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Identifying participation characteristics to adapt client-tailored intervention among children and adolescents with celiac disease

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Introduction: Celiac disease (CD) is a chronic condition precipitated by exposure to gluten. Managing a restrictive and challenging gluten free diet is the only available treatment. There is paucity in understanding the participation characteristics in food-related activities in everyday life among children and adolescents' and interventions to assist them.

Objectives: To develop and validate the Celiac Disease-Children's Activity Report (CD-Chart), a standardized measure aimed to map out these characteristics and to examine associations with quality of life (QOL) and executive functions (EF).

Method: This study included 126 children (8-11 years) and adolescents (12-18 years) with CD and 30 matched controls without CD. The CD-Chart that incorporates nine food-related activities, measured by six dimensions: frequency, preference, preparation, involvement, help, and self-determination, was administered by interview. Additional measures included the Pediatric Quality of Life Inventory (PedsQL) and the Behavior Rating Inventory of Executive Function (Brief).

Results: The CD-Chart items showed adequate internal reliability as measured by the preference dimension (α =.80). An independent-samples t-test indicated that preparation scores were significantly higher for the group with CD (M=.899, SD=.060) than the control group (M=.004, SD=.023); t(38)=76.25, p<.001. Significant differences were found between the children and adolescents with CD in specific characteristics of the CD-Chart dimensions. Different correlation patterns between QOL and EF were found in the two age groups.

Conclusion: The CD-Chart is a reliable and valid tool that together with additional tools can contribute to understanding the unique and individual needs of children and adolescents with CD in order to adapt client-tailored intervention.