

# NARRATIVE REVIEWS

Fasiha Kanwal, Section Editor

## Caregiver Burden in Adults With Inflammatory Bowel Disease

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**Inflammatory bowel disease (IBD) is a chronic condition that has a relapsing and remitting disease course. There is high degree of inpatient and outpatient health care utilization by IBD patients along with a great deal of psychosocial stress associated with the condition. Patients frequently rely on family, friends, and other informal caregivers to provide medical, instrumental, and emotional support. The role of caregiving for adult IBD patients can lead to significant caregiver burden. At present, there are limited data on the existence of caregiver burden in adult IBD patients. Moreover, there are no specific measures for evaluating caregiver burden and there are no interventions targeting caregiver burden in adults with IBD. This review outlines the limited available data on caregiver burden in IBD, explores caregiver burden in other chronic conditions, and proposes applications of these data for creating screening and assessment tools and interventions for caregiver burden in IBD.**

**Keywords:** Crohn's Disease; Ulcerative Colitis; Caregiver Burden; Caregiver Stress.

Inflammatory bowel disease (IBD), including Crohn's disease (CD) and ulcerative colitis (UC), is a chronic disease that follows a relapsing and remitting clinical course. It is estimated that the North American prevalence of CD and UC is between 400 and 600 per 100,000 persons.<sup>1</sup> Exacerbation of IBD symptoms leads to significant health care utilization, with nearly 300,000 hospitalizations and more than 2 million ambulatory care visits yearly for CD and UC combined.<sup>2,3</sup> This pattern of frequent health care use can contribute to work absenteeism, disability, and unemployment; all of which negatively impact health-related quality of life (QoL).<sup>4</sup> Other issues such as loss of control, fatigue, concerns regarding body image, feelings of isolation and fear, and fear of being a burden also negatively impact the overall quality of life and psychosocial well-being of IBD patients.<sup>5</sup> As a result of the episodic nature of their illness, IBD patients may experience increased levels of denial, hostility, despair, sadness, and grief.<sup>6</sup> The increased health care and psychosocial needs associated with IBD contribute to patient reliance on caregivers to provide assistance with activities of daily living, instrumental support (ie, medication management, transportation to medical visits, infusions, assistance with making

appointments), emotional support, and possibly financial or other material support.

Chronic illness has been shown not only to affect the lives of those suffering from a disease, but also the lives of caregivers.<sup>7</sup> For adults with IBD, family members and friends often assume the role of caregiver, particularly during disease flares. A chronic relapsing and remitting disease such as IBD can place significant strain on interpersonal relationships and alter relationship dynamics over time.<sup>8</sup> Excessive caregiver burden potentially can lead to negative long-term physical and psychosocial outcomes not only for the caregiver, but also for the care recipient.<sup>9,10</sup> To best direct clinical care, it is critical to identify and address the distress that a diagnosis of IBD can place on the caregivers. This review outlines data on caregiver burden in IBD, explores caregiver burden in other chronic conditions, and proposes clinical applications of these data.

### The Nature of Caregiver Burden in Inflammatory Bowel Disease and Other Chronic Diseases

Although definitions of caregiver burden vary across studies, most definitions focus on the adverse effects of caregiving across multiple areas of functioning (eg, physical, emotional, social, financial, and spiritual).<sup>11,12</sup> Conceptual models of caregiver burden acknowledge that the caregiver's stress and burden are related not only to the care recipient's symptoms and disease progression, but also to secondary stressors such as financial problems, work-related stressors, and the caregiver's personal health problems, as well as the broader context in which caregiving takes place (eg, cultural norms for caregiving, sociodemographic characteristics of caregivers and care recipients, and so forth).<sup>13</sup>

**Abbreviations used in this paper:** CD, Crohn's disease; IBD, inflammatory bowel disease; PIP, Pediatric Inventory for Parents; QoL, quality of life; UC, ulcerative colitis; ZBI, Zarit Burden Interview.

