The effect of dual diagnosis of type 1 diabetes and coeliac disease on quality of life and glycaemic control in children

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Article points

1. This study indicates that a dual diagnosis of coeliac disease (CD) and type 1 diabetes has no significant impact on the quality of life or glycaemic control of affected children.
2. However, their parents find the dual conditions a cause of high stress and additional burden, both at the diagnosis of CD and in daily life.
3. This needs to be considered as part of multidisciplinary management at diagnosis; for example, psychosocial input may be required.

Key words

- Coeliac disease
- Quality of life
- Type 1 diabetes

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The aim of this study was to examine the effects of a dual diagnosis of coeliac disease (CD) and type 1 diabetes on quality of life (QOL) and metabolic control, and to examine the screening regimens for CD undertaken in various paediatric diabetes centres in the Republic of Ireland. A quantitative, cross-sectional study was performed using a validated, self-reported QOL questionnaire distributed to children and young people (CYP) with a dual diagnosis of CD and diabetes. Questionnaires assessing parental disease burden and screening practices in Ireland were also distributed. No significant differences in QOL or HbA_{1c} were found between CYP with a dual diagnosis and those with type 1 diabetes alone. However, the additional diagnosis of CD was found to be a cause of significant stress for parents, 64.4% of whom scored the added stress as 5 on a 5-point scale. This should be considered as part of multidisciplinary management at diagnosis of CD in CYP with diabetes.

Coeliac disease (CD) is an immune-mediated chronic condition characterised by intestinal inflammation that resolves with dietary exclusion of gluten (Tsouka et al, 2015). CD is commonly seen in association with type 1 diabetes, probably as a result of common human leukocyte antigen (HLA) haplotypes. The presence of the HLA haplotypes DR3–DQ2 or DR4–DQ8 is associated with an increased risk of CD (Liu et al, 2014), and the HLA DR3 and DQ2 genotypes are also associated with type 1 diabetes (Saadah et al, 2004). The estimated prevalence of CD in people with type 1 diabetes ranges from 1.6% to 9.7% (Pham-Short et al, 2015).

CD can present with a number of symptoms in children, ranging from failure to thrive, abdominal distension and recurrent abdominal pain to pubertal delay, short stature and iron-deficiency anaemia (Fasano, 2005). Generally, people with type 1 diabetes have "silent CD", which is only discovered on routine screening. The importance of detecting and treating CD lies with the potential complications. These include osteoporosis, iron-deficiency anaemia, lymphoma and small-bowel cancer. In people with diabetes, untreated CD may lead to more frequent episodes of hypoglycaemia (Mohn et al, 2001).

Effects of coeliac disease on glycaemic control

Studies have identified varying effects of a diagnosis of CD on glycaemic control. In one study, young people with type 1 diabetes and CD who did not adhere to a gluten-free diet had inferior glycaemic control, as well as lower quality of life (QOL; Pham-Short et al, 2016). Conversely, in another study, no significant change in HbA_{1c} levels was observed during the one-year period before diagnosis of CD, and introduction of a gluten-free diet did not affect glycaemic control in these people (Rashid et al, 2005).

Another study found that a gluten-free diet

was associated with significantly greater insulin requirements but had no effect on HbA_{1c} (Saadah et al, 2004). One hypothesis to explain this is that, in untreated CD, villous atrophy causes reduced carbohydrate absorption, resulting in lower insulin requirements. Therefore, although classic CD symptoms may not be present, more subtle indications of an underlying disease process may be evident.

Effect on quality of life

Owing to the restrictive nature of living with both type 1 diabetes and CD, it is recognised that these conditions can have a significant impact on day-to-day life. CD in the absence of type 1 diabetes commonly presents with troublesome gastrointestinal (GI) symptoms, such as abdominal pain, bloating, flatulence and diarrhoea. Although adhering to a gluten-free diet is challenging, it generally leads to an improvement in symptoms.

There are conflicting reports on the impact of CD and adherence to a gluten-free diet on QOL. CD in type 1 diabetes is often diagnosed in routine screening, and so patients generally experience subtle or no GI symptoms. Therefore, people who receive this additional diagnosis may have to adopt a further restrictive diet without necessarily feeling physical benefits or experiencing an improvement in metabolic control.

