

CONFERENCE ABSTRACT

"If it was your child, what rules would you break to get them good care?"- Health care providers experience of working together to care for a child with complex conditions

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Introduction: There is no Australian literature on our understanding of the experiences and needs of broader groups of health care providers working in the Australian tertiary, secondary and primary health care system, whilst managing children with chronic and complex conditions. This paper addresses this knowledge gap by exploring the perceptions and experiences of health care providers in providing health care for children aged 0 to 18 with chronic and complex conditions. This information is essential in the design of future integrated health care systems for these children.

Method: A qualitative research study. Stakeholder forums, group and one on one in depth interviews were undertaken using a semi-structured interview guide. The stakeholder forums were audio recorded and transcribed verbatim. Field notes of the stakeholder forums and group and one-on-one interviews were kept. Thematic analysis underpinned by grounded theory was undertaken to identify key themes.

Results: One hundred and three providers took part in the forums and interviews across 3 local health districts, a tertiary paediatric network, and primary health care organisations. Providers expressed concern regarding family capacity to negotiate the system, which was impacted by the medical complexity of the children and psychosocial complexity of families. Lack of health care provider capacity in terms of their skills, time, and availability of resources to manage these children was also a key issue. These occurred within a health system that had impaired capacity in terms of fragmentation of care and limited communication among health care providers.

Discussion/Lessons Learned: The issues identified by health care providers in this study regarding the need to enhance family capacity, improve communication, and address system fragmentation have previously been identified in the published qualitative literature as important to families of children with chronic and complex conditions. Given the high

Zurynski; "If it was your child, what rules would you break to get them good care?" - Health care providers experience of working together to care for a child with complex conditions

concordance of views between parents and health care providers on these issues, improving these areas has high potential to improve integration of the health care system.

Conclusion: When designing integrated care models for children with chronic and complex conditions, it is essential to understand and address the challenges experienced by the health care providers who provide their care. This requires adequate training of providers, additional resources and time for coordination of care, improved systems of communication among services, with a centralised repository for information that is accessible to parents and all providers involved.

Limitations: A systematic approach was used in sampling, data collection and analysis to enhance the reliability and validity of the study: checking of transcripts against tapes and notes taken, triangulation, and feedback, to ensure rigor. Although purposeful sampling was used to select a wide range of providers with different experiences, a potential limitation was that although stakeholder consultation was audio-recorded, for the interviews only field notes were collected due to logistic limitations in terms of the project officer's time.

Suggestions for future research: Evaluation of the impact of the implementation of integrated models of care for children with children with complex and chronic conditions, on the perceptions and experiences of health care providers.

Keywords: paediatric; provider; experience; complex; chronic