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There are limited data on the prevalence and impact of caregiver burden in IBD. We searched for pertinent literature in MEDLINE and PsycINFO databases using combinations of structured and free text search terms to identify literature on caregiving and IBD. The MEDLINE search consisted of the following: caregivers (subject heading) or “caregiver burden” + inflammatory bowel diseases (subject heading); and the PsycINFO search consisted of the following: ulcerative colitis (subject heading) or “inflammatory bowel disease” or “Crohn’s disease” + caregiver burden (subject heading). Although our search yielded several empiric studies of parenting and caregiving stress among parents of young people with IBD, we found only 1 study that examined caregiver burden related to adults with IBD. Two other relevant articles were identified outside of this structured search.

Although the empiric literature in this area is scant, we believe that caregiver burden is a significant aspect of IBD care based on our clinical encounters with spouses, parents, and others who provide instrumental and emotional support to adults living with IBD. We have found, for instance, that people experience emotional, practical, and financial barriers to caregiving for their loved ones with IBD. The Crohn’s and Colitis Foundation likewise acknowledges the roles and needs of IBD caregivers by offering through its website a caregiver-specific support group and other resources. The small amount of empiric work on this topic is not representative of the burden of this group. Perhaps, however, the state of the research suggests that existing models of caregiver burden do not represent the nature of caregiving demands in this population adequately.

Much of what is known about caregiver burden in IBD comes from pediatric IBD populations. For example, Akobeng et al<sup>14</sup> conducted a qualitative study in which parents and siblings of pediatric patients with IBD participated in focus groups and were asked to identify concerns they had regarding their family member with IBD. They found that most parents were concerned about the effect of IBD on their child’s future; additional issues included feelings of guilt and concerns regarding a restricted family lifestyle. Siblings of the pediatric IBD patients showed feelings of jealousy and concerns that their parents were overprotecting the patient. Research on caregiver burden in pediatric IBD overlaps to some extent with studies of related concepts of parenting stress and general family functioning in the pediatric population, but may not apply to caregivers of adults with IBD.<sup>15,16</sup>

Despite the available literature examining caregiver burden in pediatric IBD, there is a paucity of data examining this issue in the adult IBD population. We found only 1 article that directly examined the presence of caregiver burden for adult IBD patients. Parekh et al<sup>17</sup> sought to better understand the degree and predictors of caregiver burden in a sample of adults with IBD ( $n = 162$ ). Results indicated that a lower quality of life (measured with the QoL index<sup>18</sup>) was associated with caregiver demographic factors (ie, >1 dependent in the

household), caregiver psychosocioeconomic factors (ie, history of psychiatric illness), and care recipient disease-related variables (ie, active IBD exacerbation and higher disease severity). Factors predictive of a higher degree of caregiver burden (based on the Zarit et al<sup>11</sup> Burden Interview [ZBI]) fell into similar domains including caregiver demographic factors (female sex, younger age, annual income level <\$30,000, having >1 dependent in the household), caregiver psychosocioeconomic factors (ie, history of psychiatric illness), and care recipient disease-related variables (caring for a patient with active disease exacerbation or more severe disease). Participation in religious activities and attendance at a support group were predictive of a reduced level of burden. Caregiver coping also was examined (Brief COPE survey<sup>19</sup>). Approximately one third of the caregivers endorsed maladaptive coping skills (eg, venting, substance abuse, denial), which were predicted by caregiver demographics (male sex, and living in a different household from the patient) and caregiver psychosocioeconomic variables (ie, lack of involvement in religious activity or attendance at a support group, personal history of psychiatric illness).

From these data, the investigators concluded that an increased level of support is needed during times of disease exacerbation and in patients with more severe disease. They also suggested that to better address caregiver burden, there should be a multidisciplinary approach involving psychologists, social workers, and medical professionals to help caregivers cope with the daily life challenges associated with caring for an IBD patient to overcome their burden.

