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Effects of caregiver burden on quality of life and coping strategies utilized by caregivers of adult patients with inflammatory bowel disease

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Abstract

Background While previous studies have evaluated caregivers' quality of life (QOL), burnout, and stress amongst across a variety of chronic illnesses, few such studies have been related to inflammatory bowel disease (IBD).

Methods Caregivers accompanying adult patients with IBD at 6 tertiary centers were enrolled. They completed self-administered surveys related to QOL and burden, including the QOL scale, Zarit Burden Interview (ZBI), and Brief COPE.

Results Of the 200 consecutive caregivers asked to participate, 162 (81.0%) enrolled and completed the survey. A total of 43.8% caregivers reported having a high level of burden as measured by the ZBI. Factors predictive of a high burden included female gender, younger age of caregiver, household income <$30,000, having more than one dependent in the household, caring for a patient with active disease and higher disease severity, and a personal history of psychiatric illness. Over one third of the caregivers reported a maladaptive coping pattern. The caregiver factors predictive of maladaptive coping skills included male gender, lack of involvement in a support group, a personal history of psychiatric illness, and living in a different household from the patient.

Conclusions A large proportion of caregivers of IBD patients experience a high level of caregiver burden and reduced QOL. Participation in religious/spiritual activities and support groups appeared to reduce perceived caregiver burden and improve QOL. This study suggests there is an unmet need to address the caregiver burden of adult IBD patients.

Keywords Caregiver burden, quality of life, inflammatory bowel disease

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Introduction

Inflammatory bowel disease (IBD), including Crohn's disease (CD) and ulcerative colitis (UC), is a chronic inflammatory disorder of the intestines that follows a remitting and relapsing clinical course. The annual incidence in Northern Europe and the United States is estimated to be from 2 to 11 per 100,000 for UC and 1 to 6 per 100,000 for CD [1,2]. A diagnosis of chronic illness such as IBD can be devastating, and often results in feelings of hostility, despair, and grief [3]. These psychological effects extend beyond the initial diagnosis and may lead to long-term psychological impairments that shape the daily life of an individual with IBD. It is well established that several psychosocial issues impact the quality of life (QOL) of IBD patients, including loss of energy, loss of control, poor body image, feelings of isolation or fear, feeling a burden, and inability to reach full personal capacity [4,5].

Chronic illnesses not only affect the individual patient, but also have a significant impact on the family unit [6-8]. A chronic illness, such as IBD, can completely disrupt a family's ability to function normally and often imposes a strain on family members' relationships [6]. During times of flare-up, family members and friends often become caregivers for

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the adult IBD patients. Given that IBD is currently a lifelong disease, caregivers face the challenge of learning to adapt to this disease throughout their lifespan. It has been shown that long-term chronic illnesses create an even greater burden on the family in comparison to acute illnesses [9]. Caregivers of patients with chronic physical illnesses often experience feelings of isolation and fatigue related to their increased responsibilities and challenges [8].

There has been significant research evaluating the caregiver's QOL, stress, and burnout, in relation to other chronic physical and mental health illnesses that show similarly deleterious effects [7,8]. Caregivers' well-being is an area of interest because of its potential impact on patients' long-term outcomes [10,11]. Although some studies have examined the relationship between family functioning and parental stress among caregivers of pediatric IBD patients [12-14], there is limited knowledge concerning the QOL of caregivers, the level of burden, and coping mechanisms among caregivers of adult patients with IBD. An improved understanding of these factors would allow healthcare providers to better serve this population and to provide adequate psychosocial interventions to assist these patients and their caregivers. Accordingly, this study aimed to assess caregiver burden as it relates to QOL and coping among caregivers of adult patients with IBD.

