

November, 2012

Title: Leisure characteristics and quality of life of children with Celiac compared to children without Celiac

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Abstract

Celiac is a chronic autoimmune disease precipitated by exposure to gluten and is characterized by inflammatory damage to the small intestine due to difficulty in ingestion of gluten (wheat, barley and rye).

A lifelong adherence to a strict gluten free diet is the only evidenced based treatment known today. Adaption to a gluten free diet, involving strict dietary limitations can be difficult, has financial implications and may be harmful to the patients' quality of life. Non-compliance to a gluten free diet may have a wide range of short and long term medical implications. Therefore, early diagnosis, support and help with diet adherence are of considerable importance.

Occupational therapy focuses on assisting clients in finding meaningful and goal directed pursuits through engagement in occupation to enable participation in the fabric of life. Occupational therapists acknowledge that health is supported and promoted by engagement in everyday activities within the home, school, work and social environment (American Occupational Therapy Association, 2002). Eating is one of life's meaningful activities. Leisure is a core concept in Occupational Therapy and is of central importance for building children's competence and self-determination and for social and personality development.

The World Health Organization (WHO), recognizes that health can be affected by the inability to carry out activities and participate in life situations. The International Classification of Functioning, Disability and Health (ICF) describes the relationship between these domains and well-being. According to the ICF classification, autoimmune diseases and digestive system functioning are amongst client factors that may affect occupational performance. Although Celiac disease clearly

fits this classification, no theoretical or clinical reference has been found related to occupational therapy practice and Celiac.

"Health related quality of life" examines the implications of various chronic diseases on quality of life. During recent years, the quality of life of adults with celiac disease has been studied and lately that of adolescents and children too. The studies have focused on the effects and implications of non-compliance to a gluten free diet. However, no in-depth reference has been found in regard to participation in leisure activities and the level of quality of life of children with Celiac disease.

Objectives: Evaluation of leisure participation characteristics using the Children's Leisure Assessment Scale (CLASS) and the quality of life of children with Celiac in Israel using a disease-specific health-related quality-of-life questionnaire for children with Celiac and to deepen the understanding of these characteristics.

Study hypotheses: (1) Internal reliability of $\alpha > .70$ will be established for the Children's Leisure Assessment Scale (CLASS) (Rosenblum et al., 2010). (2) No significant differences will be found in the leisure participation characteristics between children with and children without Celiac disease as measured by the CLASS. (3) Significant differences will be found between the groups in relation to the "eating activities" factor as measured by the CLASS. (4) No difference will be found in the Preference dimension of "eating activities". (5) Internal reliability of $\alpha > .70$ will be established for the Hebrew version of the Questionnaire for Children with Celiac Disease (CDDUX) (van Doorn et al., 2008). (6) Significant differences will be found between the child report and the parent proxy version of the quality of life questionnaire. (7) Significant positive correlations will be found between the children's leisure participation characteristics and their perception of their quality of life.

Participants: The study included 68 children aged 8-15 and their parents. The study group included 34 children diagnosed with Celiac disease who follow a gluten free way of life without physical and/or neurological disabilities. The control group included 34 healthy children, friends of the study

group participants, matched by age, gender, place of residence, educational and social environment criteria.

Instruments: (1) Demographic questionnaire, (2) CLASS Leisure Assessment Scale (Rosenblum et al., 2010), (3) CDDUX questionnaire (van Doorn et al., 2008), completed by the children with Celiac and their parents.

Data analysis: MANOVA, t-test and Man-Whitney tests were used to compare CLASS leisure characteristics and individual items between the 2 groups. Internal reliability for the Hebrew version of CDDUX was determined using Cronbach's coefficient alpha. MANOVA, paired t-test and Wilcoxon were used for comparison between children's self-reports on quality of life and their parent's proxy reports. Correlations between leisure participation and quality of life with celiac disease were evaluated by Pearson coefficient.

Results: Internal consistency of the CLASS questionnaire was determined to be $\alpha = .77$. No significant differences were found in the leisure participation characteristics between the two groups in the Variety, Frequency, Sociability and preference dimensions as measured by the CLASS. No significant differences were found in relation to the leisure "eating activities" factor either. Significant differences were found in a number of specific items. Internal consistency of the translated version of the CDDUX was determined to be $\alpha = .86$ for the children's version and $\alpha = .81$ for the parent's version. A significant difference was found between the parent's report of the QOL of their children compared to the children's report. Namely, the parents perceive the QOL of their children's QOL to be significantly more negative than the children's self-perception. Finally, a significant correlation was found between the CLASS sociability dimension in relation to the "eating activities" factor and the children's total CDDUX score.

Conclusions: The findings of this study are supported by the basic assumption of the ICF (WHO, 2001) and the Occupational Therapy Practice Framework (AOTA, 2002) concerning how a digestive system autoimmune disease such as Celiac disease may restrict participation in leisure activities and therefore influence quality of life. The management of celiac disease requires adjustment of

adaptation strategies to changing environments across the life span. The professional foundation of Occupational therapy framework can contribute to health of the celiac population and the focus on participation, may fill in the gap and provide a link between the medical system and the socio-cultural system (Baum, 2011). The daily coping arena of both children and adults with celiac, as expressed in the results of the children's and parent's quality of life questionnaire in this study in addition to recent research concerning quality of life with Celiac, is an arena where dietary restrictions limit participation in various occupational situations. Today, these situations are not sufficiently accommodated by health care services and the celiac population, who live with a chronic health condition remain with the personal responsibility of coping and managing their disease.

Recommendations: Further research is required to deepen the understanding of the influence of Celiac disease on the quality of life and well-being of those living with Celiac. A deeper understanding of their needs will enable the development of assessment tools and intervention programs supporting the participation in everyday activities adapted to people living with Celiac disease through the circle of life.