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CONFERENCE ABSTRACT

Integrated care for children with medical complexity living in rural Australia – an evaluation of family experiences using the Paediatric Integrated Care Survey

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Introduction

The number of children with medical complexity (CMC) residing in regional/rural Australia is growing, challenging the health system to provide equitable and accessible care. Families of CMC experience problems in accessing appropriate care locally; they have high out-of-pocket costs and family disruptions because of long travel distances to access care in metropolitan paediatric hospitals.

The Practice Change

The Murrumbidgee Local Health District (MLHD) in New South Wales (NSW), Australia, in collaboration with the Sydney Children's Hospitals Network (SCHN) partnered with families and local services to co-design a Model of Care (MoC) to better meet the needs of CMC, their families and local services

Aim and theory of change

To demonstrate changes in parent-reported experiences, we used the Paediatric Integrated Care Survey (PICS) in a longitudinal cohort design at baseline, and 6 months after enrolment in the MoC.

Targeted population and stakeholders

To qualify for enrolment in the new MoC children had a diagnosed condition involving more than one organ system, were medically fragile or reliant on medical technology, or had used health services frequently in the last 12 months e.g. >6 emergency department presentations, >4 hospital admissions and >10 outpatient clinic visits. Stakeholders included families of CMC, healthcare providers and managers working in the MLHD and and at the SCHN.

Timeline

The new MoC was implemented in 2018 and CMC have been systematically identified, and enrolled in the MoC. The PICS was administered at baseline and at 6 months.

Highlights – innovation, impact and outcome

41 CMC have been enrolled and 18 of the families completed the PICS at both time points. Difficulties navigating healthcare systems, fragmented care, poor communication, and limited care planning and goal setting were apparent at baseline. After accessing the MoC for at least 6 months (6-14 months) there was a 33% increase in written short term care goals (p=0.045). Care teams were 11% more likely to discuss healthcare decisions that impact the whole family (p=0.005) and intra-team communication improved for 5.5% of families (p=0.003). Interestingly, 22% of families were less comfortable letting team members know about concerns about their child's healthcare (p=0.001). The care coordination team in the MoC reported valuing the PICS results as an assessment of need for integrated care.

Comments on sustainability and Transferability

The Moc has been embedded into the system in the MLHD, a rural area of NSW, Australia. The clinical teams working with families of CMC felt that the the PICS results informed their practice. The MoC, including assessments using the PICS has been adapted to another rural area - the Southern NSW LHD.

Conclusions, Discussion, and Lessons learned

Using the PICS periodically during implementation of the new MoC provides feedback loops to inform future model adjustments. The PICS has highlighted the need for shared care plans and recognition of the impacts of caring for a CMC on family functioning. Qualitative research is needed to better provide context to the longitudinal PICS data.