Materials and methods

Subject recruitment and data collection

The primary caregivers identified by adult IBD patients (age ≥ 18 years) who were present at an outpatient encounter at six tertiary institutions between December 2010 and June 2011 were asked to participate. Caregivers were asked to complete an anonymous self-administered survey comprising 4 separate questionnaires:

1) General demographic information: participants were asked to complete personal demographic data, such as age, relationship to patient, gender, ethnicity, and total household income.
2) QOL index: a 33-question survey developed by Ferrans and Powers to measure QOL [15]. It evaluates four different domains: health and functioning, social and economic, psychological/spiritual, and family. The overall QOL score ranges from 0 to 30, with 30 being the best.
3) Zarit Burden Interview (ZBI): a 22-question survey, each rated 0-9 (9-highest level of burden), measuring the physical, emotional, and financial toll of providing care [16]. A score ≥21 has been defined in the ZBI as representing a high level of caregiver burden [11,16].
4) Brief COPE: a 28-question survey evaluating 14 separate coping mechanisms (Table 1). Participants were asked to rate their responses on a scale from 1-4 (1=I haven't been doing this at all, to 4=I have been doing this a lot). The total composite score for adaptive versus maladaptive coping was calculated for each participant and divided by the total components in the maladaptive and adaptive subscales [17,18].

Table 1 Brief COPE questionnaire assessing 14 different coping skills

Adaptive coping skills
1) Adaptive coping: I've been concentrating my efforts on doing something about the situation I am in
2) Planning: I've been thinking hard about what steps to take
3) Use of emotional support: I've been getting emotional support from others
4) Use of instrumental support: I've been getting help from other people
5) Positive reframing: I've been trying to see it in a different light and make it seem more positive
6) Acceptance: I've been accepting the reality of the fact that it has happened
7) Religion: I've been trying to find comfort in my religion or spiritual beliefs
8) Humor: I've been making jokes about it
Maladaptive coping skills
1) Venting: I've been expressing my negative feelings
2) Denial: I've been saying to myself this isn't real
3) Substance abuse: I've been using alcohol or other drugs to help me get through
4) Behavioral disengagement: I've been giving up trying to deal with it
5) Self-distraction: I've been turning to work or other activities to take my mind off of things
6) Self-blame: I've been blaming myself for things that happened

After the surveys were completed, information was collected onto a single spreadsheet at the lead site with double entry. All participant information was de-identified. The protocol was approved by the Institutional Review Board at each of the participating institutions.

Statistical analysis

Mean scores on the QOL index and ZBI were compared between subgroups identified according to the participants' characteristics, using t-tests and analysis of variance. A multivariate analysis was performed to identify characteristics that predicted those who were likely to utilize a predominantly adaptive coping strategy. In the final model, a P-value <0.05 was considered statistically significant.

Results

General demographics

Of the 200 consecutive caregivers asked to participate, 162 (81.0%) consented and completed the survey. The overall characteristics of the IBD caregivers are summarized in Table 2. The mean age was 49.6±14.6 years old with a female predominance (66.9%). A majority of the participants (54.3%) had a minimum educational level of high school graduation, with nearly one third (29.7%) having a college or graduate degree. A total of 66.0% of caregivers were working outside of the home on either a full-time or part-time basis. Only a minority of the caregivers (3.2%) reported having to stop working because of caregiving to the patients. Over half (55.6%) of the caregivers reported being either the patient's spouse or significant other, 22.5% reported being a parent, and 16.9% reported being a child. Approximately one third (31.1%) stated that in addition to the patient, they also had at least 1 dependent living at home. Over half reported a total annual household income of greater then $100,000. The caregivers reported that 58.0% of their patients had CD, while the reminder had either UC (36.3%) or indeterminate colitis (5.7%).

QOL among IBD caregivers

In this cohort, the mean QOL score was 19.89±12.15. Participants with a QOL index of less than the mean of 19.89 were identified as having a lower QOL. In this cohort, factors associated with a lower QOL among IBD caregivers included (Table 3): presence of a dependent (other than the patient) in the household, caring for patients with active IBD exacerbation and higher disease severity, and a personal history of psychiatric illness. In contrast, factors not predictive of a lower QOL among caregivers were gender, ethnicity, age, household income, patient's IBD subtype, relationship to patient, and patient's involvement in a support group. Interestingly, the two factors predictive of a better QOL for caregivers were participation in religious or spiritual activities and attendance at a support group.