In a smaller study<sup>20</sup> evaluating 51 IBD patients and 18 caregivers, additional themes regarding caregiver burden were elicited. Caregivers in this study reported spending at least 5 hours per week on caregiving. They also reported missing hours at work and decreased overall productivity at work as a result of their role as a caregiver. Nearly half of these caregivers reported mild-to-moderate caregiver burden based on the ZBI and nearly two thirds of the caregivers reported feeling they could do a better job in caregiving. This study was unique in that 70% of the patients were in clinical remission, however, despite this, a sizeable portion of the caregivers still experienced caregiver burden.

Finally, Magro et al<sup>21</sup> conducted a study in Portugal to evaluate the impact of inflammatory bowel disease on patients’ and their caregivers’ daily activities. The investigators discovered similar themes as compared with previous studies and noted that the caregivers’ lives were affected by anxiety with major concerns including the risk of development of cancer in the patient with IBD and lack of information and knowledge regarding the patients’ condition. The investigators also solicited opinions from the patients and their caregivers regarding what they believed would improve their care—information on new drugs and regular contact with their physician were designated as having the biggest impact on improving care.

Similar domains have been found to be predictive of caregiver burden in a variety of disease-specific populations including, dementia,<sup>13,22–24</sup> cancer,<sup>25</sup> cirrhosis,<sup>10,26</sup> heart failure,<sup>27,28</sup> chronic obstructive pulmonary disease,<sup>27</sup> and type 1 diabetes mellitus.<sup>29,30</sup> Potential risk factors for increased caregiver burden are summarized in Table 1, and include caregiver demographics (female sex, older and younger age, lower education and income, cohabitation with care recipient and >1 dependent in the household, spouse or adult child, employment), caregiver psychosocioeconomic factors (psychiatric illness, social isolation, financial stress, number of hours spent providing care, lack of choice in caregiving, use of more coping strategies), care recipient psychosocioeconomic factors (psychiatric and behavioral problems, help needed with activities of daily living), and care recipient disease-related variables (symptom burden, functional decline, active disease exacerbation, or more severe disease). Caregiving for patients with a chronic medical illness also can have a negative impact on the physical and psychological functioning of the caregiver if left unaddressed, and this is detailed in Table 2.

### Factors That Mitigate Caregiver Burden

Several studies have aimed to identify factors that buffer caregivers from the adverse effects of caregiving activities. For example, larger social networks, frequent social contact, and the ability to arrange for assistance

**Table 1.** Risk Factors for Caregiver Burden in IBD and Other Chronic Diseases

Caregiver demographics	
Female sex	<sup>13,17,58</sup>
Older age	<sup>13</sup>
Younger age	<sup>17</sup>
Low education	<sup>58</sup>
Low income	<sup>10,17</sup>
Cohabitation with care recipient	<sup>13,58</sup>
More than 1 dependent in the household	<sup>10,17</sup>
Spouse	<sup>13,26</sup>
Adult child	<sup>22</sup>
Employed	<sup>25</sup>
Caregiver psychosocioeconomic factors	
History of psychiatric illness	<sup>17</sup>
Depression	<sup>24</sup>
Social isolation	<sup>58</sup>
Financial stress	<sup>26,29,58</sup>
Greater number of hours spent caregiving	<sup>13,58</sup>
Lack of choice in caregiving	<sup>58</sup>
Use of more coping strategies	<sup>13</sup>
Longer length of relationship with care recipient	<sup>26</sup>
Care recipient psychosocioeconomic factors	
Severe psychiatric and behavioral problems	<sup>23</sup>
Help needed with activities of daily living	<sup>25,27</sup>
Care recipient disease-related variables	
Symptom burden	<sup>13</sup>
Functional decline	<sup>23</sup>
Active disease exacerbation or more severe disease	<sup>10,17</sup>
Cognitive impairment	<sup>26</sup>

