

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

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Gluten free

Celiac disease (CD)

- ▶ A chronic health condition precipitated by exposure to gluten
- ▶ The only available treatment is managing a lifelong restrictive and challenging gluten-free diet



CD research

▶ Increased worldwide research focused on life of children and adolescents with CD:

- Medical research – causes and finding a cure
- Quality of life
- Level of adherence
- Emotional aspects

(e.g., Biagetti et al., 2013; Howard & Law, 2014; Skjerning, et al., 2014)

Paucity in knowledge of CD

- Profound understanding of participation characteristics in food-related activities in everyday life among children and adolescents
- Knowledge about interventions to assist this population



Aim

To develop and validate

- The Celiac Disease-Children's Activities Report (CD-Chart)
- (Meyer & Rosenblum, 2017)

• A standardized measure to map out participation characteristics

To examine associations with

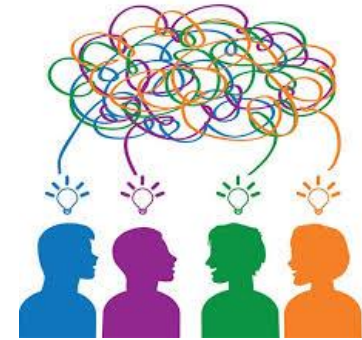
Quality of life (QoL)
PedsQL (Varni et al., 2001)

Executive functions
Behavior Rating Inventory of Executive Function (BRIEF) (Gioia et al., 2000)

Method

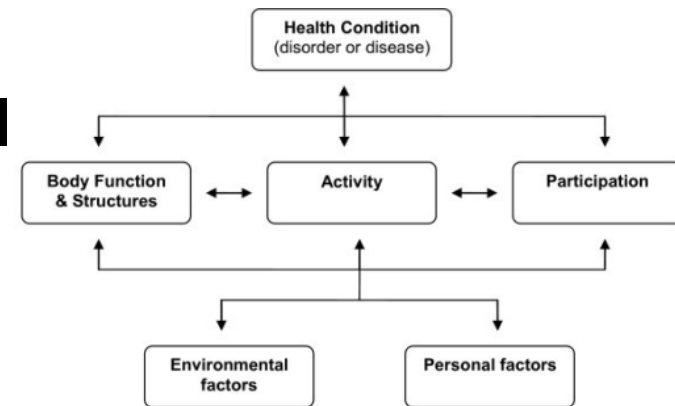
Focus group interviews

- 1) Children (8-12 years) ($n=12$)
- 2) Adolescents (13-16 years) ($n=10$)
- 3) Children's parents ($n=13$)
- 4) Adolescents parents ($n=10$)



Theory

Constructs based on the International Classification of Functioning, Disability and Health: Child and Youth Version (ICF-CY) (WHO, 2007)



9 food-related activities

1. Meals at home
2. **Family meals & events**
3. Family vacations
4. **Eating out with friends**
5. Eating out at a friend
6. Eating meals on overnight trips
7. Eating treats from the teacher
8. School food activities
9. **School overnight trips**

6 core dimensions

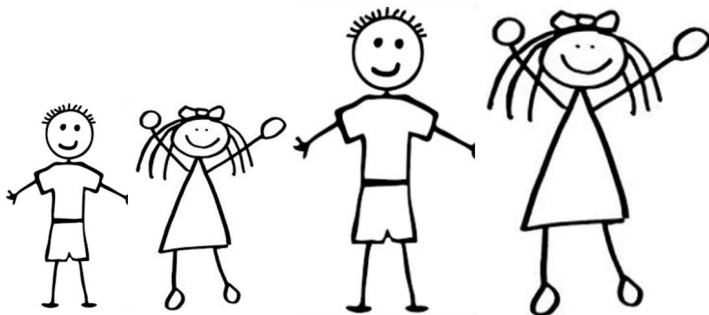
- ▶ Activity
- ▶ Frequency
- ▶ Preference
- ▶ Preparation
- ▶ Involvement
- ▶ Self-determination



Participants

Group with CD (n=126)

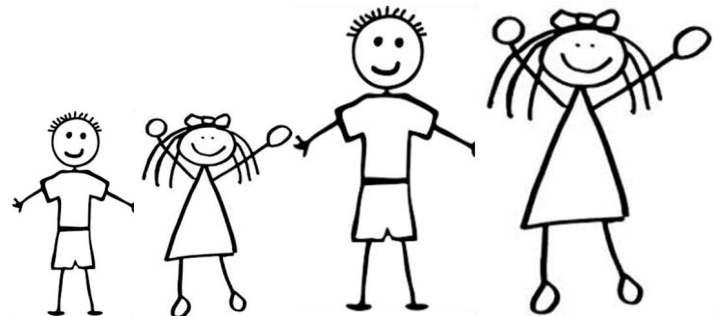
**Children (8-11 ys)
Adolescents (12-18 ys)
with CD > 6 months**



Control group (n=30)

**Healthy controls
matched by:**

- ▶ age
- ▶ sex
- ▶ living and educational environment






RESULTS



Article

Development and Validation of the Celiac Disease-Children's Activities Report (CD-Chart) for Promoting Self-Management among Children and Adolescents

Sonya Meyer *  and Sara Rosenblum

Exploratory factor analysis

Items	Factor 1: Social environment	Factor 2: Close family environment
5. Eating out at a friend	.756	
7. Eating treats from the teacher	.705	
4. Eating out with friends	.658	
8. Special food activities at school	.587	
2. Family meals/events	.448	
3. Family vacations		.747
1. Meals at home		.703

- A 3rd component "**trip environment**"
Overnight social & school trips were excluded from factor analysis due to statistical limitations, but showed good theoretical relationship, $r = .49, p < .001$.

CD group vs control group



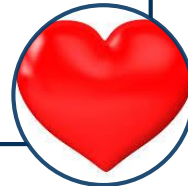
- Group with CD participate at the **same frequency** as controls

Frequency



- Group with CD **like the participation less** than controls

Preference
















- Group with CD need **more pre-preparation** before participation in food-related activities than controls

Preparation



Children vs Adolescents



Children	 GLUTEN FREE	Adolescents
     	<ul style="list-style-type: none">• Activity $p < .001$• Frequency $p < .001$• Preference $p = .002$• Preparation• Involvement $p < .001$• Self-determination $p < .001$	     



CD-Chart Correlations



PedsQL

(Varni et al., 2001)

None

Physical QoL & social preference

Emotional QoL & trip preference

Social QoL & trip preference

BRIEF

(Gioia et al., 2000)

None

Shifting & social preference

Shifting & trip preference

Initiation & trip self-determination

{ Children }
{ Adolescents }

{ Children }
{ Adolescents }



Conclusions

- ▶ The CD-Chart is a reliable and valid tool that contributes to characterizing the participation in food-related activities while managing the gluten-free diet
- ▶ Using self-reports and other tools can be valuable in understanding the individual needs of children and adolescents with CD



Clinical implications

- ▶ Client-tailored intervention can:
 - ✓ Promote effective self-management
 - ✓ Promote adherence to the gluten-free diet
 - ✓ Promote quality of life with CD

Thank You



Remarks, Questions, Ideas
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