Factors predictive of high caregiver burden

The mean score on the ZBI in our cohort was 19.9±11.07. A total of 71 of the 162 (43.8%) caregivers reported having a high level of burden, as measured by a ZBI score of ≥21 [11,16]. Table 4 summarizes the factors predictive of a high burden among caregivers of IBD patients. Factors predictive of a higher degree of caregiver burden included female gender, younger age, annual income level <$30,000, having more than one dependent in the household (other than the patient), caring for a patient with active disease exacerbation or more severe disease, and a personal history of psychiatric illness. Participation in religious activities (ZBI 17.94±11.33 vs. 22.13±14.05; P=0.41) and attendance at a support group (18.29±12.37 vs. 23.67±13.06; P=0.035) were predictive of reduced level of burden. Duration served as caregiver, ethnicity, relationship to patient, and living in the same household as the patient were not predictive of a high level of burden.

Table 2 General demographics of primary caregivers of adult patients with inflammatory bowel disease

Mean age (years)	49.6±14.6 (%)
Gender	
Male	53 (33.1)
Female	107 (66.9)
Ethnicity	
Caucasian/white	127 (79.4)
Asian/Pacific islander	10 (6.3)
Hispanic/Latino	9 (5.6)
Other	14 (8.7)
Current marital status	
Married	142 (87.7)
Cohabitation (not married)	4 (2.5)
Single (never married)	10 (6.2)
Separated/divorced	6 (3.7)
Highest level of education	
Middle school	26 (16.0)
High school	88 (54.3)
College degree	40 (24.7)
Graduate degree	8 (5.0)
Current employment status	
Employed full-time	76 (46.9)
Employed part-time	31 (19.1)
Retired	22 (13.6)
Stopped working because of caregiving	5 (3.2)
Other	28 (17.2)
Relationship to IBD patient	
Spouse	81 (50.6)
Significant other (not married)	8 (5.0)
Parent	36 (22.5)
Child	27 (16.9)
Sibling	2 (1.3)
Friend	2 (1.3)
Other	4 (2.4)
Total annual household income	
Less than 10,000	5 (3.2)
$10,000-30,000	16 (10.2)
$40,000-60,000	24 (15.3)
$70,000-90,000	31 (19.7)
Greater than $100,000	81 (51.6)
More than 1 dependent living at home	50 (31.1)
Personal history of psychiatric illness	32 (19.7)
Type of IBD loved one has	
Ulcerative colitis	57 (36.3)
Crohn's disease	91 (58.0)
Indeterminate colitis	9 (5.7)

IBD, inflammatory bowel disease

Table 3 Factors associated with lower quality of life among caregivers of inflammatory bowel disease (IBD) patients (N=162)

Factors	Quality-of-life scale	P-value
Gender		0.138
Male	18.22±11.58	
Female	21.57±14.05	
Ethnicity		0.659
Caucasian	20.29±13.10	
Non-Caucasian	21.44±14.14	
Age		0.674
≤50 years old	20.78±12.90	
>50 years old	19.89±13.80	
Income		0.047
Less than $30,000	19.65±14.24	
$40,000-60,000	19.68±12.77	
$70,000-90,000	19.67±12.90	
Greater than $100,000	22.94±12.67	
Dependents at home		0.013
None	24.01±13.37	
More than 1 dependent	18.48±12.62	
Involvement in religious/ spiritual activity		0.041
Yes	22.13±14.35	
No	17.94±11.33	
Subtype of IBD		0.716
Ulcerative colitis	20.19±10.62	
Crohn's disease	20.99±14.11	
Disease activity at time of survey		0.001
Active flaring	18.94±12.98	
In remission	21.16±13.13	
Disease severity		0.001
Mild	25.59±15.39	
Moderate	21.87±13.62	
Severe	14.73±9.34	
Years caring for IBD patient		0.981
≤5 years	21.03±14.80	
>5 years	20.98±12.11	
Relationship with patient		0.658
Spouse	20.64±13.44	
Parent	21.38±14.08	
Child	21.38±13.35	
Other	16.53±10.31	
Ever diagnosed with psychiatric illness		0.024
Yes	23.84±15.43	
No	19.50±12.43	
IBD patient attends support group		0.624
Yes	21.84±13.05	
No	20.32±13.37	
Personally attends support group		0.035
Yes	23.67±13.06	
No	18.29±12.37	