There are contrasting studies on the impact of a dual diagnosis on QOL in young people. Maintaining a gluten-free diet has been shown to impact on social and family activities, including dining out, travelling and shopping (Pham-Short et al, 2016). In addition, some children feel different and can be left out of activities at school or invitations to friends' homes (Rashid et al, 2005). However, other studies have indicated that QOL is not impacted by adherence to a gluten-free diet and that people with CD do not perceive social contact with peers as difficult (Wagner et al, 2008; Sud et al, 2012). It has also been noted that, in the general population, diagnosis of CD at an early age (before 6 years) leads to better physical and social QOL and a lower burden of disease compared with a later diagnosis (Wagner et al, 2008).

Screening

As a result of the increased prevalence of CD in people with type 1 diabetes, regular screening is undertaken as part of the overall diabetes management strategy. Studies have shown that the majority of people are diagnosed with CD 3–6 years after the initial diabetes diagnosis (Crone et al, 2003; Mitchell et al, 2016). A systematic review of CD in people with type 1 diabetes showed that, of the 546 CD cases diagnosed after diabetes, 40% were diagnosed within 1 year, 55% within 2 years and 79% within 5 years (Pham-Short et al, 2015). However, CD can occur any time following diabetes onset in susceptible individuals, and regular screening thereafter is still justified.

The International Society for Pediatric and Adolescent Diabetes (ISPAD) has outlined recommendations on the frequency of screening for CD in children and adolescents with type 1 diabetes (Kordonouri et al, 2014). Screening for CD should be performed at the time of diagnosis and every 1–2 years thereafter, with more frequent assessment if there are clinical suspicions of CD or if there is a first-degree relative with the condition. Screening is performed by testing for immunoglobulin A (IgA) antibodies: tissue transglutaminase (tTG) and/or endomysial antibodies (EMA). If these are detected, a small-bowel biopsy demonstrating subtotal villous atrophy must be obtained to confirm CD diagnosis.

The current study

The aim of this study was to examine the effects of a dual diagnosis of CD and type 1 diabetes on QOL and metabolic control in children and young people (CYP), and to examine the various screening regimens for CD undertaken in various paediatric diabetes centres in the Republic of Ireland.

Methods

A quantitative, cross-sectional study was carried out in Cork University Hospital from July to October 2014. The variables were divided into four categories: patient-reported QOL, parental burden, patient demographics, and glycaemic control and specialist screening practices. CYP aged 7–18 years attending the Paediatric Diabetes Service were included.

The case group consisted of CYP with a dual diagnosis of CD and type 1 diabetes. The control group consisted of CYP with type 1 diabetes and negative CD serology, randomly selected from the

Page points

1. People with type 1 diabetes have a greater risk of developing coeliac disease (CD) than the general population.
2. Both conditions place significant restrictions on daily life; however, studies evaluating quality of life (QOL) in children and young people (CYP) with both CD and diabetes have had conflicting results.
3. Therefore, this survey was performed to assess the effects of a dual diagnosis of the two conditions in CYP and their parents in the Republic of Ireland.
4. Current CD screening practice among paediatric endocrinologists in Ireland was also examined.

Page points

1. There was no significant difference in QOL between CYP with a dual diagnosis (*n*=14) and those with type 1 diabetes alone (*n*=15).
2. Subanalyses also revealed no differences based on gender, age or insulin regimen.
3. Similarly, HbA_{1c} was not affected by the dual diagnosis compared with type 1 diabetes alone.

database and matched for age and gender. Patients transitioning to adult care were excluded from the study. Systematic sampling was performed by the Paediatric Diabetes Clinical Nurse Specialist to select suitable patients from the database of children with type 1 diabetes attending the service. A review of selected medical records was undertaken. Demographic data, including age, gender, age at diagnosis, glycaemic control (HbA_{1c}) and insulin therapy, were recorded.

Questionnaires

The diabetes module of the revised KINDL QOL questionnaire was distributed to all CYP with diabetes. This is a validated, diabetes-specific, self-report questionnaire comprising 17 questions related to day-to-day situations that may affect a child with type 1 diabetes (available at: www.kindl.org). An overall QOL score is calculated, ranging from 17 to 85 points, with lower scores indicating a higher QOL (Ravens-Sieberer and Bullinger, 1998a; 1998b).

