

Caring for a Celiac Partner: Gluten, but not Worry Free

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Caregiver burden is defined as multidimensional biopsychosocial reaction resulting from an imbalance of care demands relative to caregivers' personal time, social roles, physical and emotional states, and financial and formal care resources given the other multiple responsibilities they bear [1]. Caregiving can generate emotional and psychological burdens often resulting in psychiatric illnesses such as depression and anxiety [2]. Furthermore, caregivers can face financial challenges due to missed workdays, changes in work schedules, and the financial costs of medications or supplies [2]. These psychological and physiological effects can contribute to immune system dysfunction, coronary artery disease, and even early death in caregivers [3].

Caregiver burden has been studied in great detail in a variety of cancers and neurological illnesses such as dementia and Parkinson's disease [1–3]. Studies of caregiver or partner burden in chronic gastrointestinal diseases have been until recently limited to the irritable bowel syndrome (IBS) [4]. Many of the chronic common functional and organic gastrointestinal ailments such as IBS, inflammatory bowel disease, and celiac disease all have significant effects on the physical and psychological health of the patients leading to poor quality-of-life [5–7]. Moreover, the treatment of gastrointestinal illnesses often involves modifying or restricting one's diet. For many of these illnesses, although limited therapeutic options are available, they can be expensive, ineffective, or have significant adverse effects. Thus, chronic gastrointestinal illnesses share many features with neurological and

oncological diseases associated with significant caregiver burden.

In this issue of *Digestive Diseases and Sciences*, Roy et al. [8] have explored partner burden in celiac disease, identifying associated factors. Among 94 patient–partner pairs studied at a tertiary care center, over one-third of partners suffered from mild–moderate degrees of partner burden [8]. Additionally, about one-fourth of the partners reported moderate–low overall satisfaction with their relationship [8]. Sexual satisfaction was reported to be low in ~15 % of the partners studied. Interestingly, they reported that mild–moderate partner burden in their cohort was significantly associated with a low level of relationship satisfaction and disease duration of ≥ 10 years [8].

In this first study exploring the caregiver burden among partners of celiac disease, significant caregiver burden was common among the partners of celiac patients. Partners of patients with celiac disease were assessed for caregiver burden using the Zarit Burden Interview (ZBI), a tool most commonly used to study the caregiver burden in other chronic diseases [8]. The mean caregiver burden score in this study (17.5 ± 12.8) was comparable to the mean caregiver burden scores reported among other chronic diseases including IBS, dementia, and advanced cancer [8]. Nevertheless, since the nature of the burden and the factors underlying it could be considerably different in every disease, numerical comparison might not be appropriate. Nevertheless, caregiver burden among partners of celiac disease is a substantial problem.

Roy et al. [8] also reported that partner burden in celiac disease was significantly associated with reduced relationship satisfaction between the patient and the partner. Similar inverse correlation between ZBI score and relationship quality was also reported in IBS patients as well as in certain non-gastrointestinal diseases such as dementia

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[4, 9]. Whether high partner burden leads to poorer relationship quality or vice versa is not clear. It is easy to imagine that partners with poor relationship quality could be more easily distressed by the factors underlying caregiver burden. Similarly, it is also possible that higher caregiver burden experienced by partners could be affecting their relationship. As this study was cross-sectional, the cause/effect relationship, although it could not be established, is worth exploring in future studies.

The authors discovered that the only factor other than the relationship quality that was significantly associated with the partner burden was a relationship duration of ≥ 10 years [8]. On further analysis, they established that a significantly higher number of these partners were afraid of what the future holds for the celiac patients [8]. Thus, it is important for clinicians to counsel patients and their partners about the long-term monitoring, complications, and prognosis of the disease. Physicians should advise their patients to bring their partners at follow-up visits so that their concerns could be answered in a timely manner.

Interestingly, partner's sexual satisfaction was significantly associated with partner burden only when using univariate analysis but not with multivariate analysis [8], possibly due to the assumption that relationship satisfaction is likely multifactorial and at least in part related to mutual sexual satisfaction. Thus, multivariate analysis revealed that relationship satisfaction remained significantly associated with partner burden but sexual satisfaction did not. It is also possible that since multivariate analysis was limited by the small sample size, future studies with larger sample size could provide additional data in regard to this important topic. Of note, sexual satisfaction is significantly associated with partner burden in IBS patients and thus would not be unique to the patients with celiac disease [4].

In this study, severity of disease reported by celiac patients was not significantly associated with partner burden [8]. The degree of correlation between the two variables is also weak ($r = 0.27$). Thus, the caregiver burden experienced by partners is likely not much influenced by the physical symptoms experienced by the patients and other factors such as financial stress or sexual and relationship satisfaction; anxiety about the prognosis of one's disease might thus be a more important determinant of partner burden.

This study opens up numerous other questions. This study exclusively focused on the burdens experienced by partners as caregivers. Yet, an underexplored area is the caregiver burden experienced by parents of children diagnosed by celiac disease. It is quite likely that the factors determining the caregiver burden among parents of celiac children would be exceedingly different from that experienced by partners. Since the majority of patients in this

study had longstanding celiac disease, were in long-term relationships, and had excellent compliance to a gluten-free diet, a population clearly not representative of all celiac patients, a multicentric study with more heterogeneous patient population might provide more insight into this problem. The interplay between caregiver burden and compliance is fascinating as one can easily affect the other. It is also unknown whether the degree of caregiver burden in more resource-limited settings such as in developing countries is higher and the underlying factors any different. A deeper understanding of the caregiver burden and relationship quality should also be further investigated in a prospective longitudinal study with serial data on relationship quality and caregiver burden at the time of diagnosis and follow-up visits.

What is the clinical relevance of these results? Gastroenterologists should consider the impact of the celiac disease on close family members, especially partners. Caregiver burden experienced by the partners of celiac disease patients is very common and probably underappreciated. It is likely that caregivers of patients with other chronic gastrointestinal studies such as inflammatory bowel diseases, chronic pancreatitis, and gastroparesis experience similar burdens, meriting further exploration. The authors also suggested that partners with disease duration < 10 years are more likely to experience financial strain and those with longer relationship duration are more likely to experience anxiety about the future. This in-depth analysis hints that the primary determinant of partner burden might shift depending on the stage of relationship. Clinicians should not only acknowledge the burden experienced by partners of celiac patients, but also try to understand the primary determinants of the burden in a patient-partner pair by asking open-ended questions. Providing them with the data that caregiver burden is a common phenomenon in celiac disease might address their guilt that often accompanies such situations. For couples anxious about the financial strain, actively helping them find less costly gluten-free options by involving nutrition services, social services, and support organizations might help strengthen the relationship in early stages and positively impact the quality-of-life of patients as well as their partners. For the patient-partner pair in a long-term relationship, addressing partners' concerns about long-term prognosis and complications of the celiac patient after considering all of the clinical variables inherent to individual patients might reduce the burden experienced by partners. A low level of partner burden and improved relationship quality is fundamental to improving the overall quality-of-life for our patients. Thus, clinicians need to look beyond the disease and the patient and treat the patient-partner pair as a whole.

Compliance with ethical standards

Conflict of interest None.

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