(*Contd...*)

Table 3 *Continued....*

Coping patterns of IBD caregivers

In our cohort, 105 of 162 caregivers (64.8%) used predominantly adaptive coping patterns while the remaining 57 (35.2%) employed maladaptive coping patterns. The caregiver factors predictive of maladaptive coping skills included male gender (OR 3.89, 95% CI 2.49-6.07), lack of involvement in religious activity (OR 2.38, 95% CI 1.23-4.61) or attendance at a support group (OR 3.88, 95% CI 1.84-17.87), a personal history of psychiatric illness (OR 2.76, 95% CI 1.25-6.05), and living in a different household from the patient (OR 95%, CI 3.56 1.74-7.27). Caregiver characteristics of ethnicity, education level, total household income, age, years caring for the patient, and relationship to patient were not predictive of the coping patterns adopted by the caregivers (data not shown).

Discussion

The presence of IBD in the home can have a long-term impact on family members and may affect their overall QOL. Recent studies suggest that household members of IBD patients have mental disorders more frequently compared with the general population [19-22]. In contrast to previous studies that examined the impact of IBD on parents of children and adolescents [13,21], our study is one of the first large-scale, multi-institutional studies to evaluate the impact of an adult IBD patient on the family unit from a caregiver's perspective. In our study, the factors associated with a lower QOL among IBD caregivers included the presence of a dependent (other than the patient) in the household, caring for patients with active IBD exacerbation, higher baseline disease severity, and a personal history of psychiatric illness. This is similar to previous findings for caregivers of patients with other chronic illnesses [6,7,9]. Our findings suggest an increased level of support is needed during times of disease exacerbation and, more generally, when the patient has a higher degree of disease severity. A better knowledge of the factors that impact

Table 4 Factors predictive of a high level of burden among caregivers of inflammatory bowel disease (IBD) patients (N=162)

	Zarit burden score
Gender	
Male	18.22±11.58
Female	21.57±14.05
Ethnicity	
Caucasian	20.29±13.10
Non-Caucasian	20.44±14.14
Age	
≤50 years old	21.78±12.90
>50 years old	19.89±13.80
Income	
Less than $30,000	22.94±12.67
$40,000-60,000	19.65±14.24
$70,000-90,000	19.68±12.77
Greater than $100,000	19.67±12.90
Dependents at home	
None	24.01±13.37
More than 1 dependent	18.48±12.62
Involvement in religious/spiritual activity	
Yes	17.94±11.33
No	22.13±14.35
Subtype of IBD	
Ulcerative colitis	20.19±10.62
Crohn's disease	20.99±14.11
Disease activity	
Active flaring	21.16±13.13
In remission	18.94±12.98
Disease severity	
Mild	14.73±9.34
Moderate	21.87±13.62
Severe	25.59±15.39
Years caring for IBD patient	
≤5 years	20.03±14.80
>5 years	20.98±12.11
Relationship with patient	
Spouse	20.64±13.44
Parent	20.28±14.08
Child	20.38±13.35
Other	18.53±10.31
Ever diagnosed with psychiatric illness	
Yes	23.84±15.43
No	19.50±12.43
IBD patient attends support group	
Yes	20.32±13.37
No	21.84±13.05
Personally attends support group	
Yes	18.29±12.37
No	23.67±13.06

negatively on the QOL in this population can guide clinical interventions by targeting caregivers with these higher risk characteristics. Herzer *et al* suggested that the caregivers and the patient make a joint contribution to both the patient's and the caregivers' QOL [22]. This highlights the need for family-based interventions that target both patients and their caregivers through a multidisciplinary approach that involves social workers, psychiatrists, nurse navigators, and primary care providers.