**Table 2.** Caregiver Outcomes Related to Caregiver Burden

Effects on physical functioning	
Higher levels of stress hormones	<sup>31</sup>
Compromised immune response	<sup>31</sup>
Greater prescription medication use	<sup>13,31</sup>
Increased use of health services	<sup>24</sup>
Greater cognitive decline	<sup>31</sup>
Effects on mental functioning	
High levels of psychological distress	<sup>31</sup>
Depression	<sup>24,26,31</sup>
Anxiety	<sup>31</sup>
Low levels of psychological well-being	<sup>31</sup>
Greater psychiatric medication use	<sup>24</sup>

from friends all exert a protective effect against caregiver burden.<sup>31</sup> Studies also have highlighted positive aspects associated with the role of caregiving, such as good feelings associated with being needed, added meaning to life, enhanced skill set, and a strengthened caregiver–patient relationship.<sup>32</sup> In a review of 35 studies, Li and Loke<sup>33</sup> found consistent evidence that spousal caregivers for cancer patients experienced positive aspects of caregiving such as an enhanced relationship with the care recipient, a feeling of being rewarded, a sense of personal growth, and personal satisfaction. Daily enrichment events and self-efficacy on the part of the caregivers were identified as the determining factors in the positive aspects of caregiving.

### Significance of Spousal/Partner Caregiver Burden

For many adults with IBD, a spouse or intimate partner is the most likely caregiver. Spouses have been shown to bear a larger proportion of the burden of care than other primary caregivers.<sup>34</sup> For cancer patients, the psychological well-being of the caregiver is linked closely with that of the patient, particularly when a spouse is the caregiver.<sup>35,36</sup> Spousal caregivers are put under significant stress because they frequently are expected to manage a variety of responsibilities including treatment monitoring, symptom management, and assisting with personal care and finances. In the review by Li et al,<sup>35</sup> the investigators evaluated the literature regarding spousal caregiver burden in caregivers for cancer patients. Several interesting findings were shown: female spousal caregivers performed more care tasks than male spousal caregivers throughout the process of caregiving. Female caregivers were more likely to perceive the caregiving process negatively; however, they also were more likely to experience personal growth from the caregiving experience than their male counterparts. Behavioral differences also were noted between female and male spousal caregivers: female spousal caregivers were more capable of planning ahead and worked to provide more tangible and emotional caregiving, whereas male spousal caregivers exercised avoidance and found it difficult to

express their emotional reaction to caregiving, providing less tangible and emotional support. These studies highlight the need to pay particular attention to gender-related stressors that can cause caregivers to feel a sense of burden and distress. This can be balanced against emotions that provide caregivers a sense of fulfillment from caring for a loved one suffering from a chronic illness. A limitation of much of the work on spousal caregiver burden is the focus on predominantly older adult populations with degenerative or terminal illnesses. In contrast, IBD is a relapsing and remitting disease that affects people across their lifespan, and therefore caution is needed when extrapolating these findings.

### *Measuring Caregiver Burden*

Recognizing and attending to caregiver burden is an important aspect of caring for a patient with a chronic disease. There are several validated tools that have been developed to identify and measure caregiver burden.

In a landmark study by Zarit et al,<sup>11</sup> they investigated factors of caregiver burden and developed the ZBI. This tool was designed to investigate the stresses experienced by caregivers of dementia patients. It can be completed by caregivers as a self-report measure or as part of a clinical interview. Caregivers are asked to respond to 22 questions about the impact of the care of recipient's disabilities on their life in areas such as physical health, psychological well-being, finances, and their relationship with the patient.<sup>23</sup> Each item on the interview is a statement that the caregiver is asked to respond to using a 5-point scale, ranging from 0 (never) to 4 (nearly always). This scale has been validated in several studies<sup>37,38</sup> including one by Hébert et al,<sup>37</sup> in which it was found that the ZBI was not influenced by age, sex, locale, language, living situation, marital status, or employment status, suggesting that it is appropriate for use with a variety of populations. Scores also were found to be correlated significantly positively with behavioral problems in older adult patients and depression scores of the caregivers.<sup>39</sup> Although only validated to measure caregiver burden in dementia patients, the ZBI now has been used to measure caregiver burden in several other disease processes such as Parkinson disease,<sup>40</sup> spinal cord injury,<sup>41</sup> heart failure,<sup>42</sup> liver disease,<sup>10</sup> and even IBD.<sup>17</sup>