In addition, a questionnaire assessing the parental burden of a dual diagnosis of CD and type 1 diabetes was distributed to parents of the case group. The questionnaire was drafted for the purpose of this study, and is reproduced in *Appendix 1*, available in the online version of this article.

A third questionnaire, also designed for the purpose of this study, was sent to ten paediatric endocrinologists across the Republic of Ireland. This questionnaire assessed their practice and whether they adhered to ISPAD guidelines in terms of when and how they screened for CD in children with type 1 diabetes.

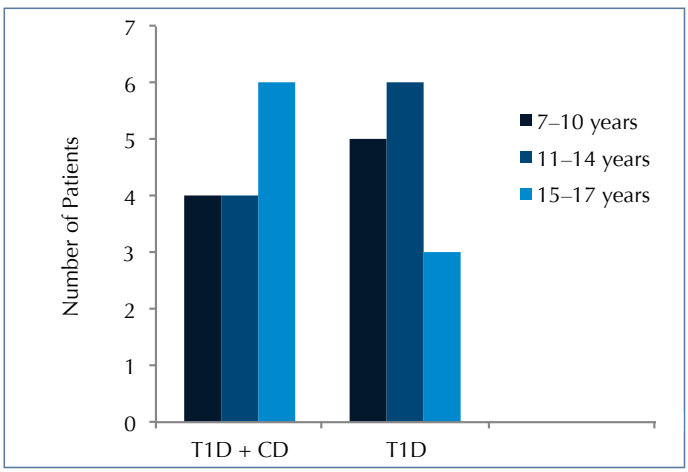

Figure 1. Age distribution of the children with T1D + CD and T1D alone. CD=coeliac disease; T1D=type 1 diabetes.

Data analysis

Data were analysed using SPSS version 20.0. Basic descriptive statistics were calculated and graphs were created to represent these data. Independent samples *t*-tests were used to compare mean total QOL scores and HbA_{1c} levels between the two groups. Pearson chi-squared tests were performed to assess how each group answered individual questions. Reliability analysis gave a Cronbach's alpha reliability coefficient of 0.891, which indicates good internal consistency of the items in the scale.

Results

Demographics

Of the 369 CYP attending the Paediatric Diabetes Service during the study period, 36 (9.8%) had a dual diagnosis of CD and type 1 diabetes. Of these, 29 were eligible to participate in the study.

In total, 45 CYP were invited to participate in the study. There were 29 responses (response rate, 64.4%) – 14 cases of dual CD and type 1 diabetes (accounting for 39% of the total dual diagnosis cohort) and 15 controls matched for age and gender. The age range of these participants was 7–17 years, with a mean age of 12.3 years (*Figure 1*).

Quality of life

The diabetes-specific KINDL QOL questionnaire was completed by 13 of the 14 participants with a dual diagnosis. There was no significant difference in the QOL scores achieved by CYP with both conditions and those with type 1 diabetes alone (mean score, 37.5 vs 43.2; *P*=0.244; *Figure 2*).

QOL scores were also analysed for differences based on gender, age and diabetes management. There were no significant differences in scores between boys and girls (39.7 vs 40.8; *P*=0.837; *Figure 3*), or between age groups (7–10 years: 40.6; 11–14 years: 41.2; 15–17 years: 38.6; *P*=0.14). There was also no significant difference in scores between CYP receiving insulin pump and multiple daily injection (MDI) therapy (37.1 vs 42.9; *P*=0.304).

Glycaemic control

HbA_{1c} levels were recorded for both case and control groups. No significant difference was observed

between CYP with a dual diagnosis and those with type 1 diabetes alone (mean, 62.1 mmol/mol [7.8%] vs 64.8 mmol/mol [8.1%]; *P*=0.456). There were also no significant differences when HbA_{1c} was analysed by gender, age or insulin regimen. Six of fourteen participants (42.8%) in the dual diagnosis group had an HbA_{1c} within the ISPAD target (≤58 mmol/mol [7.5%]) at the time of the study.

Parental questionnaire

Fourteen parents of CYP with a dual diagnosis completed the questionnaire to assess the burden added by the diagnosis of CD. Of these, 11 reported that their children were asymptomatic prior to the diagnosis of CD. The majority of parents reported a great deal of added stress (on a scale of 1–5; *Figure 4*).

