The Effect of Celiac Disease on Romantic Relationships: “Should we meet over lunch?”

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Introduction

Our study, funded by the Calgary Chapter of the Canadian Celiac Association, examined biopsy proven celiac disease from a social and relational perspective. Our aim was to explore the ways that biopsy proven Celiac disease affects relationships, with a particular focus on relationships between romantic partners. Our study also explored how Celiac disease affected individuals on a day-to-day basis. Through interviews with four individuals living with Celiac disease or their spouses/partners and an online survey of the same population, we investigated a number of issues concerning the impact this disease has on romantic relationships and individual daily life.

Methodology

To participate in this study, individuals had to be adults (a) diagnosed (via biopsy) and living with celiac disease or (b) partners of such persons. In addition, participants must have been involved in an ongoing romantic relationship at least three months in length. Posters advertising the study were distributed in doctors’ offices (including adult GI clinics), Medical Centres, coffee shops, Mount Royal University, the University of Calgary, the Calgary Chapter’s Newsletter, the Canadian Celiac Association’s web page, the Calgary National Celiac Association Conference, and via word of mouth. The interviews were conducted over the phone.

The online survey included questions related to demographics, relationship status, relationship quality (e.g., love, commitment, etc.); disease status; and, how the disease affected the participants’ romantic relationships. Here we present a sampling of our findings that may be of interest to a general audience.

Survey Findings

In total, 117 participants completed the survey (109 females, 9 males, and one who didn’t report his/her gender). The average age of participants was 40.41 (ages 18-78). The average age at which participants reported noticing the first symptoms of celiac disease was 25 and the average age at which they were diagnosed with celiac disease was 34.17. The table below presents further data concerning participants’ medical experiences with celiac disease.

Proportion of Our Sample Who Had (N = 117):

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<td>A positive blood screening test</td>
<td>n = 94 (80.3%)</td>
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<td>Additional blood screening tests</td>
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A positive biopsy | n = 110 (94%)
Immediate Family With Celiac disease | n = 45 (38.5%)
Food allergies (other than gluten) | n = 34 (29.1%)
Other autoimmune disorders | n = 35 (29.9%)
Other medical concerns | n = 61 (52.1%)
Mood disorders for which they had been prescribed medication | n = 13 (11.1%)

Overall, survey respondents reported careful adherence to a gluten free diet. The majority (94.5%) reported that they “always” follow a gluten free diet, with a further 5.1% reporting that they follow such a diet “most of the time.” Similarly, when we asked participants if they had ever risked eating gluten, the considerable majority (79.5%) reported “never” and 12.8% reported “rarely.” Just 6.8% reported that they risked eating gluten “sometimes.”

We were interested in whether participants felt comfortable disclosing to others that they had celiac disease. In answer to that question, survey participants reported high levels of comfort disclosing their disease to others (M=4.63 on a 1-5 scale, with higher numbers indicating greater comfort).

We measured the day-to-day impact of celiac disease in relation to its personal costs (e.g., if participants ever felt pressured to eat non-gluten free foods, excluded from food-related celebrations or events, or stretched financially by costs associated with living with the disease, etc.), the limitations it imposed on their lifestyles (e.g., fears about their health, whether they view the diet as adequate treatment, etc.), and its effects on their mood (e.g., whether they felt depressed, overwhelmed, worried, etc.). Participants answered these questions using a 1 to 5 scale where 1 was “never” or “not at all” and 5 was “always” or “a great deal.” Overall, they reported that celiac disease had a moderate effect on their daily lives, with greater personal costs (M=2.69) and limitations (M=2.96), than effects on their mood (M=1.83). The majority (71%) felt that the gluten free diet is sufficient treatment for their disease, but 59% also felt that there were not enough treatment options available to them. In addition, just over half of participants (57%) felt that others understand celiac disease, leaving a sizable minority feeling misunderstood. Finally, despite Canada’s new food allergen labelling regulations (which came into force on August 4, 2012 and before we conducted this study), our participants did not feel safer eating out at the time they completed the survey than they had before the new regulations came into effect (only 43% felt safer). Less than half our sample (43%) trusted servers or food prep staff at restaurants.
Given the variety of ways in which celiac disease impacts people’s lives and the moderate size of that impact in the present sample, we might have expected participants to report that celiac disease has had a moderate negative impact on their romantic relationships, as well. In actuality, however, according to participants’ responses to the survey items that asked about their relationships, celiac disease had rather mild and generally positive effects on their relationships. In fact, overall, participants reported that their romantic relationships were highly satisfying and highly committed and they perceived their partners to be very supportive (e.g., caring, understanding, willing to accommodate needs, etc.) in relation to their disease. Consistent with this latter finding very few reported ever feeling pressured by their partners to eat non-gluten free food (6.8%).

