
CONFERENCE ABSTRACT

Families as Partners: Co-design of a localised model of care for children with medical complexity living in rural Australia and evaluation using the Paediatric Integrated Care Survey (PICS)

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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 care. Families of CMC experience problems in accessing appropriate care locally, and high out-of-pocket costs and family disruptions because of long travel distances to access care in metropolitan paediatric hospitals. The Murrumbidgee Local Health District (MLHD) 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.

Theory/Methods: The MoC was co-designed with families, local healthcare providers and the SCHN. 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, long hospital stays, 4 or more admissions and >10 outpatient clinic visits. 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 enrollment.

Results: 41 CMC have been enrolled and 18 had both the baseline and 6-month follow-up PICS assessment. A preliminary analysis has been conducted on these results. 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 ($p=0.001$).

Conclusions and lessons learned: Utilising a validated tool such as 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. Ongoing engaging with families provides a wealth of unique knowledge, with their inclusion in service design and evaluation crucial to successful integration of care.

Limitations: This study is limited by its size and resourcing which limited the design to a longitudinal cohort study pre and post intervention. Although the PICS is a validated tool, there is limited published utilisation of the survey in the Australian context.

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Suggestions for future research: Ideally a step-wedge randomised controlled trial of a new MoC implemented across several sites with primary outcome measures for the family, for healthcare providers and for the healthcare system. Qualitative research is needed to better understand the longitudinal PICS data.