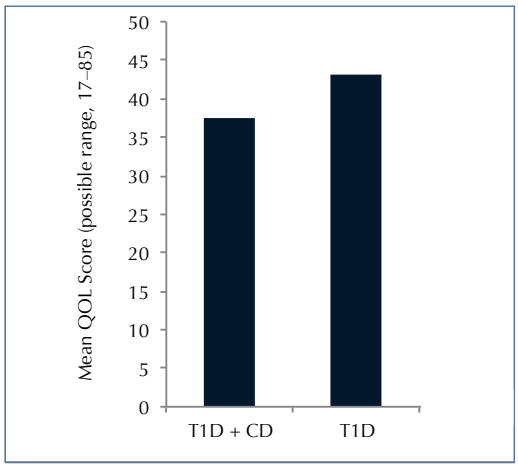

Figure 2. Mean QOL scores in children with T1D + CD and T1D alone. CD=coeliac disease; QOL=quality of life; T1D=type 1 diabetes.

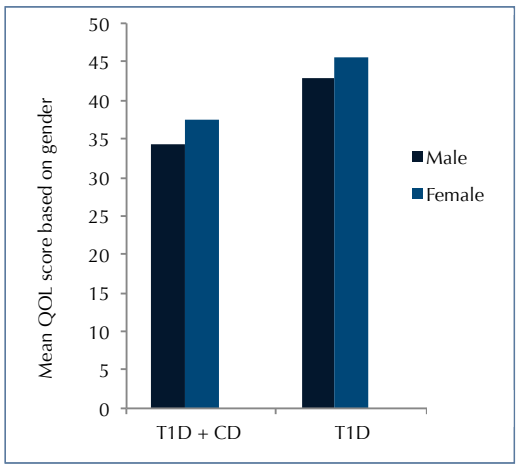

Figure 3. Mean QOL scores compared by group and gender. CD=coeliac disease; QOL=quality of life; T1D=type 1 diabetes.

Overall, seven parents (50%) reported that CD and type 1 diabetes caused them equal levels of stress, six (43%) reported that diabetes caused more stress than CD and one (7%) reported that CD caused more stress than diabetes.

Seven parents reported that their child was fully adherent to a gluten-free diet (score of 5 on scale of 1–5), six reported a score of 4 and one a score of 3.

Parents rated the added daily burden of a CD diagnosis on a scale from 1 to 5; the majority rated the additional burden as very high (*Figure 5*).

Screening practices in the Republic of Ireland

A questionnaire regarding screening practices for CD in people with type 1 diabetes was distributed to ten consultant paediatric endocrinologists throughout Ireland. Seven responses (response rate, 70%) were obtained. The results of this questionnaire are shown in *Figures 6* and *7*.

Five of the seven centres screen for CD at time of diagnosis, while the remaining two screen at the first clinic visit or annual review. Screening is

Page points

1. In contrast to the CYP with a dual diagnosis themselves, parents (*n*=14) reported significant stress at the diagnosis of CD.
2. The majority of parents also reported that additional burden associated with CD was very high.
3. In Ireland, screening for CD in CYP with type 1 diabetes is generally carried out in accordance with international guidelines.

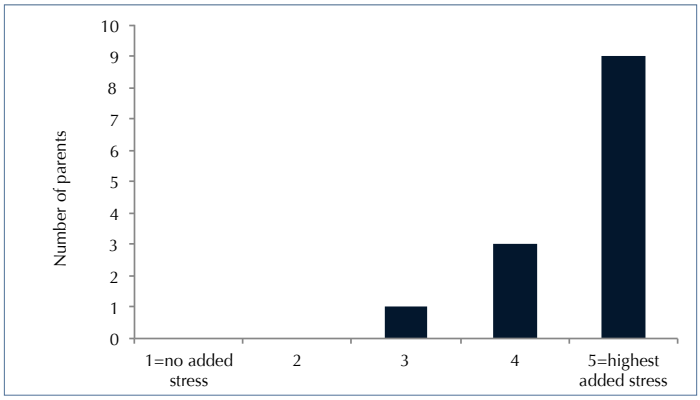

Figure 4. Added stress of coeliac disease at time of diagnosis according to parents (n=14).

