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001 - Sample Demographics and Cultural Responsiveness in Psychosocial and Behavioral Interventions with Adolescents with Type 1 Diabetes: A Systematic Review

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Background: The rate at which new cases of Type 1 diabetes (T1D) in youth <20 years old is increasing in the U.S. is a mounting pediatric public health concern; and age, race and ethnicity have significant impacts. Specific social determinants of health and sociodemographic (SD) characteristics - racial/ethnic minority, low SES, single parent home and underinsured - have consistently been associated with poorer glycemic control (GC) and self-management (SM) in adolescents with T1D.
Aims: The purpose of this systematic review was to evaluate sample demographics, and culturally responsive recruitment and reporting methods used in psychosocial and behavioral interventions focused on improving self-management and glycemic control in adolescents with T1D, to identify if studies were targeting these high risk groups and if current methods were being tailored to reach them.
Methods: Using a social determinants of health and health equity theoretical perspective, this review applied a culturally responsive research (CRR) framework to evaluate relevant interventions. Intervention studies, from 2006 to 2016, focused on adolescents (13–18 yo) with T1D and improving self-management and glycemic control by psychosocial or behavioral methods, obtained from PsychInfo, PubMed and CINAHL, were evaluated using a CRR rubric.
Results: Twenty-eight studies met inclusion criteria; 14 reported on fewer than 3 of 7 sociodemographic categories. Of those that reported, overall study samples used convenience sampling methods, focused predominantly on white, middle-high income, moderately glycemic controlled adolescents from two-parent households with private insurance. Majority of studies scored poorly in cultural responsiveness in reporting analysis and interpretation, and moderately in culturally responsive reporting of SD descriptions of participants.
Conclusions: Overall, studies lacked detailed recruitment and sampling methods, as relates to cultural inclusivity, neglecting to apply deliberate recruitment efforts and use of culturally responsive assessments for difficult to reach high risk groups. Results suggest that investigators should examine potential provider and researcher bias in sampling and incorporate greater cultural awareness and responsiveness into all phases of the research process.
Clinical implications: Pediatric endocrine nurse interventionists and researchers could increase targeted efforts toward recruiting and sampling more high-risk groups, by devising successful, culturally responsive methods of recruitment and sampling, such as those employed in community-based participatory research (CBPR). Researchers should strive to include expanded and disaggregated sociodemographic reporting in results reporting and study analysis, to account for the impact and influence of social determinants of health on outcomes, thus expanding our understanding of clinical within group differences among all racial and ethnic populations.Targeted, community-based participatory research (CBPR) efforts will engage high risk participants and improve existing and novel interventions by making them relevant to the unique needs, goals and priorities of highest risk sociodemographic groups within pediatric endocrinology. Directing T1D intervention resources to the most at risk will reduce national and personal healthcare costs, as well as improve adolescent health in the highest risks groups experiencing health disparities.

002 - Incidence and Preventative Strategies of Adrenal Crisis in Congenital Adrenal Hyperplasia

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Background: Patients with CAH are at risk for life threatening adrenal crises due to cortisol deficiency. Teaching of stress dosing to families plays a vital role in the prevention of adrenal crises.
Aims: The aim of this study was to characterize the rates and causes of stress dosing and related consequences in a group of CAH patients who were receiving routine education regarding management of illnesses.
Methods: Rates of illnesses, stress dose days, emergency room visits, hospitalizations and adrenal crises were evaluated in CAH patients followed in a longitudinal study at the National Institutes of Health Clinical Center. The group comprised of 156 patients, 60% male, 97.6% with 21-hydroxylase deficiency. 81% were children at first encounter age ranging from age 11 months to 50 years (median 5.4 years). Patients were followed for an average of 9.3 years (SD 6), with the longest duration 23.4 years.
Results: The 0–4-year-old group had highest rates of illnesses and stress dosing as compared to 4–18-year-old age group (2.5 + 3.0 vs. 1.5 + 2.3 illness episodes/year, $p < 0.0001$; 5.0 + 10.2 vs. 2.2 + 3.8 stress dose days/year, $p < 0.0001$). Females reported higher rates of stress dosing than males. Gastrointestinal, upper respiratory and febrile illnesses were the main factors requiring stress dosing across all ages. The incidence of adrenal crises was 7.2/100 patient-years in children and 10.2/100 patient years in adults. The annual rate of ER visits and hospitalizations ($p = 0.03$ and $p = 0.02$ respectively) was higher during adulthood than childhood. Only children suffered from serious hypoglycemic episodes and children had fewer instances of inappropriate stress dosing than adults.

