  
Caroline Chartrand  
CHU Sainte-Justine  
Sandra Fregeau  
CHU Sainte-Justine  
Claude-Julie Bourque  
Université de Montréal  
Niina Kleiber  
CHU Sainte-Justine

**PRIMARY SUBJECT AREA:** Complex Care

**BACKGROUND:** Quantitative studies have found that integration into a complex care program (CCP) leads to decreased number of visits to the emergency department (ED) and hospitalization days for children with medical complexity (CMC). However, little is known about CMC families' experiences regarding their healthcare resource utilization patterns following their child's integration in the CCP.

**OBJECTIVES:** To analyze parental perspectives regarding changes in healthcare resources utilization following CCP admission.

**DESIGN/METHODS:** This study was conducted in our tertiary care pediatric university hospital, between December 2019 and January 2021 using individual semi-structured interviews. To assess the effect of CCP admission on healthcare resources utilization, only patients with at least 6 months of chronic disease before inclusion were eligible (32 families). The interview guide was co-constructed by our CCP team of nurses, doctors, social worker and parents of CMC. Participation rate was over one third (12/32) throughout, for which a satisfactory level of data saturation was obtained, as core themes specific to the research question were repeatedly identified. Verbatims were analyzed with NVivo. Descriptive thematic analysis was performed by coding themes emerging from the data.

**RESULTS:** Sixteen parents from twelve families were interviewed (11 mothers, 5 fathers, including 4 couples). Most parents had experienced a decrease in ED visits with improvement in their perceived satisfaction regarding the provided healthcare services following CCP admission. Visits to the CCP pediatrician led to appreciated, continuous and tailored care. In comparison, the constant change of pediatricians in the ED and during hospitalization on the ward seemed to complicate their care experience. Also, the support from pivot nurses and social workers for daily health issues, drug prescription and paperwork was perceived as a relief. This directly favorably influenced care experience. Profound knowledge of patients' health conditions and families' personal challenges and strengths, led to personalized care and trust that greatly improved parents' confidence in care and empowered families. Individualized advice by the CCP team leading to prompt treatment and preventive measures started early at home were identified by parents as the main driving forces leading to the observed decrease in ED visits. When hospitalized, confidence in the quality of care provided by parents at home with close follow-up by CCP were identified as the main driving forces leading to the quicker discharge.

**CONCLUSION:** Changes in health care utilization following admission to CCP was associated with an improved care experience. Parents identified

individualized care and close follow-ups as key factors leading to decreased health care utilization.

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**IMPACT OF COVID-19 PANDEMIC ON CHILDREN WITH MEDICAL COMPLEXITY: PARENTAL PERSPECTIVE ABOUT THE ROLE OF A COMPLEX CARE PROGRAM**

Louis-Philippe Thibault  
CHU Sainte-Justine  
Maria Marano  
CHU Sainte-Justine  
Lydia Saad  
University of Montreal  
Marie-Joëlle Doré-Bergeron  
CHU Sainte-Justine  
Karine Couture  
CHU Sainte-Justine  
Nathalie Gaucher  
CHU Sainte-Justine  
Claude-Julie Bourque  
Université de Montréal  
Niina Kleiber  
CHU Sainte-Justine

**PRIMARY SUBJECT AREA:** Complex Care

**BACKGROUND:** The COVID-19 pandemic led to major and rapid organizational and structural healthcare changes including a switch from ambulatory services towards telemedicine and decreased access to home services. Children with medical complexity (CMC) require many medical services and are generally prone to infectious complications. Little is known about the impact of the pandemic on families of CMC. Understanding how CMC families experience the COVID-19 pandemic is essential to tailor healthcare services to answer their needs more effectively.

**OBJECTIVES:** We explored parental experience of CMC during the COVID-19 pandemic, and how the complex care program (CCP) answers their new needs.

**DESIGN/METHODS:** This qualitative study was conducted between July 2020 and January 2021 in a tertiary care pediatric university hospital centre. Semi-structured interviews were done with parents of CMC, admitted in the CCP at least 1 year prior to the beginning of the pandemic. The interview guide was co-constructed by physicians and nurses from the CCP. Interviews were transcribed verbatim and analyzed using NVivo. Data were organized into codes and categories. Thematic content analysis was performed by grouping categories and highlighting emerging themes.

**RESULTS:** Eleven families (14 parents – 4 fathers, including 3 couples) were interviewed. The first wave of the pandemic seemed to have caused important uncertainty and anxiety amongst parents of CMC. Almost all the parents reported cancelling numerous appointments in order to avoid coming to the hospital at all costs. Some parents, worrying specifically about the fragility of their child, stopped working and stayed home to reduce transmission risks. Fear of facing shortages in medications, nutritional supplements and medical equipment for home care was frequently expressed. They did not express worries about the de-confinement periods. The support provided by the CCP's staff was greatly appreciated, namely active problem-solving via phone calls, videoconferences, emails and pictures, leading to fewer hospital visits and less need to seek emergency care. Some reported that more general communication from the CCP (e.g., a weekly information email), would have helped to interpret the overwhelming amount of information from the media. Parents expressed a strong desire to maintain telemedicine services after the pandemic.

**CONCLUSION:** The COVID-19 pandemic brought additional worries to parents of CMC enrolled in CCPs, including fear of shortages and virus transmission. Direct communication with the CCP and remote problem-solving were greatly appreciated by families. Improvement to follow-up include finding ways to help interpreting data from the media.