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– **Bibliographic reference**	– **Olsson (2008): The everyday life of adolescent coeliacs: issues of the importance for compliance with the gluten-free diet**
– Study type and aim	– Qualitative cohort study to assess how adolescents with CD perceive and manage their everyday lives in relation to a GFD
– Study quality	**CASP QUALITATIVE TOOL:** 1. Was there a clear statement of the aims of the research? YES 2. Is a qualitative methodology appropriate? YES 3. Was the research design appropriate to address the aims of the research question? YES 4. Was the recruitment strategy appropriate to the aims of the research? YES 5. Was the data collected in a way that addressed the research issue? YES 6. Has the relationship between researcher and participants been adequately considered? YES 7. Has ethical issues been taken into consideration? YES 8. Was the data analysis sufficiently rigorous? YES 9. Is there a clear statement of findings? YES 10. How valuable is the research? Valuable – thorough and well planned analyses and report of patient reported outcome relating to adherence to a GFD and the difficulties associated with this – **Overall risk of bias:**
– Number of patients	– N = 47

– **Bibliographic reference**	– **Olsson (2008): The everyday life of adolescent coeliacs: issues of the importance for compliance with the gluten-free diet**
– location	– Sweden
– Patient characteristics	– **Inclusion criteria:** confirmed CD based on ESPGHAN criteria. Age range 15 – 18, a prescription of GFD for at least 1 year. A prospective incidence register, which has nationwide coverage since 1998 and local paediatric depts. were used to ID potential participants. From these databases, 159 adolescents fulfilled the inclusion criteria, and were invited by letter with info about the study. 47 were recruited and interviewed. For each focus group, 6 to 7 adolescents were invited and 3- 6 participated. The first recruitment generated 6 focus groups. A second recruitment was conducted which generated 4 additional groups. – **Exclusion criteria**: None listed – **Mean age**: 16 – **Mean age at diagnosis**: 0 – 4 years – **Mean years since diagnosis**: 15 –
– Signs and symptoms	–
– Investigations	– **Focus group interviews**: • Adolescents spoke about beliefs, perceptions, expectations, needs, and experiences in relation to CD and the GFD • Interviews focused on social life, how they perceived different situations and obstacles • In all interviews first author was moderator and one of other authors acted as assistant. • Interview lasted 60 – 80mins and were digitally recorded • For all interviews, interview shaped by topic guide consisting of illustrative statement and open-ended questions • These consisted of experiences related to eating and being on a GFD in different contexts; everyday life in terms of knowledge, attitudes, support, and reactions in other people, and views of self in relation to CD. • Core topics same in each session • To establish credibility, participants were encourages to share their experiences, and the moderator went back over the conversations to verify findings. – Analysis of interview data • Focused on problems describes as most central and how they tried to sole these by different strategies • First author complied notes immediately after interview and described the recorded discussions verbatim • Transcripts read repeatedly by all authors and thereafter analysed in 3 stages according toStraus & Corbin (1998)

– Bibliographic reference	– Olsson (2008): The everyday life of adolescent coeliacs: issues of the importance for compliance with the gluten-free diet
	methods • Open coding first used to obtain overview of the info and conceptualize data • During this process new codes emerged and some codes were renamed or modified when going back and forth in the transcripts • Most important codes compared in order to find similarities between them and group into categories • Text segments from interviews then categorized using MAXqda2 software • After categorising patterns and themes emerged • For validity all authors were involved in data analysis
– Length of follow up	– n/a
– Outcome	• Resolution of symptoms • **Patient experience** • Complications of cd • Adherence • **Health related quality of life** • Impact on carers
– Results	– **Patient experience/ health related quality of life** – – GFD in everyday life • Most raised easier compliance at home compared with other places • Socially convenient circumstances at home where do not need to ask questions or explain diet • Situations outside home troublesome due to limited support and lack of disease-related knowledge in significant others (teachers, school kitchen staff, friends, grandparents) • Dissatisfaction with availability and sensory quality of GF foods • Attitudes and behaviours of signif. Others affected decision to comply or not in social situations • Limited knowledge about CD/GFD impaired social support and reinforced feelings of social inconvenience • Felt embarrassed when served special meals at school, socially inconvenient