Previous studies have uniformly demonstrated that caregivers of patients with chronic disease are placed under significant financial, psychological, and physical strain [23-26]. A higher burden has also been linked to increased mortality among caregivers [23]. Though it is difficult to compare across studies, the caregivers in our cohort demonstrated a similar or perhaps even greater level of burden to that reported among caregivers of patients with acute brain injury (ZBI 21.7±10.1), Alzheimer's disease (ZBI 15.0±10.0), and advanced cancers (12.0±8.5) [27]. Our study supports previous findings that the level of burden for caregivers was inversely related to the level of social support they received [11,28,29]. Though not directly measured in this study, previous studies have demonstrated that a patient's adherence to medical therapy depends heavily on the ability of the family unit to absorb the challenges [30,31]. Interestingly, we clearly demonstrated that participation in spiritual activities and social support groups may help reduce the level of burden for the caregiver. This underscores the fact that, as IBD practitioners, we should encourage caregivers to attend these group-based activities, which we have demonstrated in our previous study to be an effective outlet for patients and their caregivers [32].

Over one third of the caregivers in our cohort employed maladaptive coping patterns. The factors predictive of impaired coping skills included male gender, lack of involvement in spiritual activity or a support group, a personal history of psychiatric illness, and living in a different household from the patient. These characteristics could help identify caregivers who might require a greater psychological level of support. The utilization of maladaptive coping patterns has been linked to impaired social functioning and poor psychological well-being [18,33]. It is important for healthcare providers to identify patients or caregivers with maladaptive patterns, as there could be untreated depression. In our study, approximately 20% of caregivers reported having a personal history of mood disorder, whereas over 30% of caregivers were utilizing maladaptive coping patterns. Given that some maladaptive coping strategies (i.e., self-blame) may overlap with depressive symptoms, it suggests that we may miss approximately one third of caregivers who may have concomitant undiagnosed depression. In addition, as healthcare providers we need to help caregivers identify which coping strategies they naturally use, which strategies are effective and which ones are futile. This has been shown to facilitate maximally effective coping, even among caregivers who normally cope ineffectively [18]. Future studies will be needed to identify whether the caregiver's coping mechanisms also parallel those of the patient, and whether maladaptive mechanisms predict poorer long-term patient outcomes.

This study had several limitations. First, it had a cross-sectional design that allowed for the assessment of coping skills only at one single point in time. To fully study coping patterns as a process will require a longitudinal study, as patterns of QOL, burden, and coping are likely to fluctuate with the patient's disease activity. Second, given that this was a survey-based study, there is likely to have been a recall bias, while the self-reporting aspect may have selected a subset of caregivers with a higher level of burden. Third, the terms utilized in our study, such as disease exacerbation, may not have been sufficiently specific. Exacerbation might include anything from increasing abdominal bloating to symptoms severe enough to require hospitalization. Therefore, various aspects of our comprehensive survey leave significant room for personal interpretation.

In conclusion, a large proportion of caregivers of IBD patients experience a high level of caregiver burden and a reduced QOL. The caregiver's QOL was most reduced when the patient had a higher level of disease severity or when their disease was actively flaring. The highest level of burden was associated with female caregivers, those of younger age or lower income level, having additional dependents in the household, patients with higher disease severity, and a personal history of psychiatric illness. Participation in religious activities and attendance at a support group appeared to improve QOL and reduce the perceived caregiver burden. This study suggests the importance of a multidisciplinary approach involving psychologists, social workers, and medical professionals to help caregivers absorb these daily life challenges and overcome their burden.

Summary Box

What is already known:

- Chronic illness affects not only the patient but the entire family unit
- A high level of caregiver burden may result in poorer healthcare outcomes for the patient
- Household members of inflammatory bowel disease (IBD) patients have mental disorders more frequently compared with the general population

What the new findings are:

- Caregivers need an increased level of support during times of IBD exacerbation and when the patient has a higher level of disease severity
- Caregiver characteristics strongly predictive of the use of maladaptive coping mechanisms included male gender, lack of participation in spiritual activity or a support group, a personal history of psychiatric illness, and living in a different household from the patient
- Observance of religious activities and attendance at a support group appeared to improve quality of life and reduce perceived caregiver burden

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