POSTER ABSTRACT

Living in Rural and Remote Australia: Health care impacts for children with medical complexity and their families
18th International Conference on Integrated Care, Utrecht, 23-25 May 2018

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Introduction: The number of children with medical complexity CMC residing in rural areas is growing as the life span of CMC increases, placing an increased, unsustainable load on tertiary health services. Families of children with CMC also experience significant challenges relating to regular, long distance travel to receive health care treatment. A review of how we deliver care to CMC living in rural and remote locations identified opportunities to deliver care closer to home, avoiding frequent visits for routine care to tertiary hospitals. There remains a knowledge gap about how best to structure a model of care for such children and the specific health care needs of the children and families have nor been adequately described. We aim to address this gap.

Method: We conducted semi structured interviews with eighteen parents of CMC. The interview schedule included questions based on themes from the Agency for Clinical Innovation ACI Patient-Centred Dimensions of Care. Patients were provided flexible interview method options, including face-to-face, phone and email. In addition two carers were interviewed using a patient story format. Detailed field notes were taken by the interviewer. Using an inductive approach we conducted qualitative thematic analysis of the field notes.

Results: There were several key issues/themes which emerged related to barriers experienced when accessing health care locally, including limited services available, financial constraints and out-of-pocket costs, difficulties navigating systems, poor communication across services, and the impact these barriers had on the child’s health and the family unit as a whole. Although these issues were not dissimilar to those experienced by families living in metropolitan locations, geographical isolation heightened the level of complexity and negative impact on providing necessary health care for their child. This was particularly related to the need to travel long distances to receive specialist treatment and review, and the fragmentation between local and tertiary services.

Discussion: Results indicated the need for increased collaboration, better linkage of cross-sector care, coordination of health care and community support services. Patients identified opportunities for building local capacity enabling service delivery closer to home and indicated
that this would alleviate the burdens that families currently experienced while up-skilling local services.

**Conclusions comprising key findings:** Engaging with families of CMC provides an added level of understanding of the effect geographical isolation has on care delivery. Inclusion of the views of patients/parents in the co-design of services is crucial to the success of any new service.

**Lessons learned:** Engaging directly with families can provide a wealth of unique knowledge important in driving successful integration of care.

**Limitations:** The families who took part in the interviews were from a sample area of the district, which excluded children and families located in the most isolated/remote areas.

**Suggestions for future research:** A larger sample group which distinguishes CMC by condition, facility, and those involved with additional clinical supports such as Clinical Nurse Consultant’s CNCs would provide a greater understanding of gaps specific to subgroups within this paediatric population.

**Keywords:** children with medical complexity; rural and remote; integrated care