Interview Findings

We interviewed four individuals in-depth about their experiences living with celiac disease. The interview began with questions about celiac disease and diagnosis and then moved on to ask about participants’ romantic relationships and experiences in social situations.

Stigma was a prominent theme in the interviews with these four individuals, as was a feeling of not being believed from the medical community as well as close friends and partners. Both those living with the disease and their romantic partners discussed feeling overwhelmed physically and psychologically by the symptoms of the disease and their impact on day-to-day activities. They discussed a variety of ways in which the disease restricted their lives, including issues around locating toilet facilities when away from home, exhaustion that limited their participation in activities about which they were passionate, difficulty finding suitable places to eat out, and financial and resource hardships associated with the limited options and costs of gluten free foods. Interview participants also spoke of the hypervigilance required to be symptom free—or to avoid exacerbating chronic symptoms—and how that hypervigilance led to strain on couples within their romantic relationships as a result of the day-to-day restrictions they encountered and adaptations that were required when living with the disease.

At the same time, and on a more positive note that echoes the key relationship findings from the survey, interviewees also argued that their efforts to live with the symptoms of celiac disease and the implications of the diagnosis helped them to be closer to their romantic partners. Changes in relationships with extended family and friends were not always as positive, however, because limited food options and the greater effort required for food preparation interfered with opportunities to socialize.

In sum, these interviews highlight the significant challenges that are—or at least can be—part of the experience of living with celiac disease and demonstrate that these challenges are experienced by bot the affected individual and his or her romantic partner (and family).

Discussion

Research indicates that the quality of people’s relationships affects their wellbeing (Lucas & Dyrenforth, 2006; Myers, 2000; Myers & Diener, 1995; see also Berg & Upchurch, 2007). But there is virtually no research examining the opposite possibility: that people’s health and wellbeing affects their relationships. Celiac disease presents an interesting case, in this context, because individuals with celiac disease may not look sick and are generally able to engage in most or all of the same activities that healthy individuals do. Going into this study, we expected that the “apparent healthiness” of individuals living with celiac disease might have the ironic effect of exacerbating the disease’s impact on people’s relationships. For example, we thought that partners of persons living with celiac disease might struggle with accommodating dietary
restrictions because their partners often neither act nor look “sick.” Partners might also be inclined to minimize the severity and impact of afflicted individuals’ health concerns in such a case (Sieffge-Krenke, 2000), again because their partners often neither look nor act sick (particularly if they are managing their disease effectively).

Our results suggest that such potential problems may be rare. In fact, although they recognized that the disease affected their daily lives and their relationships in nontrivial and diverse ways, our participants generally reported that their partners were supportive and caring and believed that the disease strengthened their relationships. This is an important finding and one that deserves further exploration with larger samples and a greater number of interviews for fleshing out participants’ experiences in greater depth.

There is very little research on the social and relational impact of celiac disease and few studies have examined samples with biopsy-proven disease. Our results will thus make an important contribution to our understanding of celiac disease and its effects on people’s lives. It was limited, however, by the number of participants. The restrictive focus on biopsy proven celiac disease clearly limited the number of individuals who qualified for participation. However, the findings obtained in this study can lead to prospective longitudinal research in this area which would shed valuable light on the extent to which the associations observed here are casual and whether (as seems likely) the quality of individual’s relationships affects their experience of their disease.

References