– Bibliographic reference	– Olsson (2008): The everyday life of adolescent coeliacs: issues of the importance for compliance with the gluten-free diet
	• Being served same food as everyone i.e. at home or CD camps was very socially convenient – Different approaches to GFD: – Compliers who strictly follow, occasional noncompliers mostly eating GFD and resorting to GD in problematic situations; noncompliers, principally eating normal diet. • Compliers: ○ Presence of obvious signs and symptoms after gluten ingestion important motivator for adhering ○ Appropriate knowledge about importance of following strict GFD also contributed to compliance ○ Compliers saw options for finding acceptable solutions in different situations outside of home and usually found something to eat and if GF food not available still abstained from choosing gluten-containing food. ○ Also took control by planning and foresight by either bringing own food when were i.e. travelling or at sports camps ○ Consensus that normal food tasted better, but best strategy to manage this was to never expose self to sensory aspects of normal food ○ Practical and/or emotional support from significant others facilitated compliance i.e. by helping with bread baking, routinely offering GF alternatives, or just recognizing the importance of following a strict GFD were good enough motivators for compliance • Occasional compliers ○ Whether symptoms after gluten ingestion present or not, and severity of symptoms affected probability of compliance ○ Absence of immediate symptoms after ingestion described as option not to comply in socially inconvenient situations or because of sensory acceptance and/or lack GF foods ○ Also expressed doubts about compliance importance because of absence of immediate symptoms ○ Lack of knowledge gave rise to incorrect beliefs about CD and GFD, which sometimes explained noncompliance i.e. if adolescents were convinced that small amounts of gluten did no harm ○ Lack of GF alternatives was an excuse for noncompliance ○ For those who were concerned about following a GFD but found it difficult to abstain one solution was to choose alternative with the smallest amount of gluten ○ Curiosity about taste of food was another excuse for noncompliance ○ Felt that feelings of social inconvenience related to GFD could be avoided by eating normal food whereby

– Bibliographic reference	– Olsson (2008): The everyday life of adolescent coeliacs: issues of the importance for compliance with the gluten-free diet
	occasional noncompliance described as solution to ‘feel like all the others’. • Noncompliers ○ Absence of immediate symptoms and lack of knowledge abot the importance of GFD for long-term health central to non-compliance decisions ○ Sensory qualities of GF foods seemed to have greater impact on compliance than availability – conviction that normal foods always taste better than GF foods and will choose the food with the most favourable taste. ○ Disease not become an integral part of their life and had not accepted their diagnosis ○ Belief that would comply better in the future i.e when had own kids and as consequence of impaired health they believed would arise in the future because of noncompliance
– Source of funding	– The study was funded by grants from Magnus Bergvall foundation, the Gastronomic academic foundation, and the Solstickan Foundation
– Comments	
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– Bibliographic reference	– Bystrom (2012): Health-related Quality of life in children and adolescents with celiac disease: from the perspectives of children and parents
– Study type and aim	– Qualitative cross sectional study to examine how children and adolescents on GFD valued their HRQOL, and if age and severity of disease at onset affected children’s self-valuation later in life. Parent’s valuations of their child’s life also assessed.
– Study quality	**CASP QUALITATIVE TOOL:** 1. Was there a clear statement of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes

– **Bibliographic reference**	– **Bystrom (2012): Health-related Quality of life in children and adolescents with celiac disease: from the perspectives of children and parents**
	3. Was the research design appropriate to address the aims of the research question? Yes 4. Was the recruitment strategy appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered? Not applicable 7. Has ethical issues been taken into consideration? Yes, the study has ethical consent 8. Was the data analysis sufficiently rigorous? Yes, normality was assessed and nonparametric statistics were used accordingly 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Valuable –
– Number of patients	– N= 160 families with children 8 – 18 years
– location	–
– Patient characteristics	– **Inclusion criteria:** Children who visited south eastern paediatric clinics in Sweden for CD follow-up between 2006-2007. – **Exclusion criteria**: Children with comorbid diabetes, poor understanding of the Swedish language, or with cognitive difficulties – **Mean age**: 13 years (8 – 18) – **Mean age at diagnosis**: – **Mean years since diagnosis**: 10 years (1-17) – – In 9 of the participating families there were 2 children with CD
– Signs and symptoms	– N/A

– **Bibliographic reference**	– **Bystrom (2012): Health-related Quality of life in children and adolescents with celiac disease: from the perspectives of children and parents**
– Investigations	– DISABKIDS chronic generic measure (Swedish version) questionnaire • Child estimates QoL based on: ○ mental health; 4 Q's about independence: autonomy and ability to live without restrictions related to CD, and emotion (anxiety, anger, and worries) ○ social health; 2 Q's about social community, including acceptance and good relations with others; and 2 Q's about social exclusion ○ Physical health: Q's focused on functional limitations and physical health status. Also Q's on medical treatment which is of no relevance to this study. • Constructed to address chronically ill children between 8 – 18 years • Proxy version where parent estimates QoL of their child • Short term version used (is also a long term version not used here) • 5 point Likert scale scores each question where high represents high HRQoL. • At analysis, each question recoded from 1-5 points to 0-100 points, according to user's manual for DISABKIDS –
– Length of follow up	– N/A
– Outcome	• Resolution of symptoms • Patient experience • Complications of cd • Adherence • **Health related quality of life** • Impact on carers
– Results	– **Health related quality of life** – – Total score • Median value of children's score was 92 (85.5 – 96) ○ Mental health median value:85 points (75 – 95) ○ Social health median value 95 points (90 – 100)

