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On Treatment Outcomes in Coeliac Disease Diagnosed in Adulthood

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1. Introduction

Coeliac disease (CD) is generally regarded as an intestinal disorder that can be fully treated by a gluten free diet (GFD). Indeed, this remains perfectly true in most medical aspects as regards the recovery of the small intestinal mucosa appearance, the blood count as well and the mineral bone density. In fact, life expectancy is similar to that of general population.

From a wider perspective, however, taking the subjective outcome of treatment into account the health-related quality of life (Hallert & Lohiniemi, 1999) and well-being i.e. patient-based perspectives refer to the perceived health state such as social, emotional, physical well-being or functioning, incorporating both positive and negative aspects of life. In Gastrointestinal (GI) disease the most relevant aspect of well-being pertains to relief of abdominal pain.

For adults struggling with a GFD for years to remain in clinical remission CD is not just associated with troublesome bowel complaints such as Indigestion, Diarrhoea, Constipation and Abdominal pain (Midhagen & Hallert, 2003). CD is also connected with a wide range of persistent symptoms outside the GI tract typically experienced by women diagnosed in adulthood that include various bodily pain syndromes and frank mood disorders (Ludvigsson et al., 2007), all making them apt to seek more health care services than women of same age in general population (Roos et al., 2011). Of interest considering the concept of CD in remission, a study compared health care costs per patient over 2 consecutive yrs of 137 women with CD treated median 7 yrs with 411 age-matched female population in Southeast Sweden using data derived from a local administrative database covering all health care services including prescribed drugs, imaging and lab. The results showed that the 93 per cent of the women CD used health-care services the 2-yr period amounting to mean Eur 5675 as compared with Eur 5414 for controls ($p < 0.05$), the difference mainly accounted for by excessive use of hospital care (Eur 5864 vs Eur 5215) and prescription of drugs (Eur 993 vs Eur 702) (Hallert et al., 2011).

All of this is consistent with the idea that reduction in well-being is a feature of longstanding CD at least in women living in Sweden but not in men for largely unclear reasons (Roos et al., 2006).

2. Bowel symptoms vs well-being

A study addressing whether the high rate of GI symptoms would explain the poor well-being of women living on a GFD confirmed close negative correlations between the GI symptoms and psychological well-being as assessed by the Gastrointestinal Symptom rating Scale (GSRS) total score and the Psychological General Well-being (PGWB) index, respectively. However, looking at directions of relationships the study showed that women with a high rate of GI symptoms showed no lower well-being than men with high rate GI symptoms. Furthermore, women with reduced well-being had not higher rates of GI symptoms than men with reduced well-being. Awaiting further studies it was concluded that any causal interrelations of bowel symptoms and subjective poor health remain unproven (Roos et al., 2009).

3. Well-being and coping

The poorer treatment outcome of women with CD may to some extent reflect the way they cope with the disorder and what factors they believe adversely impact on the subjective well-being.

To this connection studies indicate that women living with CD understand well-being and quality of life quite differently than men with CD. Men living with CD for years tend to focus on bodily sensations like physical endurance and bowel symptoms and they are prone to use a problem-oriented coping strategy approach.

Women treated for CD, on the other hand, are seeking an emotionally oriented strategy and emphasise the social consequences of being a coeliac and refer to the value of food, role identification, social functioning and feeling restricted by constant fatigue. Women are generally more frustrated men by the various bothering bowel symptoms that continue to despite adhering closely to the GFD.

4. Everyday life with CD

It may rather be that the numerous dilemmas and restrictions in everyday life facing especially women living with CD account for much of their perceived disease burden, comprising concerns about having to abstain from important things in life and the possibility that the children may develop CD in addition to the unmet expectations of the treatment. (Hallert et al, 2003), amounting to a sense of frustration and disappointment beyond the early happy phase of remission. As rightly pointed out (Ciacci, 2010) being diagnosed with CD implies accepting to have got a chronic illness and in addition to this a tricky dietary treatment that must last for life. Most people are capable to handle the ensuing psychic reactions pretty uneventful, whereas some develop signs of depression suggestive of a coeliac profile comprising two principal characteristics, namely, reactivity with anger and/or frustration and Pessimism including a cluster of symptoms signalling, powerlessness and constant fatigue.