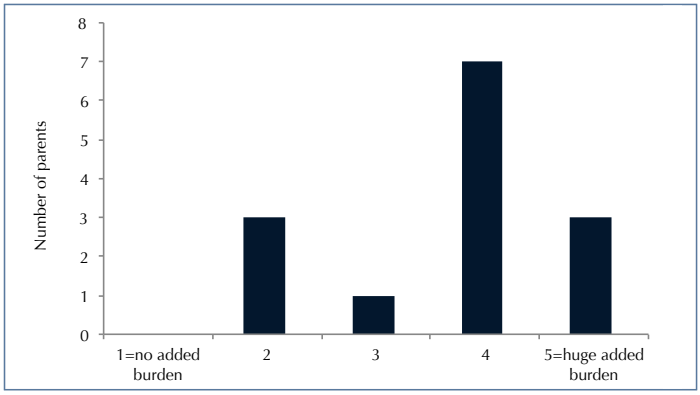

Figure 5. Additional burden of a coeliac disease diagnosis on daily basis according to parents (n=14).

Page points

1. These findings are in line with previous studies showing that, while CYP are not significantly impacted by a second chronic condition, their parents report greater stress and burden, and perceive their children's QOL to be lower than the CYP do themselves.
2. This may be because the responsibility for planning meals and coping with CD mainly falls to the parents, and because they are more aware of the difficulties that arise in social situations.

performed by testing for IgA antibodies. If tTG or EMA are detected, five of seven centres then refer for jejunal biopsy to confirm the diagnosis of CD, in line with ISPAD guidelines.

The majority of centres, five of seven, continue to screen for CD on an annual basis. Of the remaining two, one centre screens every 6 months and the other every 2 years. Screening is performed more frequently if signs or symptoms associated with CD are present in all centres. Six of the seven centres do not adjust their screening practices according to individual patients' family history. No centre reported using HLA typing when screening for CD in people with type 1 diabetes.

Discussion

Estimates of the prevalence of dual CD and type 1 diabetes vary between studies but typically range from 1.6% to 9.7% (Pham-Short et al, 2015), although some studies have reported higher upper rates of up to 11.1% (Camarca et al, 2012). A prevalence of 9.7% was noted in this cohort, which is unsurprising given that Ireland has a higher rate of CD than other countries (Cronin and Shanahan, 2001).

There was no significant difference in QOL scores between CYP with a dual diagnosis and those with type 1 diabetes alone. This suggests that, despite the additional burden, living with a second chronic condition does not have a significant effect on their day-to-day lives. Similarly, Sud et al (2012) found that adolescents living with type 1 diabetes and CD did not have an impaired QOL.

In contrast, the parents of CYP with a dual diagnosis have reported worse social functioning for their children than the parents of those with type 1 diabetes alone (Sud et al, 2012), and they have estimated lower health-related QOL scores than their children (Byström et al, 2012). This could reflect the fact that parents are mostly in charge of planning meals and having gluten-free foods readily available for their children, and because they are more aware of the difficulties that arise in social situations and of the planning and foresight involved. They may also feel that their children are missing out, as they cannot have the same foods, for example, as their peers.

In this study, 76.9% of parents reported a significant day-to-day burden of CD, giving a score of 4 or 5 on a five-point scale. Furthermore, 69% reported the maximum level of additional stress at the diagnosis of CD. It is clear from this that the need to manage a second chronic condition such as CD is a cause of significant stress for parents.

With regard to glycaemic control, there was no significant difference noted in HbA_{1c} levels between CYP with a dual diagnosis and those with type 1 diabetes alone. This held true when comparing HbA_{1c} between different age ranges, genders and insulin regimens (insulin pump vs MDI). Similar results have been reported in other studies, with no change in HbA_{1c} noted following introduction of a gluten-free diet (Saukkonen et al, 2002; Saadah et al, 2004; Fasano, 2005).