– **Bibliographic reference**	– **Bystrom (2012): Health-related Quality of life in children and adolescents with celiac disease: from the perspectives of children and parents**
	○ Physical health median value 100 points (90 – 100) • Median value of parent's score was 85 (35 – 90) ○ Mental health median value:80 points (75 – 90) ○ Social health median value 95 points (90 – 100) ○ Physical health median value 100 points (20 – 100) – Correlations with HRQoL • Years since diagnosis correlated with QoL r = 0.26 • Age at diagnosis correlated with increased QoL 92 (88 -96) vs 85 (35 – 90) • Parents score for their child was lower than child's estimate: 86 (80 – 92) vs 92 (84 – 96). These were correlated r 0.43 •
– Source of funding	–
– Comments	
– Final response rate: 97.5% children (n=156), and 95% parents. (n=152): One child questionnaire was ruined and 3 parents visited clinic without their children. Eight adolescents visited the clinic without their parents, hence loss of parent data. –	

– **Bibliographic reference**	– **Zarkadas (2012): Living with coeliac disease and a gluten-free diet: a Canadian perspective** [d]
– Study type and aim	– Cross sectional study to evaluate difficulties experienced strategies used and emotional impact following GFD in those with CD
– Study quality	**CASP QUALITATIVE TOOL:**

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[d] Same group as Rashid paper – cohort from Canadian celiac association

– **Bibliographic reference**	– **Zarkadas (2012): Living with coeliac disease and a gluten-free diet: a Canadian perspective** [d]
	1. Was there a clear statement of the aims of the research? Yes - aims clear 2. Is a qualitative methodology appropriate? YES 3. Was the research design appropriate to address the aims of the research question? Yes - standardised questionnaire 4. Was the recruitment strategy appropriate to the aims of the research? Yes - mailed to all members of CD society 5. Was the data collected in a way that addressed the research issue? yes 6. Has the relationship between researcher and participants been adequately considered? Not applicable 7. Has ethical issues been taken into consideration? Not applicable / unclear 8. Was the data analysis sufficiently rigorous? Yes - data was analysed and cross-analysed by 4 data clerks. Extraneous factors sufficiently controlled for. 9. Is there a clear statement of findings? Yes - data clearly outlined in tables 10. How valuable is the research? Valuable to inform specific Canadian CD population and wider general CD population on life on GFD and living with CD diagnosis and management. –
– Number of patients	– N = 5912 adults with biopsy-confirmed CD
– location	– Canada
– Patient characteristics	– **Inclusion criteria:** 10, 693 households with membership of CCA or FQMC were mailed questionnaire in 2008. Individuals >18 years following a GFD were eligible. A total of 7823 completed questionnaires – **Exclusion criteria**: of 7823 forms filled out, 436 were excluded because of: forms that were not filled out correctly (incomplete datasets), a further subset excluded due to no biopsy confirmation of CD. – **Mean age**: 56years (15.2) – **Mean age at diagnosis**: NA

– **Bibliographic reference**	– **Zarkadas (2012): Living with coeliac disease and a gluten-free diet: a Canadian perspective** [d]
	– **Mean years since diagnosis**: NA –
– Signs and symptoms	–
– Investigations	– QUESTIONNAIRE • Developed collaboratively between CCA and FQMC • 59 questions: demographics, diagnosis, symptoms, adherence, info sources, knowledge of GFD, emotional impact, difficulties, life situation (Leffler, 2009) • Difficulties, strategies, and emotions presented in questionnaire were identified in the scientific literature, by clinical experts, and finalised in consultation with psychometric experts. • Questions on usefulness of info sources, emotional impact, difficulties, and strategies were asked on a 5 point scale with options: never, rarely, sometimes, often, very often • Questionnaire mailed to 10 693 households of members of CCA and FQMC – total of 7823 were received • Emotion questions – respondents asked to report on emotions during the month before survey and their first recollections of the emotions experienced in first few months after diagnosis –
– Length of follow up	–
– Outcome	• Resolution of symptoms • **Patient experience** • Complications of cd • **Adherence** • Health related quality of life • Impact on carers
– Results	– **Adherence:** • 68% never intentionally consumed gluten • 18.8% had intentionally consumed gluten once or twice in previous year • Remaining 13.2% reported intentional consumption at least once a month in previous year. • percentage of respondents reporting intentional consumption was lower in those who had been following a GFD for a

