

Pediatric Celiac Disease Management and Perceived Quality of Life

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Introduction

Background:

Celiac disease (CD) is recognized as one of the most common disorders diagnosed within the realm of pediatrics, and affects approximately 1% of the U.S. population. CD is a chronic autoimmune disease provoked by the ingestion of gluten-containing foods; leading to a number of short- and long-term health effects. Currently, the only effective treatment for the disease is life-long adherence to a gluten-free diet (GFD) which excludes any products derived from wheat, barley and rye grains (Black & Orfila, 2011). Though adherence to the GFD promotes overall health and well-being, children and families often face significant challenges. Previous studies have readily examined the practical, social and economic implications experienced by children with CD and their families. The results obtained from these various studies have focused almost exclusively on the challenges associated with the child's adherence to the GFD. Less attention has been given to the impact on quality of life (QOL), such as the emotional outlook and self-perception of children with CD. Furthermore, few studies have addressed the parental perspective of their child's QOL, in reference to the management of the child's disease. The lack of current studies addressing QOL in children with CD indicates the need to investigate this idea further.

Celiac Disease

What is Celiac Disease? Celiac disease (CD) is a chronic autoimmune disease triggered by dietary gluten in genetically susceptible individuals.

Common Symptoms in Children: The typical gastrointestinal symptoms experienced by children with CD include diarrhea, weight loss, failure to thrive, vomiting, abdominal pain, bloating, distention and constipation (Roma et al., 2010). However, some have no identifiable symptoms.

Long Term Implications of Unmanaged Celiac Disease: The long term implications include but are not limited to: development of other autoimmune disorders such as Type 1 diabetes, multiple sclerosis, dermatitis herpetiformis; anemia, osteoporosis, infertility and miscarriage, epilepsy, migraines, short stature, intestinal cancers, arthritis, tooth enamel loss, alopecia, vitamin and mineral deficiencies, and lactose intolerance.

What is a Gluten-Free Diet? The gluten-free diet completely excludes all foods and beverages containing gluten, which is most commonly associated with wheat, but is also found on the surface layer of the cereal grains barley, rye, and potentially oats (Marcel, 2014, n.p.).

Social Implications: A chronic illness such as CD can reduce a child's QOL and have a negative effect on family relationships, scholastic achievement, and social activities (Barous, 2013).



School Age Child-Specific Challenges

- Nutritious school lunches
- Attending summer camp
- Birthday parties
- Sleepovers
- Sporting events
- Religious ceremonies (e.g. first Communion)



Adolescent-Specific Challenges

- Partaking in social events
- Having to educate others
- Preparing for college
- Difficulty in eating out at restaurants with friends

Financial Cost: Gluten-free products are significantly more expensive than comparable products. Cost of gluten-free foods can be a burden for lower-income families.



Regular pretzels = \$2.89
Gluten-Free pretzels = \$6.87



Regular Loaf of Bread = \$2.99
Gluten-Free Loaf of Bread = \$5.69

Quality of Life

What is Quality of Life? Quality of life (QOL) is a subjective assessment of physical, mental, and social dimensions of well-being and daily functioning.

Why Quality of Life in this Study? It can be hypothesized that celiac disease management (specifically, adherence to the gluten-free diet) can have a negative impact on the child's QOL: Regimented dietary changes required of the gluten-free diet can have negative impact on the child's QOL (Rashid et al., 2005) and subsequent desire to comply with dietary requirements • Compliance with the gluten-free diet can influence various practical, social and economic challenges which can impact the child and parents' perceived QOL.

Quality of Life Matters!

- Research suggests a negatively perceived QOL decreases the desire to comply with the gluten-free diet
- Gluten-free diet compliance in children can vary from 42-91%. Low GFD compliance can lead to long-term health implications.