In addition, women are inclined to express worries about having CD that affects all areas of life past, present and future when they do something that is outside the daily routines to such extent that the well-being of adults with CD in remission is in the same range as in adults with quiescent Crohn's disease.

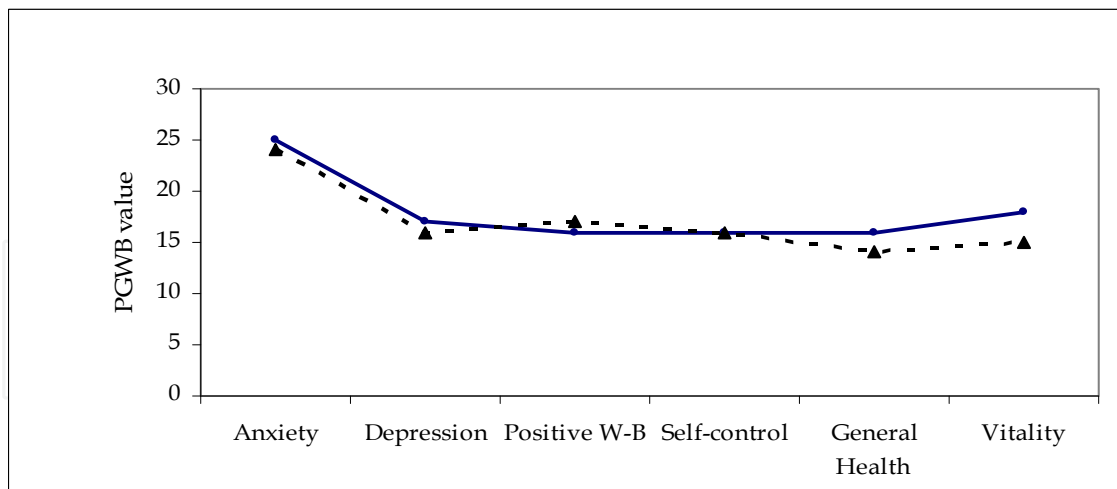


Fig. 1. Graph comparing dimensions of well-being in CD (solid line) and Crohn's disease (dotted line) (Stjernman, 2011).

For being a basically benign disorder these characteristics are an intriguing and unexpected feature of CD (Fera et al.(2003) that may be easily overlooked by gastroenterologists in charge. A tentative explanation for the poor treatment outcome of especially women living with CD diagnosed in adulthood may reside in the problematic transition into a life as a coeliac in association with poor insights into the nature of CD, sometimes, referred to as an allergy necessitating constant control of every dish that is often dated from the time of the diagnosis and rarely entertained since by the health care system, Yet current wisdom considers the once assumed fears of ingesting traces of gluten to be no longer valid (Collin et al., 2004). Gaining proper disease knowledge would thus be reassuring to most women and particularly when put into a structured education programme like a Coeliac School as outlined (Ring Jacobsson L et al., 2011).

5. The Coeliac School™

The Coeliac School an educational concept is based on the problem based learning pedagogy and includes weekly meetings in groups of 7-9 conducted by a tutor acting as a moderator. Each educational session is set to cover a predetermined topic presented as a scenario. The topics are decided by the group members according to specific needs and desires, thought promote active rather than passive learning. The group members were encouraged to perform self-studies between the meetings to find answers on raised issues. At the next meeting the group members were expected to evaluate and reflect upon the gathered information and to what extent it impacts on their daily life. Developing issues were treated by a new brainstorming allowing the group to invite an outside expert as needed. The benefits from taking part in the Coeliac School include improvement in mood and reduction in GI complaints as well opportunities to update diet knowledge.