– **Bibliographic reference**	– **Zarkadas (2012): Living with coeliac disease and a gluten-free diet: a Canadian perspective** [d]
	linger amount of time • 87.8% indicated considered preventing long-term complications and avoiding immediate reactions as being equally important in avoiding gluten • 9.9% preventing long term complications most important reason for adherence • 2.2% preventing reactions most important – Info about gluten • Obtained info about gluten free diet from various sources. Very good/exclellent sources indicated as follows: o Coeliac support association – 90%; another patient, 67%, cookbooks, 62%, internet 52%, dietician, 52%, medical books 51%, gastroenterologist 43%, magazing 28%, family doctors 25% – Knowledge about gluten • 49% able to ID item correctly on list of 15 foods the 7 no gluten foods. Further 32.5% correctly identified 6/7 items. • 38% people on GFD identified all 7 non allowed items vs 52% people on GFD >5 years – more knowledge longer follow diet. – – **Patient experience/complications from CD** – – Emotions associated with GFD • Emotions experienced often or very often in first few months after diagnosis compared to month before survey (overall population): o Relieved 58% vs 44% o Accepting 57% vs 70% o Frustrated 57% vs 21% o Overwhelmed: 49% vs 8% o Isolated: 42% vs 17% o Confused: 37% vs 6% o Anxious: 37% vs 6% o Sad: 34% vs 9% o Angry: 31% vs 9%

– **Bibliographic reference**	– **Zarkadas (2012): Living with coeliac disease and a gluten-free diet: a Canadian perspective** [d]
	○ Depressed: 23% vs 7% • All of these were highly significant in difference in score between months after diagnosis to present – – Difficulties experienced • 39 key difficulties identified: 12/39 experienced by a significantly higher % of women than men • Those on diet for >5 years experienced few difficulties overall • Most common difficulties experienced by all: ○ Limited food choices in restaurants: 88% ○ Concern that gluten not always on food labels:80% ○ High cost of GF foods : 61% ○ Not liking others to feel sorry for them: 66% ○ Worrying about cooks in restaurants not being trained in preparing GF meals: 64% ○ Lmited choices of food for lunches in school/work cafeteria: 85% ○ Variety of food-associated difficulties when travelling i.e not reading labels: 69% ○ 25% suspected their family and friends were afraid to invite them over for meals ○ Difficulty obtaining GF meals in hospital and retirement homes: 43% ○ Difficulty obtaining gluten content in drugs 36% ○ Limitations in religious practice: 25% ○ Feeling guilty on having passed CD onto children/grandchildren: 25% • Emotional difficulties: ○ I feel I am a burden – 34% ○ Im ambarassed about my diet: 27% ○ I avoid social events because of food: 32% ○ I feel neglected: 15% ○ I do not like others to feel sorry for me: 66% ○ People think a bit of gluten will not hurt me: 46% – Strategies used:

– **Bibliographic reference**	– **Zarkadas (2012): Living with coeliac disease and a gluten-free diet: a Canadian perspective** [d]
	• Strategies used by largest proportion of people included: • Reading every ingredient list – 96% • Using CCA pocket dictionary: 55% • Labelling all GF items (flours) – 84% • Storing GF foods in separate area: 75% • Enquiring about gluten in foods when out – 75% • Having snacks on hand at school and work – 78% • Talking to others about CD and GFD – 68% • If an event involves food, reminding others about my GFD : 58% • Taking translated information about the GFD when abroad – 44% • Overall, participants who reported a great number of strategies reported a reduced likelihood to intentionally consume gluten • This true between both men and women, but overall men used fewer strategies –
– Source of funding	– Funding provided from bureau of chemical safety, food directorate, health Canada, and the JA Campbell Research Fund of the Canadian Celiac association
– Comments	
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– **Bibliographic reference**	– **Cederborg (2011): Living with children who have Coeliac disease: a parental persepective**
– Study type and aim	– Qualitative cross-sectional study: uses interpretative phenomenological approach to enhance the understanding of how to support family adjustment to a GFD

