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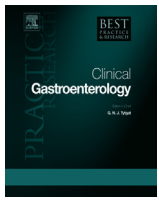

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Preventing complications in celiac disease: Our experience with managing adult celiac disease

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A B S T R A C T

Celiac disease is, as we know it, rather than being a rare and incurable disease until the 1950's, both quite common in screening studies and readily treatable. Three conditions are triggered by gluten consumption: celiac disease, the skin rash dermatitis herpetiformis and gluten ataxia. We describe our follow up for out clinic management, as evidence based data about such an approach are lacking in current literature. No food, beverages or medications containing any amount of gluten can be taken. Compliance is often difficult especially when patients are asymptomatic. We control a cohort, in daily practice, of over 700 adult patients. The majority of patients manage the diet without any problems. We describe our follow up in general, for serology, laboratory and histology. Forty percent of our newly diagnosed celiac patients do have a BMI over 25 kg/m^2. An appropriate attitude for this problem is lacking. The problem of slowly weaning off Dapsone over 5–10 years in DH is recognized. The bone density is checked in all newly diagnosed celiac patients. We control, if necessary, by telephone and lab controls done in local cities and see our patients only every two years face-to-face for follow up.

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The main question is if the adherence to a GFD, quality of life and prevention of complications is improved by visiting a dedicated celiac clinic. We hope to standardize this attitude on evidence data in the years to come.

Introduction

Celiac disease is a chronic enteropathy in genetic predisposed individuals in response to gluten intake [1]. CD as we know it is, rather than being a rare and incurable disease until the 1950's, both quite common in screening studies and readily treatable. The treatment is a gluten-free diet (GFD) [2]. Most patients report clinical improvement within weeks. However, mucosal recovery may last years after the start of a GFD [3]. CD occurs only in patients who express HLA-DQ2 and/or DQ8 molecules [4]. The prevalence of CD in adults varies between one in 100 and one in 300 in most parts of the world [5].

Three conditions are triggered by a systemic immune reaction to gluten consumption: celiac disease, the skin rash dermatitis herpetiformis, and gluten ataxia, which involves damage to the brain, especially the cerebellum. Celiac disease is a serious medical condition that requires a long-term follow-up plan to maintain excellent health and to prevent complications from occurring.

Maintaining a strict GFD is difficult in the East and West and has both financial and quality of life implications [6]. Evidence based follow-up for out clinic management is lacking in current literature.

Gluten free diet

The one and only therapy for CD is a life-long gluten-free diet. Willem-Karel Dicke started this in the Netherlands in 1933 already, this is over 80 years ago [2]. No food, beverages or medications containing any amount of gluten from wheat, rye, barley, spelled, kamut or other gluten containing cereals can be taken, even small quantities can be harmful. Only food and beverages with a gluten content of maximum 20 ppm are accepted. Oats have been reported to be non-toxic in almost 100% of patient of patients with CD [7]. GFD will result in symptomatic, serologic and histological remission in most patients. With a strict GFD, antibody levels (tTgA and EMA) decrease very rapidly [1]. However, histological normalization takes 2–5 years, especially in adults [3]. In children histological normalization occurs within 3–6 months, although antibody levels can take 1–1.5 years before normalization is reached. Compliance is often difficult, especially when a patient is “a-symptomatic” or does not have the classical symptoms. It helps patients and their relatives to be properly informed about the chronic disease, the do's and don'ts and the risk of untreated CD to increase knowledge and encourage self-empowerment of the patients. Despite the importance of adequate information leading celiac support groups and working groups did not define guidelines so far to assess the outcome and standardize adherence to the GFD.

Follow up in general

There is lack of evidence based and observational data about the best logistic out patient clinic approach of patients during a lifelong GFD. Amongst the many guidelines for celiac follow-up there is a lack of clarity regarding “What, who and when”. Since 25 years I do see over 400 celiac patients yearly in our so-called dedicated doctor-lead celiac clinic. An additional 300 other patients are controlled at the out-clinic every two years. In the past we saw the majority of patients on a regular annual face-to-face follow up. Now we control if necessary by telephone and laboratory controls in their local cities and make appointments “at request”. We have the impression that the adherence to a gluten free diet improves by having a regular follow up even by telephone within the setting of a dedicated celiac clinic.

The question is if the adherence to a GFD, quality of life and the avoidance of complications is indeed improved by a dedicated celiac clinic. In the past one of the key factors relating to the