In addition to the ZBI, other indices have been developed to assess caregiver burden. For example, Cliff and MacDonagh<sup>43</sup> created and validated a questionnaire to evaluate psychosocial comorbidity in patients with prostate cancer and also their caregivers. This approach was particularly unique because it not only created a disease-specific questionnaire, but also the same questionnaire was administered to patients and partners alike, thus allowing concordant and discordant responses to guide further interventions.

More specifically for IBD, Vergara et al<sup>44</sup> created and validated a questionnaire which is used to assess QoL in household members of patients with IBD. This questionnaire consists of 14 items assessing mental health and daily life activities. The questionnaire was validated in 126 household members of IBD patients and it showed good validity and reliability. Of note, this questionnaire was administered to any household member and was not limited to the primary caregiver.

There are no tools designed particularly for measuring caregiver burden that have been validated in the adult IBD population; however, 1 study has validated a measure of caregiver burden in pediatric IBD patients. Gray et al<sup>16</sup> validated the Pediatric Inventory for Parents (PIP), a measure of parental stress associated with caring for a chronically ill child. The investigators sought to validate this tool in 130 adolescent IBD patients to validate its use in the relapsing and remitting course of IBD. They found excellent internal validity and reliability of the PIP in assessing caregiver stress in pediatric IBD.

To better measure caregiver burden for adult IBD patients and to identify target areas for intervention, validated measurement tools are needed. Modification and validation of existing validated tools may be an efficient means of caregiver burden measurement tool development. Measures used to assess caregiver burden in patients with dementia may not be adequate to assess caregiver burden in patients with IBD because of the episodic and unpredictable nature of the disorder. Existing measures may need to be modified to consider how to address caregiver burden and how it shifts during different periods of disease exacerbation. The PIP (for caregivers of children with IBD) may be a good starting point, but factors specifically relevant to adult IBD (eg, disease duration/extent, comorbidities, psychological issues, adherence to therapy, and quality of life concerns) should be considered.

### *Why Should Providers Address Caregiver Burden in Inflammatory Bowel Disease?*

Addressing caregiver burden is an important part of caring for patients with IBD, particularly because a caregiver's well-being may affect the patient's outcomes. [Table 3](#) highlights signs of caregiver burden in the caregiver and the effect this may have on the patient themselves.

Excessive caregiver burden may lead to the inability to care for the patient and ultimately can contribute to poorer health outcomes for the patient. This has been well examined in dementia patients. In a meta-analysis by Gaugler et al,<sup>45</sup> older adults who were dependent on their caregivers for 3 or more activities of daily living or who had cognitive impairment, were significantly more likely to require nursing home admission and suffer from potentially questionable quality of care and negative health consequences. Similarly, in caregivers of



**Table 3.** Signs of Caregiver Burden

Caregiver	Patient
<ul style="list-style-type: none"> <li>• Psychological distress (eg, depression/anxiety, guilt)<sup>10,46,58</sup></li> <li>• Decline in physical health<sup>31</sup></li> <li>• Sleep disturbances<sup>58</sup></li> <li>• Changes in lifestyle (inability to exercise, follow nutritious diet)<sup>58</sup></li> <li>• Social isolation<sup>7,10,58</sup></li> <li>• Missed hours at work or decreased productivity at work<sup>20</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Strain on interpersonal relationship with caregivers<sup>8</sup></li> <li>• Medication/treatment plan nonadherence<sup>26</sup></li> <li>• Psychological distress (eg, depression/anxiety)<sup>10</sup></li> </ul>

patients with chronic diseases following a relapsing and remitting course, such as type 1 diabetes mellitus, issues such as increased psychological distress and perceived burden can contribute to negative health outcomes for the patient.<sup>30</sup> For example, caregivers of diabetes patients with more depressive symptoms may feel overwhelmed by the caregiver role and may become uninvolved in critical parts of management (eg, glycemic monitoring, medication administration). Alternatively, a caregiver experiencing anxiety symptoms may be overly attentive (ie, hypervigilant) to diabetes care and may engage in constant monitoring.