– **Bibliographic reference**	– **Cederborg (2011): Living with children who have Coeliac disease: a parental persepective**
– Study quality	**CASP QUALITATIVE TOOL:** 1. Was there a clear statement of the aims of the research? Yes - aim to understand impact on family of child with CD 2. Is a qualitative methodology appropriate? Yes - no other method applicable 3. Was the research design appropriate to address the aims of the research question? Yes - structured interview 4. Was the recruitment strategy appropriate to the aims of the research? NO - unclear recruitment. No mention of how participants were found or approached 5. Was the data collected in a way that addressed the research issue? Yes - thematic analyses of key interview themes undertaken 6. Has the relationship between researcher and participants been adequately considered? NO - unclear relationship between researcher and participant, and who analysed data 7. Has ethical issues been taken into consideration? Not applicable 8. Was the data analysis sufficiently rigorous? Yes - key themes thoroughly explored 9. Is there a clear statement of findings? Yes - thematic analyses and supportive quotes supplied in text 10. How valuable is the research? Valuable - limited information available to date on impact on family of having a child with CD. –
– Number of patients	– 20 parents of 14 children interviewed
– location	– Sweden
– Patient characteristics	– **Inclusion criteria:** families of which children who had a definite diagnosis of CD and had been livin with the disease and a GFD for at least 2 years. Among those that met inclusion criteria consecutively chose 15 families with a child diagnosed

– **Bibliographic reference**	– **Cederborg (2011): Living with children who have Coeliac disease: a parental persepective**
	with CD. All but one of the representatives consented to being interviewed. Interviewed in 3 groups: 1. First group: parents whose children performed their first small intestine biopsy (SIB) before 2 years of age (7 children, 13 parents) at time of interview children between 3 and 5 years 2. Second group parents whose children were >23 years when went through first SIB (3 parents and 3 children) 3. Third group: parents whose children had performed first SIB before 2 years of age but were older than first group at time of interview (16 years old) – **Exclusion criteria**: None listed – **Mean age**: group 1: 4.3 years; group 2: 16.3 years, group 3: 16 years – **Mean age at diagnosis**: NA – **Mean years since diagnosis**: NA –
– Signs and symptoms	– NA
– Investigations	– Interview: • Interview took place in home • Recorded all interviews and used semi-structured interview guide that includes open ended questions about how parents experienced their children’s disease • Depending on parents answers, asked follow-up questions to obtain a deeper understanding of their experiences • Transcribed verbatim and exhaustively examined for references to similarities and differences • Then identified sections of the text that illustrate how parents experience their children’s disease before and after diagnosis and how manage to adopt a GFD • Then chose among the examples to find those that most obviously captured participants’ thoughts and beliefs
– Length of follow up	–
– Outcome	• Resolution of symptoms • **<u>Patient experience</u>** • Complications of cd • Adherence • Health related quality of life

– **Bibliographic reference**	– **Cederborg (2011): Living with children who have Coeliac disease: a parental persepective**
	• **<u>Impact on carers</u>**
– Results	– Organized results into 2 categories with subthemes: 1) struggle to understand child's disease before the diagnosis; 2) process of transforming to a GFD – – Struggle to understand disease • Mother of a 5 year old boy suspected something was wrong with her son when she tried to give him ordinary food – " when we gave him ordinary food hejust cried…he bawled through meals" • 5 year old lost weight dramatically – " she lost more than a kilo so she was really weak. It was terrible" • One parent did not suspect. Her child was coincidentally tested with no symptoms – " she never showed any symptoms, she had never been sick" • Parents described process of gaining understanding among HC professionals before the diagnosis as a 'struggle' and concerns not taken seriously • Mother 4 year old, 5 months to diagnosis. Staff at well-baby clinic told her not to worry – " I felt everything was not as it should be. They went against me many months before the diagnosis was made. Now looking back, I regret I did not stand my ground more than I did or go to a private doctor". • Most of parents said they were relieved when they knew what was wrong with their child • Mother 4 year old girl – "it was wonderful to get the diagnosis. It was a relief" • Getting diagnosis meant parents knew how they could help their child to reduce symptoms – – Transforming to a GFD • Most parents reported rapid normalization process to a GFD. • One mother of 2 year of said was confused for about 2 months after diagnosis – "I panicked about everything…the first 2 months were a mess. • Parents express appreciation of child's response to GFD – "as she gets older she is more aware of this" • Mother 17 year old who got diagnosis as teen said harder for her child – "it might be different if she got sick as soon as she ate gluten food. Theyn you know you cannot eat this because you will get sick and not feel well afterwards" • Parents whose children were diagnosed when young have had opportunity to socialize their children into a GFD. These children usually haven't experienced taste of gluten food and were not aware of what they are missing.