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Conclusions: Pediatric patients followed stress-dosing guidelines more often than adults and had fewer emergency room visits and hospitalizations, although adrenal crises still occurred. The youngest patients are most vulnerable to life-threatening events. Revised stress dosing recommendations could be considered.
Clinical implications: Further preventative measures should be taken by endocrine nurses to pay more attention to youngest and oldest age groups. This intervention should include increased emphasis on fluid and glucose intake during illness to prevent severe adrenal crises with hypoglycemia in children and improve teaching retention in adults.

003 - International Survey Examining Structure, Process and Outcomes of Transitional Care for Young Adults with Chronic Endocrine Disorders: A Research Protocol

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Background: Most children with chronic health conditions survive into adulthood and require life-long care. Effective models of transitional care (TC) are needed to seamlessly move young adults from pediatric settings to adult-oriented care. A significant body of literature supports that poor TC results in disconinuity/gaps in care, preventable complications, and avoidable costs. Research demonstrates that effective TC can support self-management and improve patient outcomes, satisfaction, and adherence to treatment. Despite this evidence, practices vary and implementation has been incomplete.
Aims: We propose an international survey of clinics providing TC for young adults with chronic endocrine disorders to better understand current practices across healthcare systems. We will examine respective structure, process and outcomes of TC across settings to identify barriers to implementation as well as key stakeholders for TC.
Methods: A web-based, international survey (United States, Canada, United Kingdom, Netherlands, Switzerland) will be employed to assess structure, process and outcomes in line with Donabedian's model of quality healthcare. Drawing from 'Got Transitions' (endorsed by the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians), we aim to examine transition policy, tracking/monitoring, readiness, planning, transfer of care and transfer completion. Additional questions will specifically evaluate outcome measures, financial aspects, barriers to implementation and stakeholders/champions. Descriptive statistics will be used to summarize survey results and thematic analysis for assessing open-ended responses.
Results: Envisioned results will facilitate identification of commonly-used approaches for developing and implementing structured TC. Similarities and differences will be identified across healthcare systems providing insights into the promoters and barriers to implementation. Synthesis of findings will create the basis for a roadmap that can be adapted to local healthcare systems and reimbursement structures.

Conclusions: Across settings and countries, healthcare delivery is largely influenced by organizational and policy drivers. We anticipate that this proposed study will fill a knowledge gap by providing context and a deeper understanding of TC implementation.

Clinical implications: This study may help providers improve the care for young adults with chronic endocrine disorders. Specifically, it could provide a TC framework and toolkit for developing a model adapted to the specific local environment.

004 - Family Routines-Healthy Families: Impact of Parenting/Family Routine Intervention on Families of Young Children with Type 1 Diabetes

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Background: Maintaining glycemic control in young children with type 1 diabetes requires caregivers to carefully monitor blood glucose and eating behaviors in an unstructured environment to calculate insulin dosing. If there is less than two hours between dinner and bedtime snack, the bedtime glucose reading may be high and parents may be unsure of what to do. This can result in overnight hyperglycemia and elevated A1C.
Aims: The purpose of the study was to examine a parenting/family routine intervention program for caregivers of children ages 2–5 with type 1 diabetes. The intervention, Family Routines - Healthy Families, contains an established effective parent skills training curriculum uniquely integrated with a newly-developed family evening routine to promote improved metabolic control.
Methods: We used a mixed methods approach to measure outcomes of the program including evening routine variables, glucose, parent decision-making and quality of life. This feasibility study examined program attendance, activities completed, and participant feedback regarding helpfulness and preferences. We used focus group interviews to explore facilitators and barriers to program completion.
Results: Five caregivers completed the program. Two families had improved bedtime and morning blood glucose. Four families maintained greater than two hours between dinnertime and the bedtime blood glucose reading. Two families had fewer issues with decision-making at bedtime. Although glucose averages improved between bedtime and morning, the only child who demonstrated a decrease in A1C was the youngest.
Conclusions: Data demonstrated that caregivers of young children with diabetes already had a goal of providing an evening routine for their child. This feasibility study suggests that a parent program such as this may be a useful tool for parents of young children who need assistance with establishing routines. Further research is suggested to test this intervention in a broader sample.
Clinical Implications: A simple program such as Family-Routines-Health Families may facilitate accurate monitoring of time intervals between dinner and bedtime glucose checks for the benefit of patients and parents. In the course of glucose screening, nurse educators may identify families who would most benefit from a parent guidance program such as this.

005 - Parents' Underestimations of Child Weight: Implications for Obesity Prevention

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Background: Approximately 1 in 5 children in the U.S. are obese. Given the increasing incidence of type 2 diabetes in children and the increased risk of hypertension, heart disease, arthritis, sleep apnea and premature death in adulthood associated with obesity, obesity prevention remains a public health challenge for nurses. Obesity prevention efforts may be ineffective if parents lack awareness of their children's overweight status.
Aims: The purpose of this study was to examine how health literacy and social determinants of health predicted parents' underestimation of child weight status. Influenced by the ecological model, we