

Abstract

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Development of a Pilot Application for Children with Chronic Medical Conditions Using the Personal Health Library

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Abstract

Objective: Caregivers are responsible for the in-home care of children with chronic medical conditions (CMCs) and may have care-related questions in order to support the child's higher quality of life. We propose using a digital health platform, the personal health library (PHL), facilitating collection, organization, utilization, storage, and retrieval of health information, that will allow us to develop an mHealth smartphone app to facilitate patient/caregiver engagement and self-care management of children with CMCs.

Methods: Pilot Application of the PHL in the Pediatric Chronic Medical Conditions Population: We will design the PHL to collect and integrate data from health and non-health information, in various formats and modalities, including 1) Parent/caregiver-reported data; 2) Clinical data and; 3) Social determinants of health (SDoH) data; 4) Observations of Daily Living (ODL) data including the PedsQL Parent Questionnaire and the Functional Status Scale. The app will be customized to provide information regarding training in post-acute hospitalization care and deliver information on troubleshooting medical technology care, i.e. tracheostomy care.

Conclusion: We expect that the design of the PHL application will ultimately provide a layer of support for parents and caregivers of children with CMCs for whom home health is not available following hospitalization.

Supplementary material. The supplementary material for this article can be found at <http://doi.org/10.1017/dmp.2024.243>.