– **Bibliographic reference**	– **Cederborg (2011): Living with children who have Coeliac disease: a parental persepective**
	• Mother of 5 year old could not stop worrying about what woud happen if her daughter tasted something she should not eat – 2 it is always ther that she could get access to crumbs” • Most parents reported seldom visited restaurants for reason such as not trusting staff’s description of ingredients or lack fo food for child • One parent spoke of restricted leaisure activities for her 16 year old son – “ he cannot spontaneously be with his oeers, everything has to be checked and questioned if he eats with them, I think he fears his peers will think he is a bother to be with. I think the disease hinders him socially” • Parents said travelling could be demanding because of difficulties getting acces to propoer food • Visiting houses can be difficult. One parent always called house before to check food and make soue would be GF food available • Expressed struggle to get staff at daycare and school to understand their childrens GFD • Daycare staff not sufficiently educated • Negative attitudes from staff at school’s dining hall • Parents actively and constantly try to find out as much as possible about the disease and how to meet childs GFD needs. • Aprents of a 3 year olf search for knowledge through people who know about the disease, on the internet, and through the CD association • Most parents have regular contact with a dietician • Parents have concerns for children’s future. • Mother of 5 year olf worries about how child will cope when living alone • Parents put hope into new treatments based on scientific breakthroughs
– Source of funding	– Swedish society for coeliacs, FORSS and the Swedish research council
– Comments	
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– **Bibliographic reference**	– **Bellini (2011): Compliance with the gluten-free diet: The role of locus of control in celiac disease**
– Study type and aim	– Case-control study to verify whether subjects with CD have a different locus of control (LoC) compared with healthy subjects, and to evaluate relationship between LoC and compliance with GFD and quality of life
– Study quality	**CASE - CONTROL STUDY > USE QUADAS**
– Number of patients	– N = 509: 156 CD patients on GFD and 353 healthy controls
– location	– Italy
– Patient characteristics	– **Inclusion criteria:** CD group: biopsy-proven patients with CD diagnosed using ESPGHAN criteria. Recruited at children's hospital during follow-up visits in patients ho had been on a GFD for at least a year. HC group: controls without chronic disease who were aattending school in Trieste, Italy. – **Exclusion criteria**: none listed – **Mean age**: CD patients = 10 years; HC = 12 years – **Mean age at diagnosis**: 6.4 years – **Mean years since diagnosis**: na –
– Signs and symptoms	– na
– Investigations	– Questionnaires – Nowicki-Strickland Locus of control scale (NSLCS) and QoL questionnaire filled out with help of 2 investigators blinded to subject data. Beforehand, detailed explanation of study was given to each child's parents, and informed consent was obtained. – – NSLCS: • Children aged 6-8 completed preschool and primary school version which contained 13 items • Children 9 – 16 completed 40 item test • Both consist of Y/N questions ie. "are some ids born lucky"; "Do you feel that most of the time it doesn't pay to try hard because things never turn out right anyway?" and "most of the time, do you feel that you can change what might happen tomorrow by what you do today?"

– **Bibliographic reference**	– **Bellini (2011): Compliance with the gluten-free diet: The role of locus of control in celiac disease**
	• LoC values calculated following NSLCS manual instructions • High score indicates externality and low LoC; low score indicates high LoC and internality – QoL • To evaluate QoL and GFD compliance, version of Kindl test modified for children withCD • 40 item questionnaire assessing 4 domains of QoL: Psych well-being, social relationships, physical function, everyday life activities in chiroically ill children • Modified version comtained 10 items that measure subjective well being • noncompliance with GFD was defined as findings positive TTG on serology assay or patient's self-reported transgressions
– Length of follow up	– N/A
– Outcome	• Resolution of symptoms • **Patient experience** • Complications of cd • **Adherence** • **Health related quality of life** • Impact on carers
– Results	– Adherence: • At follow-up 34/156 patients defined as noncompliant with GFD after admission of monthly transgressions (ave 3 pm), especially during social occasions. Of these, 12/34 had positive IgA tTG – – LoC and QoL • CD patients with good compliance to GFD had lower levels of LoC score and higher internality than those with poor compliance (5 +/- 1.9 vs 5.1 +/- 2.0)in younger patients with CD p=0.8 • CD patients with good compliance to GFD had lower levels of LoC score and higher internality than those with poor compliance (12.6 +/-4.2 vs 25.2 +/-3.6) in older patients with CD, p = 0.01 • CD patients who reported satisfcatory QoL (127/156) had lower LoC values than those who perceived their life as negatively affected by the disease (4.7 +/-1.7 vs 6.1 +/-) in younger children and (12.6 +/- 4.0 vs 16.3 +/- 4.0) in older