Purpose of Study

✦ The purpose of this study was to examine children's and parental perspectives of Quality of Life (QOL) in relation to management of the child's diagnosis of Celiac Disease. The specific aims for this study are:

- Investigate the impact of celiac disease on child's perceived QOL
- Investigate the parents' perceived impact of celiac disease on his or her child's QOL
- Identify differences between parental and child perception of celiac disease and QOL
- Identify any correlation between length since diagnosis, demographic variables, and QOL
- Describe overall experience and stressors of managing celiac disease and the gluten-free diet

Search of Evidence

Literature for this review was collected utilizing several literature databases representing multiple disciplines that address celiac disease and QOL. Disciplines of interest included nursing, psychology, biomedicine, and nutrition. Databases included: CINAHL, Medline, and OVID (2006-present). Key words searched included: celiac, coeliac disease, gluten, children, pediatric, quality of life, health, diet, tool and questionnaire. The titles and abstracts from 52 articles were reviewed for relevance. A total of 16 were considered most applicable to the clinical issue. Due to few studies focusing only on children with CD, several studies were included that involved adults with CD to provide richer information on the underlying concepts of QOL and CD.

Methods

Design:

A comparative-descriptive study to explore the perceived QOL of children diagnosed with celiac disease, compared to the parents perceived impact of celiac disease on his or her child's QOL. Secondary qualitative data was also collected.

Instruments:

Instruments used for this study are based on the CD-specific pediatric Health Related Quality of Life Instrument (CDPQOL) for 8-12 year olds and for 13-18 year olds. These instruments are specifically developed for children diagnosed with celiac disease living in North America: CD-specific pediatric HRQOL instrument (CDPQOL) 8 to12 y/o -19 item
CD-specific pediatric HRQOL instrument (CDPQOL)13 to18 y/o -24 item
A similar parent instrument was developed to measure parental perceived QOL.

Recruitment:

Participants were recruited via convenience sample of parents and children ages 8-18 seen in a pediatric GI clinic.

Data collection:

- At the time of the child's scheduled appointment in the Pediatric GI department, the parent and child reviewed the inclusion criteria.
- Qualified participants received the questionnaire packet containing surveys and information sheet including: explanation of the study, risks and benefits, data collection procedure, confidentiality, and primary investigator information.
- The parent and child surveys were filled out during the appointment if time permitted, or filled out afterward and then returned to the primary

Ethical Compliance: Study given IRB Approval from the University of Wisconsin-Eau Claire Institutional Review Board for the protection of human subjects. Anonymity has been protected.

Celiac Quality of Life Surveys

Scoring: Never, Almost Never, Sometimes, Often, Almost Always (0-4 Likert Scale)

Sample Questions - Child (8-12 years)

- In the past ONE month, how much of a problem has this been for you...
- I feel like my friends think I'm different
 - I don't get anything when someone brings treats to school
 - I have to bring my own gluten-free foods to school or a friend's house

Sample Questions - Adolescent (13-18 years)

- In the past ONE month, how much of a problem has this been for you...
- I believe that celiac disease will affect what college I choose
 - I get jealous when I can't eat what my friends eat
 - I have to bring my own gluten-free foods to school or a friend's house

Sample Questions - Parent Form

- How much of a problem do you believe this is for your child...
- Having trouble enjoying social activities with friends
 - Being embarrassed to bring their own gluten-free foods to school or a friend's house
 - Finds it difficult to follow a gluten-free diet

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Review of Findings

Data Analysis:

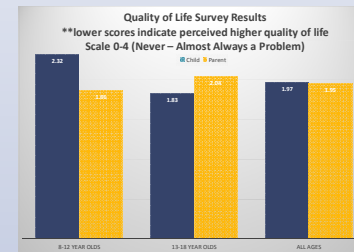
A total of 15 pairs of child and parent participants completed the surveys. Due to small sample size, it was not possible to analyze the data on a question-by-question basis or provide a comparison of data between length of diagnosis, or demographic variables. Length of time since child's diagnosis ranged from 2 months to 8 years. Overall means were compared by age groups.