Another important consideration is that a caregiver's ability to cope with and overcome the challenges associated with a chronic disease may influence a patient's adherence to prescribed treatment. Nonadherence can be particularly detrimental because it can set a patient on a downward spiral of progression of disease and ultimately irreversible complications of their disease. In a study by Bajaj et al,<sup>26</sup> evaluating caregiver burden in cirrhosis patients, the investigators found that financial insecurity was a contributor to patient nonadherence to therapy for hepatic encephalopathy. Financial stress is a significant contributor to the perception of burden in caregivers and an area that is addressed less commonly by clinicians.

Finally, a more abstract concept in determining how to handle caregiver burden is whether it is the ethical duty of a physician to ease the burden of a caregiver caring for a patient with a chronic illness. Traditionally, the approach to patient care has been one of patient-centeredness and, thus, in the strictest interpretation of this method, caregiver burden would fall outside the purview of the patient-physician relationship. However, in an article by Witt et al,<sup>46</sup> the investigators argued that expanding the focus of care to include caregivers ultimately benefits the patient and still fits within the medical ethos of providing patient-centered care. Caregivers are crucial to improving the health of a chronically ill patient, and a healthy caregiver who is equipped with adaptive coping strategies can better support a patient and enhance their health outcomes than a caregiver who

is burdened excessively by this task. Although physicians may not be equipped to provide in-depth psychosocial support to caregivers, they still can provide empathy by listening to and consoling caregivers and by referring them to trained professionals, such as psychologists or psychiatrists, who can provide additional care.

### *What Interventions Can Be Used to Address Caregiver Burden in Inflammatory Bowel Disease?*

Thus far, there have been no studies assessing outcomes of interventions aimed at addressing caregiver burden in the adult IBD population. There are specific interventions from dementia and cancer populations that can be used as models to develop caregiver interventions in IBD, but it is important to recognize that there are notable differences between these conditions and IBD. Specifically, the relapsing and remitting course of IBD is a unique quality for which any caregiver interventions must be tailored because the burden may be greatest during periods of disease exacerbation.

### *Goals of Interventions Addressing Caregiver Burden*

The goals of interventions for caregiver burden include those focused on the patient's outcomes (improved symptoms and functioning) and those focused on the caregiver's outcomes (improved mood and functioning). An enhanced ability to sustain the caregiving role can be considered a shared positive outcome. Caregiver interventions often aim to enhance skills to manage caregiving tasks more effectively.<sup>47</sup> For example, interventions for dementia caregivers have focused on the development of skills to more effectively manage challenging behavioral symptoms, whereas interventions for cancer caregivers often focus on enhancing knowledge and skills about the patient's treatment and recovery.<sup>48</sup> Additional factors to be considered regarding caregivers of adults with IBD may need to include consideration of the relapsing nature of the disease, changes in medication or medication monitoring, and issues related to social isolation in times of disease flare.

Caregiver interventions also may focus on helping caregivers cope more effectively with stressors and enhance protective factors or buffers against caregiving-related stress. For example, caregiver-focused interventions may aim to modify caregivers' unrealistic expectations of themselves, increase effective use of social support, or enhance problem-solving skills. Especially relevant to spousal caregivers, some interventions in cancer survivors have been designed to target both partners with the goal of enhancing relationship adjustment and the ability to engage in shared coping with the disease.<sup>49,50</sup>

### Modalities to Address Caregiver Burden

Research examining interventions for caregivers of Alzheimer disease patients has highlighted evidence for the benefits of different modalities of treatment including face-to-face interventions, and telephone or computer-based interventions. No one modality has been shown to be superior to another and thus it would be possible to use all of these approaches as an example to develop IBD-specific interventions to address caregiver burden. Table 4 summarizes some interventions used in other chronic diseases and suggests applications to IBD.