A GFD is no single diet, nor simply foods devoid of gluten. Indeed, studies across Europe show that the composition of a GFD vary considerably between people and differ in several aspects from intakes as reported by general populations using food diaries. A study of adults in Sweden who had been on a GFD for 10 years revealed they had the same energy intake as general population controls of same age but lower daily intakes of fibres, niacin,

folic acid, vitamin B-12, calcium, phosphorus and zinc. Moreover, clear discrepancies were observed between the groups in selecting foods among 28 food groups under study, particularly true for women (Grehn et al., 2001). A similar study conducted in UK showed generally adequate macronutrient intakes, while women tended have low daily intakes of fibre, magnesium, iron, zinc, manganese, selenium and folic acid but no differing energy intakes, suggesting they are prone to have sugary snack foods. (Wild et al, 2010).

There are good reasons to believe that a GFD is nutritionally unbalanced more often than routinely recognised in clinical practice, at risk to cause nutritional deficiencies that may be clinically important. Indeed, the low intakes of B vitamins in CD populations account for raised levels of plasma homocysteine, a marker of functional B vitamin deficiency. Lack of B vitamins may very well explain part of the depressive features of CD, gaining support by the results of a randomised controlled clinical trial adding 0.5 mg of vitamin B-12, 3 mg of vitamin B-6 and 0.8 mg of folic acid to the daily diet for six months that showed general improvement in well-being of adults on a GFD for many years, notably within Anxiety and Depression unlike for controls receiving placebo (Hallert et al., 2009). Accordingly, advising people to avoid of gluten should not be the sole focus of a GFD knowing eating oats, represents a major advance in CD therapy not only in adults (Högberg et al., 2004).

Indeed, oats is rich in dietary fibres and taking oats is generally found to raise the palatability of a GFD also largely appreciated for being cheap. Unfortunately. Oats is widely looked upon as cattle food that is at best just prejudice.

Over the past decade gluten intolerant sufferers have witnessed a vast increase in the availability of suitable foods in most Western countries only hampered by unfounded ideas that wheat starch or trace amounts of gluten can be harmful to the coeliac mucosa and thereby entertaining social phobia and restrictions in daily life. With an expanding food market on the internet novel gluten free products will be steadily entering the global arena. Rendering cereals like barley non toxic is however less likely to be seen in the near future.

6. Managing CD beyond remission

The ever growing prevalence of CD approaching 3 per cent (Myleus et al., 2009) represents an increasing challenge to any health provider to ensure that CD is successfully coped with by supporting CD sufferers to master every day life dilemmas through proper self-management i.e learning to take control rather being controlled by food absorbing the entire life (Sverker et al., 2005)

To date, nursing appears to be a neglected component of the follow-up of adults with CD. In fact it may add values to the care of adults with CD, knowing that in some countries only 60 per cent of patients have a high level of confidence in the information provided from a dietician or gastroenterologist. Even more so, 1,000 adult members of the German Celiac Society identified dissatisfaction with the doctor-patient communication as one of the strongest predictors of poor well-being (Häuser et al., 2007)

In our experience CD sufferers diagnosed in adulthood only rarely need monitoring of the diet adherence. Follow-up routines should rather focus on life adjustments, medical procedures to symptom control and measures to uncover depression signs preferably managed by a dedicated multi-disciplinary team as employed in the care of adults with other chronic disorders.

This is in good keeping with an observation (Dorn et al., 2010) that psychosocial factors more strongly affect well-being and bowel symptoms in CD than the appearance of the gut mucosa, underscoring the limitations of a biomedical model to help understanding adults living with CD in proven remission. This would allow for applying biopsychosocial approach in assessing health in CD since there is no underlying mucosal damage to treat. Instead CD sufferers may require attention to their psychosocial distress and worries that may include psychological support and treatment for the IBS-like symptoms.

7. Conclusions

CD is a benign yet sometimes a troublesome disorder of the GI tract often surrounded by obsolete patient's beliefs dated from the time of the diagnosis, making the condition especially hard to successfully cope with. This is apparently true for many women who are frustrated find the outcome of the long-term treatment and self-management worse than expected at start. The complexity of living with CD and remain well extends far beyond keeping the mucosa free from signs of inflammation. Given the increasing prevalence of CD across the globe improving the long-term health of these people represents a major challenge for any health care provider.

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