Findings: Comparing the mean averages, in the **8-12 year olds the child group indicated a lower perceived QOL than the parent group.** These results may suggest that this age group has a lower level of QOL than what parents perceive.

| Quality of Life Survey Results | Child Mean(SD) | Parent Mean(SD) |
|--------------------------------|----------------|-----------------|
| Ages 8-12 years (n=6) | 2.32(1.07) | 1.86(1.345) |
| Ages 13-18 years (n=9) | 1.83(1.14) | 2.04(0.679) |
| All Children (n=15) | 1.97 (1.19) | 1.95(0.92) |

In the **13-18 year olds the child group indicated a higher level of QOL than the parent group.** These results may suggest that this age group has a higher level of QOL than what parents perceive.

The mean comparison of child and parent perceived QOL for both age groups combined resulted in no notable difference.



Qualitative Feedback

Child Survey 8-12 years (n=6)

Child Feedback

Most difficult thing about having celiac disease?

- Always waiting what I eat (5)
- Not having good food (2)
- Not be able to go favorite restaurant anymore (2)
- My friends eat in front of me foods I cannot have (3)
- Don't get birthday cake at school (2)
- Pizza at parties(1)

What would help you in maintaining a GF diet?

- If everyone was gluten-free (1)
- If teachers told parents to quit bringing cake (1)

Child Survey 13-18 years (n=9)

Child Feedback

What is the most difficult thing about having celiac disease?

- Going with friends to a restaurant that has no GF food (1)
- Can only eat certain foods (4)
- Have to plan ahead & bring own food for parties/sports/school events (6)
- Can never stop just anywhere to eat (4)
- Always having to read food labels (4)
- Get embarrassed when have to ask waiter for GF food (1)
- Don't get any treats when friends bring them to school (6)
- Never get to eat hot-lunch (5)
- Same foods get boring (5)

What would help you in maintaining a GF diet?

- If people knew more about celiac (4)
- If more restaurants had GF food (5)
- If they had more GF food at school (2)
- If my friends learned more about my diet (1)
- More variety of foods (2)
- Lower cost of GF foods (3)

Parent Feedback (n=6)

What major difficulties has your child had to cope with while on a GF diet?

- Not sneaking food (4)
- Doesn't like new gluten-free foods (3)
- Missing out on eating foods at parties with friends (4)
- Always has to take food along (2)

What do you find most difficult about managing your child's GF diet?

- Having to cook different foods for one meal (2)
- Cost of gluten-free foods is too much for whole family to go GF (1)
- Cost of food (2)
- Always have to plan ahead for sleepovers/parties (2)
- Extra shopping trips to grocery store for GF food (1)

What would help you and your child most?

- More knowledge in schools (teachers and other parents) (3)
- Lower cost of GF foods (3)

Parent Feedback (n=9)

What major difficulties has your child had to cope with while on a GF diet?

- Social activities with friends always requires bringing own food (2)
- Always having to plan ahead for sport practices, events, parties (4)
- Doesn't get many choices when eating out (3)
- Feeling left out when everyone else is eating food they cannot have (2)
- Going to birthday parties, going out to eat (2)

What do you find most difficult about managing your child's GF diet?

- Making sure they get a variety of foods (2)
- Cost of GF foods (5)
- Modifying recipes (1)
- Many grocery shopping trips to make sure food is available (1)
- Planning ahead for trips (2)
- Finding restaurants with good GF options (3)
- Finding foods that taste like normal food we eat (2)

What would help you and your child most?

- Lower cost of GF foods (7)
- Have more GF options at grocery stores (5)
- More education in schools for teachers (5)
- More awareness in other parents of GF diet (2)

The limitations of this study were:

- Limited time for recruitment of participants and short follow-up period.
- Small sample size.
- Limited control over recruitment of participants in healthcare facility.

Clinical Practice Implications

The data gathered from this study will provide nurses and other clinicians with a better understanding of the child and parents' perceived quality of life in relation to the management of the child's diagnosis of Celiac disease. With knowledge of these perceptions, nurses are in the ideal position to provide the appropriate education and support necessary to address family-specific challenges in regards to maintaining optimal management outcomes. By working in collaboration with the child and parent(s), nurses can assist families to develop life-long skills which will aid in gluten-free diet maintenance and a successive enhanced quality of life.