Engaging Families in Management of New Onset Diabetes in Youth
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Introduction/Context: The management of type 1 diabetes (T1DM) in children is complex with availability of many insulin regimens and delivery technologies. However, the most efficacious insulin regimen may not be appropriate for some families, resulting in nonadherence and poor outcomes. Clarifying families’ needs and priorities may help engage families and guide development of appropriate treatment plans.

Description of practice innovation: In 2007, our Inpatient Diabetes Program addressed this issue by introducing the Insulin Treatment Decision Questionnaire, which described two insulin plans and five typical insulin plan characteristics and asked families to rank these characteristics in order of importance to their family at that time. This was used by the team and family to select a treatment plan. In 2015, the program found that this tool no longer adequately represented the complex scope of insulin management plans being offered at diagnosis and undertook a complete redesign. The new tool, the Patient insUulin Profile (PUP), was designed to focus on the areas relevant to insulin plan choices including the home environment (e.g. number of households), school/daycare, family skills (e.g. comfort with calculations), and mealtime structure. Families were also asked to rank the priority of these issues for their family. This information was then used to facilitate discussion between the family and medical team about the child’s insulin plan options and to ensure concerns were being met. Development of the PUP was informed by multiple treatment stakeholders as well as pilot testing with families. The final tool was written at the 6th grade level and made available in both English and Spanish. The PUP was launched in May 2015.

Evaluation/impact: Our inpatient diabetes quality improvement program has conducted ongoing evaluation of the utilization of our tool to facilitate family-centered decision making since its inception and fields a voluntary, anonymous survey completed by families at discharge regarding their experience. Response rate for the survey is approximately 45%. Since 2013Q2, on average, 98% of families have used the tool without significant change with the introduction of the PUP. Prior to launch of the PUP, 80% of families reported being “very satisfied” with the degree to which they could participate in treatment decisions (Figure). Introduction of the PUP tool initially led to a decline in this metric, prompting additional orientation and education about the new format of the tool at all staff levels. However, following this transition, to date, 89% of families reported the highest level of engagement in decision-making from September to December 2015.

Discussion/implications: A family-centered approach to new onset diabetes management in youth can engage families with the medical team and identify an insulin plan consistent with families’ needs and priorities. Our new tool captures the complexity of issues that the medical team needs to understand in order to engage families in a dialogue about treatment options. Ongoing evaluation of families’ perception of engagement in decision-making is needed along with consideration of the impact on quality of life and outcomes in T1DM management.

Figure. Proportion “Very Satisfied” with Involvement in Decision-Making