Screening practices in Ireland

ISPAD has made recommendations for the screening of CD in people with type 1 diabetes. It suggests that screening for CD should be performed at the time of diabetes diagnosis and every 1–2 years

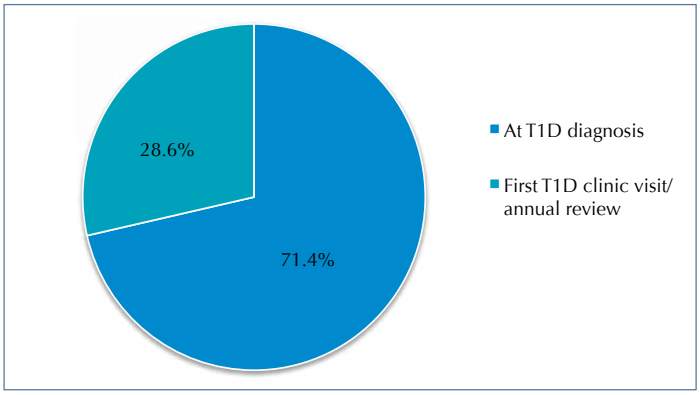

Figure 6. Timing of first coeliac disease screening in children with newly diagnosed T1D. T1D=type 1 diabetes.

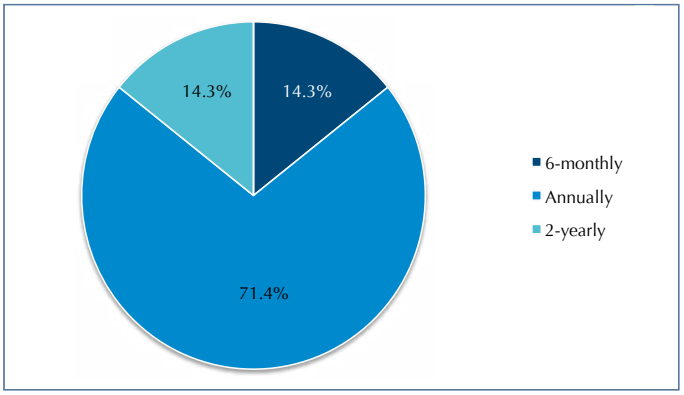

Figure 7. Coeliac disease screening frequency post diagnosis of type 1 diabetes.

thereafter, with more frequent assessment if clinical suspicions of CD arise or if there is a first-degree relative with CD (Kordonouri et al, 2014). The screening practices noted in our study were generally in line with these recommendations. Five of the seven centres screen at diagnosis, with all centres screening at least every 2 years thereafter and most screening annually.

The delay in screening at diagnosis in some centres is due to concerns relating to the impact of an additional diagnosis of CD while families are already coming to terms with the diagnosis of type 1 diabetes. However, the authors' impression is that it may be easier for families to learn to deal with the dietary implications of both conditions simultaneously, with the opportunity to learn about carbohydrate counting for their gluten-free foods from the outset. Carbohydrate counting increases flexibility, allowing more varied food intake at meal times (Smart et al, 2009), and may result in improved glycaemic control and QOL. This approach to the management of type 1 diabetes may improve QOL in relation to the old, restrictive diabetes diets, which in turn may help if a young person is diagnosed with CD. This intensive education starts at diagnosis and continues in outpatient clinics thereafter. Furthermore, we propose that, if CYP have a good knowledge of carbohydrate counting, with multidisciplinary support from diagnosis, they will be more empowered to make the necessary adjustments if CD is diagnosed later on.

It was noted that 85.7% of the centres in this study do not screen more frequently based on family history, as is recommended in the ISPAD guidelines. If the interval between screening tests is to be lengthened on the basis of previous negative screens and lack of symptomatology, then family history is an important factor to consider.

Study limitations

The authors acknowledge some limitations of this study, including the small sample size and low response rates. Responses were obtained from 39% of the cohort with dual CD and type 1 diabetes attending Cork University Hospital. However, an equal number of controls with type 1 diabetes was included in the study, which adds strength to the results by providing a comparator group. Future studies would benefit from an increase in the number of control subjects and inclusion of further centres throughout the country, in order to strengthen the power of the study.

The minimum age of the case subjects included in this study was 7 years. This is due to the use of a self-report questionnaire. Using age-based questionnaires could have allowed for the inclusion of younger subjects in the study.

Questionnaire limitations

The diabetes-specific KINDL questionnaire was used to compare QOL in CYP. Although this is a validated questionnaire, it only assessed the impact of CD on diabetes-related QOL, and it is possible that CD may affect QOL in other ways not outlined in the questionnaire.