**Screening for caregiver burden.** The first step in treating caregiver burden is effective identification of the existence of this issue. In a case study by Bevans and Sternberg,<sup>51</sup> the investigators described the case of a patient with myelodysplastic syndrome undergoing hematopoietic stem cell transplant. In this case, the patient's sole caregiver was his wife and she was responsible for all medical and instrumental support. At clinic visits, the patient and his wife met with an interdisciplinary team including an oncology social worker to screen for any caregiving needs. This screening included assessment of the knowledge level of the caregiver related to role expectations, the patient care needs or degree of burden, and the presence of competing responsibilities. For IBD patients, screening of patients and their caregivers can be conducted at clinic visits at which disease progression has been noted or significant changes in the treatment plan have been suggested.

Although caregiver burden may be elicited from a clinical interview, standardized screening tools such as the brief 4-item version of the ZBI<sup>52</sup> also may help identify caregivers who may benefit from intervention.

**Face-to-face interventions.** The most successful in-person interventions are based on a combination of psychosocial training and educational sessions.<sup>53</sup> The goals of these interventions are to provide information about the disease, how to better organize care, practical advice for coping with the effects of the disease, skills training to deal with common issues that arise with the patient, decision-making skills, and recommendations for self-care.

**Telemedicine interventions.** Telephone or computer-based intervention systems represent an accessible, low-cost tool in which to address caregiver burden. For example, in a study by Tremont et al,<sup>54</sup> the investigators evaluated the efficacy of a telephone-based intervention system, Family Intervention: Telephone Tracking-Dementia, which was developed to enhance caregiver coping through active problem solving and facilitating positive changes within the family. They found that caregivers receiving Family Intervention: Telephone Tracking-Dementia showed significantly lower ZBI scores and had less severe reactions to memory and behavior problems than caregivers who did not receive this intervention.

**Interventions targeting improved well-being.** When a caregiver is involved heavily in the care of a chronically ill patient, it has been shown that they are prone

**Table 4.** Interventions to Reduce Caregiver Burden and Potential Application to IBD

Intervention type	Example	Potential application in IBD
Screening for caregiver burden	Oncology <sup>51</sup> Oncology social worker meeting with patient and caregiver during clinic visits to assess needs and screen for caregiver burden	Conduct screening with questionnaires such as ZBI or Brief COPE, particularly during visits with increased disease activity or change in treatment plan
Telemedicine	Family Intervention: Telephone Tracking-Dementia <sup>54</sup> Telephone-based intervention system Enhance caregiver coping through active problem solving and facilitating positive changes within the family	Telemedicine resources to provide coping skills training to caregivers Telemedicine appointments for patients to reduce the need for caregiver transportation to clinical visits
Face-to-face interventions	Cancer care <sup>53</sup> Combination of psychosocial training and educational sessions Provide information about the disease, how to better organize care, coping skills, skills training to deal with common issues that arise with the patient, advice about the emotional consequences associated with caring for the patient, and advice about self-care	In-person counseling for patients and caregivers about disease education and self-care In-person support groups connecting caregivers with each other
Therapies to improve caregiver well-being	Oncology <sup>49</sup> Use of a yoga program can help to ease patient symptoms and improve quality of life in patients and their caregivers	Implementation of complementary and alternative medicine strategies such as meditation or yoga in IBD for patient and caregiver well-being

to neglecting their own health and well-being.<sup>55</sup> Interventions that are targeted toward improving the well-being of patients and their caregivers have been shown to reduce overall caregiver burden. For example, in a study by Milbury et al,<sup>49</sup> high-grade glioma patients and their caregivers were enrolled in a 12-session yoga program that focused on breathing exercises, gentle movements, and guided meditations. At the end of the study, the investigators found clinically significant reductions in patient's sleep disturbance and also improvement in patient and caregiver mental quality of life. Such a strategy may translate to IBD, in which yoga therapy has been shown to contribute to improvement in symptom control of patients.<sup>56</sup> Implementing interventions targeting the well-being of both patients and their caregivers may help not only to ease caregiver burden, but also could help to improve patient outcomes. Moreover, targeting interventions at both the patient and their caregiver also may help to strengthen this relationship.

