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Coeliac disease in adolescence: Coping strategies and personality factors affecting compliance with gluten-free diet

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ABSTRACT

Objectives: Patients suffering from a chronic condition such as coeliac disease (CD) need to develop coping strategies in order to preserve emotional balance and psychosocial functioning while adhering to their obligatory life-long gluten free diet (GFD). However, this can be particularly challenging for adolescents and may lead to dietary transgressions. Little is currently known about the influence of coping strategies and personality factors on dietary compliance. This study aims to explore these factors for the first time in adolescents with biopsy-proven CD.

Study design: We included 281 adolescents with CD and 95 healthy controls. We classified patients according to their GFD adherence status (adherent vs. non-adherent) and assessed coping strategies using the KIDCOPE and personality traits using the Junior-Temperament and Character Inventory (J-TCI).

Results: Adolescents with CD adherent to GFD used less emotional regulation and distraction as coping strategies than non-adherent patients. In terms of personality traits, adherent patients differed from non-adherent patients with respect to temperament, but not with respect to character, showing lower scores in novelty seeking, impulsivity and rule transgressions and higher scores in eagerness with work and perfectionism compared to non-adherent patients. No differences were found between healthy controls and adherent CD patients across these personality traits.

Conclusions: Coping strategies and personality traits differ in adolescent patients with CD adherent to GFD from those not adherent, and may therefore relate to risk or protective factors in adherence. Targeting coping and temperament using psychological interventions may therefore be beneficial to support adolescents with CD and optimise their adherence to GFD.

1. Introduction

Coeliac disease (CD) is an autoimmune mediated disease that occurs as the result of an immune response to gluten, which – left untreated – leads to intestinal malabsorption and atrophy of the duodeno-jejunal mucosa. Prevalence rates range from 1:100 when patients are diagnosed by screening methods to 1:1000 when diagnosed according to symptoms. Ten to 20% of those affected experience full symptomatology such as diarrhea, vomiting, weight loss, abdominal distention, abdominal pain, and in the long run failure to thrive, small stature, pubertas tarda, as well as psychomotoric and psychosocial developmental disorders (Di Sabatino & Corazza, 2009; Holtmeier, Henker, Riecken, & Zimmer, 2005). Complications are an early onset of osteoporosis, increased risk of abortions and intestinal lymphoma (Vogelsang, Propst, Dragosics, & Granditsch, 2002). The only available treatment is a lifelong gluten free diet (GFD) that requires avoidance of wheat, rye and

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barley leading to symptomatic, serologic and histologic remission (Green & Jabri, 2006). Strict adherence to this diet is essential to prevent long-term complications and represents the cornerstone in the therapy of CD (Troncone, Auricchio, & Granata, 2008), whereas untreated CD can lead to serious and potentially life-threatening long-term health complications (Green & Jabri, 2003; Rubio-Tapia & Murray, 2010).

Compliance to GFD is extremely variable and ranges between 36% and 95% (Errichiello et al., 2010; Hall, Rubin, & Charnock, 2009; Mazzone et al., 2011; Rashid et al., 2005; Roma et al., 2010). Difficulties with dietary compliance have been reported especially for adolescents (Edwards George et al., 2009; Kautto et al., 2014). Reported barriers to GFD include inferior taste of gluten-free food, inaccurate food labelling, absence of symptoms after dietary transgressions and psychological problems (Edwards George, et al., 2009). No association between dietary transgressions has been found with demographic or disease-inherent factors, concluding that cognitive and emotional characteristics might influence GFD adherence (Hall et al., 2009).

Chronic illness confronts a patient with numerous threats and challenges. Strategies need to be developed in order to preserve emotional balance, satisfactory self-image, and a sense of competence and mastery. Especially in children with CD, the introduction of a gluten-free diet results in a radical change of eating habits and lifestyle, and it can be hard to accept and stressful to follow (Mazzone et al., 2011).

During adolescence, peer-group orientation and engagement in risk-taking behaviours are typical and can lead to harmful consequences in the context of treatment and compliance. Strictly adhering to GFD requires constant attention and higher control around food, with greater effortful control and monitoring of labels of food ingredients, relying on limited (e.g. 'free from') food ranges in the supermarket, and needing to pay close attention to ingredients and having limited meal options when eating in social contexts, for example in a restaurant. This can be particularly challenging in transitional periods as adolescence (Edwards George, et al., 2009). Difficulties with adherence to GFD are most prominent in the peer-group environment, and less so within the family environment (Cinquetti et al., 1999).

