

The Dynamic System of Parental Work of Care for Children with Special Health Care Needs: A Conceptual Model to Guide Quality Improvement Efforts

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BACKGROUND: The work of care for parents of children with complex special health care needs may be increasing, while excessive work demands may erode the quality of care. We sought to summarize knowledge and develop a general conceptual model of the work of care.

METHODS: Systematic review of peer-reviewed journal articles that focused on parents of children with special health care needs and addressed factors related to the physical and emotional work of providing care for these children. From the large pool of eligible articles, we selected articles in a randomized sequence, using qualitative techniques to identify the conceptual components of the work of care and their relationship to the family system.

RESULTS: The work of care for a child with special health care needs occurs within a dynamic system that comprises 5 core components: (1) performance of tasks such as monitoring symptoms or administering treatments, (2) the occurrence of various events and the pursuit of valued outcomes regarding the child's physical health, the parent's mental health, or other attributes of the child or family, (3) operating with available resources and within certain constraints (4) over the passage of time, (5) while mentally representing or depicting the ever-changing situation and detecting possible problems and opportunities. These components interact, some with simple cause-effect relationships and others with more complex interdependencies.

CONCLUSIONS: The work of care affecting the health of children with special health care needs and their families can best be understood, studied, and managed as a multilevel complex system.

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