

An Engaged Approach to Developing Tools for Measuring Caregiver Knowledge and Caregiver Engagement in Juvenile Type 1 Diabetes

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Abstract : Background: Type 1 Diabetes (T1D) is a chronic autoimmune disease, typically diagnosed in childhood. T1D puts an enormous strain on families; controlling blood-glucose in children is difficult and the consequences of poor control for patient health are significant. Successful illness management and better health outcomes can be dependent on quality of caregiving. On diagnosis, parent-caregivers face a steep learning curve as T1D care requires a significant level of knowledge to inform complex decision making throughout the day. The majority of illness management is carried out in the home setting, independent of clinical health providers. Parent-caregivers vary in their level of knowledge and their level of engagement in applying this knowledge in the practice of illness management. Enabling researchers to quantify these aspects of the caregiver experience is key to identifying targets for psychosocial support interventions, which are desirable for reducing stress and anxiety in this highly burdened cohort, and supporting better health outcomes in children. Currently, there are limited tools available that are designed to capture this information. Where tools do exist, they are not comprehensive and do not adequately capture the lived experience. Objectives: Development of quantitative tools, informed by lived experience, to enable researchers gather data on parent-caregiver knowledge and engagement, which accurately represents the experience/cohort and enables exploration of questions that are of real-world value to the cohort themselves. Methods: This research employed an engaged approach to address the problem of quantifying two key aspects of caregiver diabetes management: Knowledge and engagement. The research process was multi-staged and iterative. Stage 1: Working from a constructivist standpoint, literature was reviewed to identify relevant questionnaires, scales and single-item measures of T1D caregiver knowledge and engagement, and harvest candidate questionnaire items. Stage 2: Aggregated findings from the review were circulated among a PPI (patient and public involvement) expert panel of caregivers (n=6), for discussion and feedback. Stage 3: In collaboration with the expert panel, data were interpreted through the lens of lived experience to create a long-list of candidate items for novel questionnaires. Items were categorized as either 'knowledge' or 'engagement'. Stage 4: A Delphi-method process (iterative surveys) was used to prioritize question items and generate novel questions that further captured the lived experience. Stage 5: Both questionnaires were piloted to refine wording of text to increase accessibility and limit socially desirable responding. Stage 6: Tools were piloted using an online survey that was deployed using an online peer-support group for caregivers for Juveniles with T1D. Ongoing Research: 123 parent-caregivers completed the survey. Data analysis is ongoing to establish face and content validity qualitatively and through exploratory factor analysis. Reliability will be established using an alternative-form method and Cronbach's alpha will assess internal consistency. Work will be completed by early 2024. Conclusion: These tools will enable researchers to gain deeper insights into caregiving practices among parents of juveniles with T1D. Development was driven by lived experience, illustrating the value of engaged research at all levels of the research process.

Keywords : caregiving, engaged research, juvenile type 1 diabetes, quantified engagement and knowledge

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