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Title of project: Illness identity and social relations in adolescents and emerging adults with type 1 diabetes

ABSTRACT

Background: Treatment of type 1 diabetes (T1D) requires adherence to a daily treatment regimen that imposes constant self-management. However, non-adherence and suboptimal glycemic control are significant concerns for adolescents and emerging adults (young people) with T1D. Consequently, young people have an elevated risk for future diabetes-related complications. Additionally, approximately one-third of young people with T1D experience psychological distress or psychiatric disorders, such as poor self-esteem, anxiety, depression or eating disorders. Moreover, they struggle with high levels of conflict within their families, lack of support from friends and stigmatization due to T1D. Taken together, these challenges may influence their quality of life (QoL) negatively. As young people with T1D constitute a high-risk population, it is crucial to find ways to minimize diabetes-related challenges in this population.

Aims: To explore how illness identity and social relations in young people affect and are affected by T1D and self-management behaviors, the goal being to pave the way toward identification of appropriate and relevant support methods. To reach this goal, the study aims to meet the following objectives. **Objective 1:** To translate and validate the Illness Identity Questionnaire (IIQ) in a Danish population of 13- to 25-year-olds with T1D and explore associations between illness identity, adherence and QoL in this population. **Objective 2:** To conduct a qualitative study informed by the results of the survey to gain deeper insights into how illness identity and social relations affect and are affected by T1D and self-management behaviors. **Objective 3**: To operationalize the results of the survey and the qualitative study to make the concept of illness identity and the role of social relations applicable to and appropriate for young people with T1D and in healthcare practice and future support interventions.

Design and methods: The study consists of four consecutive phases corresponding to the three objectives. To establish the analytical framework of the PhD, **Phase 1** consists of a systematic review of literature on illness identity and the role of social relations in young people with T1D. In **Phase 2**, the IIQ is translated into Danish (IIQ-DK), pilot-tested in 7-10 young people with T1D, and tested in a broad population of young people (age 13-25) with T1D in the Capital Region of Denmark (CRD). Eligible participants (inclusion criteria: a T1D diagnosis, 13-25 years of age, currently attending a diabetic clinic in the CRD) are recruited by their clinicians. Confirmatory factor analysis (CFA) is applied to evaluate the factorial validity of the IIQ-DK. Associations between illness identity dimensions, adherence and QoL in the Danish population are investigated. Illness identity is measured by the IIQ-DK. Adherence is measured by HbA_{1c} and complication status. HbA_{1c} values are collected from medical records through the Electronic Patient Journal (EPR) in the CRD. QoL is measured by the Danish WHO Quality of Life Questionnaire (WHOQOL). Descriptive statistical analysis of data distribution and occurrence of illness identity dimensions are performed. Associations between all factors are investigated using multiple logistic regression. In **Phase 3,** a qualitative interview study is designed and performed to elicit information on illness

identity and social relations. Data are collected through qualitative, semi-structured interviews with young people with T1D. Data are thematically analyzed. **Phase 4** establishes a framework for future development of relevant and realistic interventions to help young people with T1D targeting their diabetes-related challenges through an explicit focus on illness identity and social relations. This phase employs concepts and techniques from design-based research and entails ideation and prototyping through co-creation processes. Advisory boards (young people with T1D, their families, healthcare professionals) participate in workshops and focus groups to generate authentic and contextually relevant ideas based on the findings from Phase 1, 2 and 3.