The questionnaire used to assess parental burden was designed by the authors for the purpose of this study and, therefore, has not been externally validated. Although it only gives a subjective measure of QOL and burden of disease for parents of CYP with CD and type 1 diabetes, it does examine specifically how these co-existing chronic conditions impact on daily life.

Different questionnaires were used to assess the QOL of parents and CYP. The impact of a chronic condition on children's QOL is different to that of their parents; therefore, it is necessary to use different methods of assessing QOL in these groups, especially given the broad age range of the study population. However, this makes direct comparison difficult.

Finally, the questionnaire used to assess healthcare professionals' practice when screening for CD in CYP with type 1 diabetes was again designed by the authors for the purpose of this study, and has not been externally validated.

Conclusions

In conclusion, this study indicates that a dual diagnosis of CD and type 1 diabetes has no significant impact on the QOL or glycaemic control of affected children. It does, however, cause added burden and stress for the parents of these children, and this needs to be considered as part of multidisciplinary management at diagnosis. For example, psychosocial input may be required. Further studies to evaluate the specific cause of

Page points

1. Some centres in Ireland delay screening for CD at diabetes diagnosis, owing to concerns over adding to the burden of families who already need to come to terms with the diagnosis of type 1 diabetes.
2. However, it may be easier for families to learn to deal with the dietary implications of both conditions simultaneously, with the opportunity to learn about carbohydrate counting for their gluten-free foods from the outset.

Read more online

Article

The development of joint multidisciplinary clinics for children and young people with type 1 diabetes and coeliac disease

Gita Modgil and colleagues describe a simple change in service delivery that has had a great impact on children and young people with type 1 diabetes and coeliac disease.

Diabetes Care for Children & Young People **5**: 71–4

Available at:
https://is.gd/DCCYPcoeliac

"This study indicates that a dual diagnosis of coeliac disease and type 1 diabetes has no significant impact on the quality of life or glycaemic control of affected children. It does, however, cause added burden and stress for the parents of these children, and this needs to be considered as part of multidisciplinary management at diagnosis."

stress for parents should be carried out in order to ascertain the additional support needed to ease the burden for these families. ■

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Appendix 1. Questionnaire for parents

Type 1 Diabetes and Coeliac Disease

1. What age was your child at the time of diagnosis of type 1 diabetes?

   ☐

2. What age was your child at the time of diagnosis of coeliac disease?

   ☐

3. When was your child diagnosed with coeliac disease?

   - ☐ Suspected at time of diagnosis of type 1 diabetes and investigations were required
   - ☐ >1 year after diagnosis of type 1 diabetes
   - ☐ >2 years after diagnosis of type 1 diabetes
   - ☐ No clear diagnosis to date but ongoing investigations

4. Did your child have symptoms of coeliac disease at the time of diagnosis? (e.g. diarrhoea, abdominal pain, unexplained hypoglycaemia, weight loss)

   - ☐ Yes
   - ☐ No

5. Were you informed that your child was being screened for coeliac disease at the time he/she was diagnosed with type 1 diabetes?

   - ☐ Yes
   - ☐ No

6. A diagnosis of type 1 diabetes is a stressful event. However, a second diagnosis of coeliac disease may add extra stress.

   If your child's screen was positive, how much extra stress was this for you?

   On a scale of 1-5, 5 being the most stress.

	1	2	3	4	5	
No added stress	☐	☐	☐	☐	☐	Highest stress

Appendix 1. Questionnaire for parents

7. If your child's screen was positive, but he/she had no symptoms of coeliac disease, do you think having the screen performed a year after the diagnosis of coeliac disease would have been more or less stressful?

   - ☐ Less stressful
   - ☐ No difference
   - ☐ More stressful

8. Which diagnosis caused you more stress at the time of diagnosis?

   - ☐ Type 1 diabetes more than coeliac disease
   - ☐ Coeliac disease more than type 1 diabetes
   - ☐ Both equally

9. In addition to their diabetes, how much of an extra burden has your child's coeliac disease been on your day-to-day living?

   On a scale of 1-5, 5 being a huge burden.

	1	2	3	4	5	
No extra burden	☐	☐	☐	☐	☐	Huge burden

10. How adherent is your child to a gluten free diet?

    On a scale of 1-5, 5 being always compliant with gluten free diet.

	1	2	3	4	5	
Not compliant with diet	☐	☐	☐	☐	☐	Always compliant with diet