

CONFERENCE ABSTRACT

Barriers and facilitators to integration of care for children with complex care needs across 30 European countries: A MOCHA study

18th International Conference on Integrated Care, Utrecht, 23-25 May 2018

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Introduction: Approaches to the management of care of children with complex care needs CCN is known to vary among countries. Conducted as part of Models of Child Health Appraised MOCHA, an ongoing EU Horizon 2020 funded project, the aim of this study was to provide a contemporary account of the approaches to the integration of care at the acute/community interface for children with CCN across 30 European countries.

Methods: In this non-experimental descriptive study, utilising a mixed-methods design, 30 European countries were surveyed, using a local country agent who was an expert in child health. Each survey consisted of a vignette and open and closed-ended questions adapted from the Standards for Systems of Care for Children and Youth with Special Health Care Needs 1 and the Eurobarometer Survey 2. Vignettes were developed based on three clinical exemplars: Long-term Ventilation LTV, Intractable Epilepsy, and Traumatic Brain Injury TBI. Categorical data were analysed using descriptive statistics. Textual data were analysed using Attride-Stirling's thematic network analysis 3. This abstract presents results pertaining to the qualitative analysis of the main barriers and facilitators to the integration of care for each exemplar.

Results: Twenty-three countries 76.7% responded to the three surveys. Barriers to integration of care were similar across all exemplars and included; poor care coordination, lack of clinical expertise and training, insufficient funding, the absence of standards of care, lack of specialist clinical pathways, geographical variation in care, limited progress in the use electronic health, and inadequate access to psychological support. Training and retention of skilled healthcare staff were identified as a facilitator of integration of care across all exemplars. The need for a national database LTV & TBI, timely transfers to specialist services LTV & TBI and enhanced family and school support TBI & Intractable Epilepsy were identified for two of the three exemplar conditions.

Discussions: Although commonalities exist across the results presented, there may be individual critical junctures in care delivery that will demand care provisions that are specific to particular cohorts of children with different complex conditions.

Conclusions: The results suggest that there are a variety of processes and structures that act as barriers and facilitators to the integration of care for children with CNN across Europe.

Lessons learned: This study was reliant on data from a large number of informants being collated by local country agents across the 30 MOCHA countries. The process was assisted by the development and utilisation of a glossary of terms in each survey, which ensured uniform comprehension of the included terms.

Limitations: Previous research has posed concerns regarding the external validity of using clinical vignettes to elicit opinion 4,5. Nonetheless, the use of clinical vignettes in this study allowed for the creation of a variety of care delivery situations pertaining to complex care that could be utilised in a standardised manner in surveys developed for use across 30 European countries.

Suggestions for future research: Future research should be considered to explore innovative ways of minimising the barriers to integration of care for children with CCN.

Keywords: children; complex care needs; integrated care; europe