– Bibliographic reference	– Bellini (2011): Compliance with the gluten-free diet: The role of locus of control in celiac disease
	patients with CD.
– Source of funding	– Supported by grant 36/08 from institute of child health IRCCS “Burlo Garofolo”
– Comments	
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– Bibliographic reference	– Leffler (2008): Factors that influence adherence to a gluten-free diet in adults with celiac disease
– Study type and aim	– Qualitative cohort study to determine factors that influence GFD adherence in cohort of CD patients
– Study quality	**CASP QUALITATIVE TOOL:** 1. Was there a clear statement of the aims of the research? Yes - objecective to identify factors influencing GFD adherence in adults with CD clearly stated 2. Is a qualitative methodology appropriate? Yes - survey design appropriate 3. Was the research design appropriate to address the aims of the research question? Yes, questionnaire carefully devised with range of experts from different areas within the field. 4. Was the recruitment strategy appropriate to the aims of the research? Yes - all eligible participants approached 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered? Not applicable

– **Bibliographic reference**	– **Leffler (2008): Factors that influence adherence to a gluten-free diet in adults with celiac disease**
	7. Has ethical issues been taken into consideration? Yes - informed consent taken before research 8. Was the data analysis sufficiently rigorous? Yes. Statistical methodology clearly outlined 9. Is there a clear statement of findings? Yes - findings clearly outlined 10. How valuable is the research? Valuable as large multicentre study with thorough questioning in multiple domains –
– Number of patients	– N = 154
– location	– USA
– Patient characteristics	– **Inclusion criteria:** adults diagnosed with biopsy-confirmed CD for longer than 3 months were elisted through recruitment posters that were mailed to New England support groups and adverstisements placed in regional CD newsletters and publications frequented by CD patients. In addition, eligible patients with CD being treated at Celiac centre at MIDMC were invited to participate – **Exclusion criteria**: – **Mean age**: 50 years – **Mean age at diagnosis**: 45 years – **Mean time on GFD:** 58 months –
– Signs and symptoms	–
– Investigations	– Expert panel assembled to identify factors perceived to be important in living with CD and influential in GFD adherence – Set of domains relevant to life with CD were elucidated – These included: psychosocial burden of disease; symptoms; social and health support; self-efficacy; perceived adherence; general health – Bank of items developed to assess these – Items were assessed for clarity and comprehensiveness by 2 successive focus groups of 8 – 12 adults with biopsy-confirmed CD into the final questionnaire – Final questionnaire = global celiac assessment scale (GCAS) – 142 items

– **Bibliographic reference**	– **Leffler (2008): Factors that influence adherence to a gluten-free diet in adults with celiac disease**
– Length of follow up	– N/A
– Outcome	• Resolution of symptoms • Patient experience • Complications of cd • **Adherence** • Health related quality of life • Impact on carers
– Results	– Adherence: – • Population found to adhere well to GFD with 44% (test) and 34% (clinic patients) rated as excellent or good by expert nutritionist. • Tended to overestimate adherence as 70% reported to be strict adheres • Married participants more adherent than unmarried • Significant correlations between CGAS items and adherence • 75% did not feel cost made it difficult to adhere • 51% reported cost important issue in living with CD • 56% reported finding GF foods when eating outside of home • 75% rated quality of GF foods a significant concern • 75 – 79% reported believed accidental and purposeful consumption of gluten had important health ramifications • 44% reported excellent understanding of the GFD • 46% reported good understanding of GFD • 16/28questions correct in adheres on GFD knowledge test vs 14/28 in poor adherers • 75% reported were able to follow a GFD when travelling • 24% avoided travel due to food restictions • 82% able to follow GFD at social events and parties • 21% avoided social engagement involving food

– **Bibliographic reference**	– **Leffler (2008): Factors that influence adherence to a gluten-free diet in adults with celiac disease**
	• Only 45% felt were able to follow GFD in religious practice and 37% reported avoiding certain religious practices to maintain a GFD • 59% belonged to CD association and of these 8&% felt this was beneficial • 75% reported felt comfortable following GFD at work • Reported receiveing adequate support form HC providers: dietician 63%; gastro 57%; GP 36%; pharmacist 22% • 41% reported keeping GFD increased stress • 33% reported following GFD to have negative effect on social life • 62% being diagnosed positively affected their life • 96% avoided gluten from worry of long term consequences • 84% avoided gluten to avoid symptoms
– Source of funding	– Charitable dontations to celiac centre at BIDMC, the celiac sprue association, NIH T32 training grant, and the Harvard –Thorndike general clinical research center M01 RR01032
– Comments	
– –	

– **Bibliographic reference**	– **Jacobssen (2007)**
– Study type and aim	– RCT to assess benefit of ‘celiac school’ educational program for women with CD to improve GI symptoms
– Study quality	– **NICE RCT quality checklist:** –