"Coping", broadly defined as a behaviour to manage stressful situations, may have an impact on or modify adherence to GFD, however very few studies have examined this and studies are mainly limited to adult populations. Coping is considered to be a complex process of cognitive, behavioural, and emotional responses to stress which is not caused by the event itself, but by its cognitive evaluation (Skala & Bruckner, 2014). An individual's coping strategy may be adaptive or maladaptive. Trying to find a solution to one's problems i.e. is regarded as a task-oriented coping strategy, whereas screaming and other externalizing aggressive behaviour is considered as emotional coping. Increased task-oriented coping combined with decreased emotion-oriented coping is considered as an adaptive and the reverse as a maladaptive coping style (Sainsbury, Mullan, & Sharpe, 2013a). Findings suggest an association between emotion-focused coping strategies and poor illness adjustment in general, as well as avoidant coping and withdrawal from social support and poor adherence to treatment (Seiffge-Krenke, 2001). This contrasts the assumption that a broader coping repertoire, consisting of both problem-focused and emotion-focused strategies, increases the possibility of a matching response to the particular demands of a stressful situation (Taylor, 1999). Effective coping strategies improve emotional, physical, and social functioning, as well as quality of life (de Ridder & Schreurs, 2001). Adolescents strict adhering to GFD do not differ from adolescents without a chronic disease with respect to their quality of life in different areas including family, school, peer group and general wellbeing (Wagner et al., 2008).

When analysing psychological factors in treatment adherence, previous research indicates that personality traits should be included. It has been hypothesized, that identifiable personality traits might moderate reactions to a diagnosis of CD and facilitate or impede adherence to GFD in individuals with CD (Rashid et al., 2005). For example, adult individuals with higher conscientiousness, i.e. an overall tendency to plan and be organized in carrying out daily tasks, have been found to be more adherent with GFD (Edwards George, et al., 2009). Despite this, no studies to-date have included personality features and coping in adolescents with CD.

Therefore, the aim of our study was to assess coping strategies applied in disease specific situations and personality dimensions in adolescents with biopsy-proven CD and to compare patients adherent and not adherent to GFD.

2. Methods

2.1. Procedure

Recruitment for this study was part of a larger project on eating pathology and quality of life in adolescents with CD, which is described in full elsewhere (Karwautz et al., 2008; Wagner et al., 2008). The study protocol was approved by the Medical University of Vienna's Ethics Committee and written consent was obtained from participants and their parents in the case of minors. Inclusion criteria for involvement were: age range from 10 to 20 years, a CD diagnosis verified by a duodenal biopsy and positive CD specific antibodies, a minimum duration of illness of one year and obligation for a GFD. Exclusion criteria were the presence of a second chronic condition such as diabetes, ulcerative colitis, autism, and verbal and intellectual disability. Participants were contacted via the Austrian and German Coeliac Disease Societies as well as 7 Austrian gastroenterology departments. Those willing to participate contacted us via telephone, internet or e-mail. Participants fulfilling the inclusion criteria received a letter with study information, consent letters and questionnaires. A total of 118 patients manifested their interest via the Austrian Coeliac Disease Society, 101 patients through the German Coeliac Disease Society and 120 (out of 259 approached) through the Austrian gastroenterology departments. Of the 339 interested CD patients, 308 returned completed questionnaires. Inclusion criteria were fulfilled by 281 (91.2%) participants and not fulfilled by 27 (8.8%). Sixteen patients (5.2%) were excluded because they had a second chronic disease, 5 (1.6%) did not have a definite diagnosis of CD or were not obliged to GFD, 3 (1%) did not fulfil the one year criterion since diagnosis, 2 (0.6%) did not meet criteria for intellectual ability, and one patient 1(0.3%) did not fulfil the age criterion. In addition, 95 age and gender matched healthy controls (without a chronic illness) were recruited from the general population. Controls were matched to the whole CD group, independently of the adherence status and were approached by medical students involved in the study and recruited in school classes. Both, CD population and healthy controls were from urban and rural areas of several provinces.

2.2. Measures

Dietary transgressions were rated by the adolescents, the following options were provided: strict diet, 2–3 dietary transgressions per month, more than 3 dietary transgressions per month or no adherence to a GFD. For further analyses, we classified patients following a strict diet as adherent and all others as non-adherent to GFD and we compared coping strategies and personality traits in these two groups.