Depressive symptoms among caregivers of colorectal cancer patients during the first year since diagnosis: a longitudinal investigation

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Abstract
Objective: Few studies have examined prospectively and longitudinally depressive symptoms of family caregivers who provide care to colorectal cancer patients, and fewer have addressed ethnic minorities in this regard. This study investigated the relations of social support and caregiving stress with caregivers’ depressive symptoms during the first year since the relative’s diagnosis, as well as the role of ethnicity in such relations.

Methods: Seventy-nine caregivers provided complete data at 2 months (T1), 6 months (T2), and 12 months (T3) after their relative’s cancer diagnosis. Demographics and caregiving experiences were measured at T1. Depressive symptoms were assessed at T1 through T3.

Results: Greater caregiving stress and lack of social support were significant predictors of greater depressive symptoms. The adverse effect of caregiving stress was more pronounced among African American caregivers, whereas the beneficial effect of social support was more pronounced among White caregivers.

Conclusions: The findings highlight the importance of both caregiving stress and lack of social support early in caregiving. Findings also suggest that caregivers may benefit from programs tailored for their ethnicity.

Keywords: cancer caregivers; depressive symptoms; ethnicity; caregiving stress; social support

Introduction
Psychological sequelae of diagnosis and treatment among cancer patients have been studied extensively [1]. However, comparable information for family caregivers during the first year after the diagnosis—a volatile period for caregivers as well as patients—remains sparse. Those studies that do exist have indicated that the levels of psychological distress among family caregivers are equal to, or even greater than, those of the patients [2]. These findings imply that the impact of cancer on the family is substantial. Furthermore, identification and management of adverse reactions among family caregivers is an important concern not only because of the direct effect on the caregivers’ well-being [3], but also because it may diminish the quality and quantity of the health care they provide to the patient during that critical period [4].

Existing studies, however, are primarily cross-sectional [5–7], mostly focused on breast cancer with an exception [8], and done largely among non-Hispanic Whites (hereinafter referred to as Whites). Thus, the generalizability of existing knowledge to caregivers besides those for breast cancer patients or non-Whites and the likelihood of replicating the findings at other time points in the illness trajectory are both questionable.

The study reported here intended to go beyond these limitations in three ways. First, we targeted caregivers of colorectal cancer patients. This is the third most common cancer diagnosis and cause of cancer deaths for both men and women, yet its impact on family caregivers is understudied. Second, we prospectively and longitudinally investigated the impact of psychosocial factors on depressive symptoms at 2, 6, and 12 months after the cancer diagnosis of the relative. These time points were chosen because psychological adjustment among caregivers is most challenging during the first year post-diagnosis [9].

Third, we explored the possibility that there were ethnic/cultural differences in the impact of various aspects of the caregiver experience. To do so, we examined a sample that was evenly divided between African Americans and Whites. Both the incidence of and the mortality from colorectal cancer are higher among African Americans than among Whites [10]. Thus, the burden of caregiving for this type of cancer is very significant among African Americans.

There is some evidence that when dealing with major stressors such as cancer, African Americans report greater need for social support than Whites, independent of education level, marital status, age, and treatment status [11]. This suggests that the well-documented
benefits of social support (e.g. Refs. 12,13) may play a more significant role in psychological adjustment among African Americans than other ethnic groups. Another possible role of ethnicity in caregivers’ adjustment is that the experience of caregiving stress may have a greater impact on members of one ethnic group (more likely to be ethnic minority group) than those of the other by exacerbating the adverse effect of caregiving stress.

In sum, the current study had three aims: (a) to document depressive symptoms among family caregivers of colorectal cancer patients across the first year since the patient’s diagnosis; (b) to investigate the effects of caregiving stress, social support, and ethnicity (African Americans versus Whites) on depressive symptoms during that time; and (c) to examine the possibility that caregiving stress and social support played different roles in depressive symptoms during that time as a function of ethnicity.

Methods

Participants

Participants were either family members or close friends of a person diagnosed with colon or rectal cancer within the past 2 months prior to participating in the study (T1) and who was being treated at one of five hospitals in Atlanta, Georgia. Eligibility criteria for patients were being 18 years or older, being able to read and speak English, and residing within 50 miles of the study hospital. Patients were asked to identify family members or close friends from whom they were expecting to receive consistent help with their experience with cancer. Eligibility criteria for caregivers were being 18 years or older and able to read and speak English.