– **Bibliographic reference**	– **Jacobssen (2007)**
	1. Was an appropriate randomisation method used? UNCLEAR - randomisation carried out locally by primary author according to town of residence using consent forms as lots. What does this mean? Unclear whether author was blinded. If randomised according to residence, unclear whether it was pseudo or complete random allocation 2. Was there adequate concealment of allocation? Not applicable 3. Were groups comparable at baseline? Yes. Groups comparable in all domains at baseline, except I the domain of abdominal pain 4. Did the comparison groups receive the same care apart from the intervention of interest? Yes - waitlist control so controls received nothing and intervention group received intervention only 5. Were participants receiving care kept blind to their treatment allocation? Not applicable 6. Were individuals administering care kept blind to treatment allocation? Not applicable 7. Were all groups followed for equal amount of time? Yes - all groups had same follow-up of 10 weeks. 8. Were groups comparable for treatment completion? NO - intervention group had higher rate of completion than waitlist control 9. Were groups comparable with respect to availability of outcome data? Yes 10. Did the study have an appropriate length of follow-up? Yes - 10 weeks seems appropriate as is an experimental intervention. 11. Did the study use a precise definition of outcome? 12. Did the study use a valid and reliable method to determine outcome? NO - 2 x pairwise regression models used. A multiple regression examining the treatment x group interaction would have been preferable and more statistically stringent. Presumably this interaction was non-significant and they have not reported this. 13. Were investigators kept blind to participant's exposure to intervention? NO - unclear whether investigators blinded 14. Were investigators kept blind to other confounding and prognostic factors? NO - unclear whether investigators blinded LOW QUALITY: Randomisation unclear, level of blinding of experimenters to exposure to intervention or other confounding factors unclear, Statistical methods are not sound and show only a turned towards a statistical effect as no significant group x intervention interaction was found
–	– N = 105 (n=54 intervention group; n=52 in control group)
– location	– Sweden

– **Bibliographic reference**	– **Jacobssen (2007)**
– Patient characteristics	– **Inclusion criteria:** women from 5 hospitals in southeast Sweden with a diagnosis of celiac disease. Diagnosis must be based on histology showing findings compatible with CD, female gender, aged 20+ years, a history of GFD for a minimum of 5 years – **Exclusion criteria**: None listed – **Mean age**: 23 – 80 years – **Mean age at diagnosis**: – **Mean years since diagnosis**: –
– Signs and symptoms	– Indigestion – Diarrhea – Constipation – Abdominal pain – Reflux –
– Investigations	• Education program. • Women randomised to each arm, educational school for celiacs, or sent leaflets at home • 3 main features emphasized in education program : ○ Working in small groups ○ Starting from real-life situations ○ Using a problem-solving process that stimulated self-directed learning • Celiac school: ○ 10 sessions that included weekly meetings in groups 7 – 9 persons ○ Each tutor was familiar with problem based learning (PBL) pedogogy and acted as moderator ○ Main purpose of program was to support and encourage participants to find possible changes in lifestyle and thereby reduce GI symptoms and achieve knowledge in the area ○ 7 intervention groups set up in 5 cities ○ Each session covered pre-determined specific topic: anxiety and fears associated with CD; attitudes to surroundings, psychological reactions, coping strategies, obstacles in daily life, new knowledge, and various

– **Bibliographic reference**	– **Jacobssen (2007)**
	questions associated with food and cooking. ○ With this as starting point, group members decided what to discuss together on basis of specific needs and desires that came to light after the inventory • Controls ○ Received total of 5 circulars by post over a 10 week period ○ These contained written info ○ The info covered evidence-based details on CD ○ Brochures dealing with origins, symptoms, diagnosis, and treatment concerning CD and info about current research in the area
– Length of follow up	– 10 weeks and 6 months after completing education
– Outcome	• **Resolution of symptoms** • Patient experience • Complications of cd • Adherence • Health related quality of life • Impact on carers
– Results	– GI symptoms • Difference in total mean index value regarding GI symptoms between groups at baseline where control patients reported slightly fewer symptoms • After 10 weeks total mean index value was not significantly different between the groups at 10 weeks • Comparison within intervention group between baseline and 10 week follow up showed significant impriovement in total GI score, particularly for: • Constipation • Abdominal pain • Total index improvement also showed significant improvement after 6 months in comparison to baseline with general improvmen in all dimensions except reflux. • Comparison between changes in mean scores within intervention group and control group from baseline to 10 weeks

– **Bibliographic reference**	– **Jacobssen (2007)**
	showed statistically significant difference in improvement regarding abdominal pain, but there was no significant difference regarding other clinical symptoms or the GI total index
– Source of funding	– Medical research council of southeast Sweden and the Ostergotland country council