### *Practical Approaches in Addressing Caregiver Burden*

It is possible that many physicians caring for IBD patients may not always have ready access to social work and psychiatric services. However, there are many low-cost resources that exist for identifying and assisting caregivers of IBD patients. For example, the Crohn's and Colitis Foundation has web-based and in-person support groups for patients and their caregivers (<http://www.crohnscolitisfoundation.org/chapters/local-chapters-index-page.html?referrer=https://www.google.com/>). Other resources include the Family Caregiver Alliance ([www.caregiver.org](http://www.caregiver.org)) and the Caregiver Action Network ([www.caregiveraction.org](http://www.caregiveraction.org)), which are not specific to IBD but represent useful general resources for family caregivers.

Caregiver intervention does not necessarily need to be intensive to be effective. The most important step for providers is to be aware of the existence of significant caregiver distress and perceived burden in those caring for IBD patients. It is imperative to remain proactive in offering educational materials, problem-focused advice, and referrals (to psychologists/psychiatrists or social workers if necessary). Caregivers appear to benefit most when offered both information on managing the patient's condition and advice that will aid in their own coping.<sup>57</sup>

### *Important Considerations in Development of Caregiver Burden Interventions*

A recent systematic review<sup>47</sup> examined the impact of family and caregiver interventions on patient outcomes among adults with cancer or memory-related disorders. Despite evidence that family based interventions are not

superior to usual care, patient-focused interventions, or interventions that only involve education, there was evidence to suggest that family interventions developed for a subset of patients (eg, cancer patients with late-stage cancer, couples in newer relationships, hospice patients), or for a specific symptom (eg, sleep hygiene, incontinence), are more effective at improving psychological symptoms for both patient populations. In the case of IBD patients, it could be more effective to target families of sicker patients, such as those who are experiencing disease progression or perhaps exhausting medical therapy and heading toward surgical interventions.

In the same review, the investigators also highlighted important distinctions between the roles of the caregiver for cancer patients vs those with a memory-based disorder, given the varying disease course for these 2 conditions. For example, family based interventions for cancer focus on reducing psychological symptoms (eg, distress, depression, and anxiety), improving relationship quality, and managing symptoms, whereas family roles for patients with a memory disorder focus more on improving and/or maintaining quality of life and managing problem behaviors among care recipients.

When designing a tool to reduce caregiver burden in the adult IBD population, it would be important to address the unique relapsing and remitting course of this disease and ensure that interventions are available during times of increased disease activity when caregiver distress may be highest. Physicians must take the initiative to screen caregivers, with some of the aforementioned tools, at times of increased disease activity and provide access to IBD-specific caregiver burden interventions. For example, this could include support groups that connects IBD caregivers, a tool that could be used easily in times of greatest need.

## **Conclusions**

Caregiver burden is a significant issue in caregivers for patients with chronic disease. Feelings of excessive burden and distress can lead to negative consequences such as increased rates of depression and anxiety. The chronic relapsing and remitting course of IBD puts caregivers of IBD patients at particular risk for burden; therefore, it is important to be able to assess and address caregiver burden for IBD patients. The development and validation of IBD-specific caregiver burden measurement tools is a necessary next step. There are robust data for the assessment and management of caregiver burden in cancer and dementia care; however, the relapsing nature and younger age of the IBD population compared with the cancer and dementia populations may require different means of assessment and treatment. Finally, further research would be needed to validate these tools to incorporate this into the routine clinical care of IBD patients.

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