A total of 156 caregivers were enrolled and provided valid information for the study at T1. Of those, 94 provided complete data at T1 and at T2 (6 months post-diagnosis). No significant differences were found between caregivers who participated in both assessments and those who did not (p values >0.17), with one exception of a marginal difference in age: caregivers who participated in both assessments tended to be older than those who did not (t=1.76, p=0.081). Seventy-nine caregivers provided complete data for all three time points. By comparing caregivers who participated in all three assessments with those who participated only at T1 and T2, no significant differences in any study variables were found (p values >0.20). Finally, caregivers who provided complete data at T1 through T3 (12 months post-diagnosis) did not differ from caregivers who provided incomplete data in study variables at any assessment point (p values >0.25), with the exception that White caregivers were less likely to provide complete data than African Americans (χ² = 5.98, p = 0.018).

Procedure

This study was conducted in compliance with the Institutional Review Board of each of the five hospitals. Eligible participants were generally recruited at the clinic. In other cases, the participants were contacted by the project manager by letter or telephone to introduce the study and to invite them to participate. Returned signed consent forms and completed surveys documented informed consent to participate. The caregivers’ time spent completing the survey at each time point was reimbursed with a $20.00 gift card.

Measures

Demographic characteristics

Caregivers’ self-reported age, gender, ethnicity, household income, and relationship to the care recipient were measured at 2 months post-diagnosis (T1).

Caregiving stress

The extent to which caregivers felt overwhelmed by care tasks and responsibilities at 2 months post-diagnosis was measured by the four-item stress overload subscale of the Pearlin Stress Scale (e.g. ‘I work hard as a caregiver but never seem to make any progress’). Each item was rated for extent of agreement on a four-point Likert-type scale [responses ranging from ‘not at all’ (1) to ‘completely’ (4)] [14]. Items were averaged, with higher scores reflecting a greater perceived level of caregiving stress. The subscale had good internal consistency (α=0.89). The frequency of providing cancer care was also measured using a 17-item Caregiving Task Scale [15] on a four-point Likert-style format (1, monthly; 2, weekly; 3, 2 to 3 days a week; and 4, daily). The average frequency score (α=0.83) served as a covariate.

Social support

The perceived availability of social support at 2 months post-diagnosis (T1)—that is, the extent to which the caregivers perceived that emotional (e.g. ‘When I feel lonely, there are several people I can talk to’), informational (e.g. ‘When I need suggestions on how to deal with a personal problem, I have someone I can turn to’), and tangible support (e.g. ‘If I were sick, I could easily find someone to help me with my daily chores’) were available to them—was measured using the six-item version of the Interpersonal Support Evaluation List [16]. A four-point scale was used [responses ranging from ‘definitely false’ (1) to ‘definitely true’ (4)], and items were averaged. This scale had good internal consistency (α=0.78).

Depressive symptoms

The level of depressive symptoms experienced in the past 4 weeks was measured at 2 months (T1), 6 months (T2), and 12 months (T3) post-diagnosis using the 20-item Center for Epidemiologic Studies Depression Index (CES-D) [17]. Item responses were summed, and a CES-D score of 16 or above was a common criterion for clinically meaningful depression. The
items had good internal consistency (0.69 < \alpha < 0.95 at T1 through T3).

Data analysis plan

Descriptive statistics (mean, standard deviation, and range of study variables, and prevalence of caregivers whose scores meet the clinical level of depression) were computed across assessment points, and the two ethnic groups were compared on these variables. General linear modeling was employed to test the main effects of caregiving stress, social support, and ethnicity, as well as their interaction effects, on depression scores repeatedly measured across the three time points.

Results

Descriptive statistics

Demographic information, separated by the two ethnic groups, is presented in Table 1. Participating caregivers were middle aged, more often female than male, evenly divided between African Americans and Whites, and had middle to higher household income. Approximately one-third were spouses of the patient, 27.6% were adult offspring, 6.5% parents, 3.2% siblings, and 17% close friends. The care recipients were diagnosed primarily with localized or regional colon cancer. African American caregivers were more likely than White caregivers to be female, but there were no other significant ethnic differences in caregivers’ demographics or patients’ medical characteristics studied. As shown in Table 1, perceived caregiving stress was relatively low; perceived social support availability was relatively high; and the two ethnic groups were comparable on both of these variables.

Overall, the levels of depressive symptoms were relatively low across all three assessment points, and mean change in symptoms levels across time was not significant (p values >0.12). Overall, 3.8% of caregivers at T1, 10.1% at T2, and 5.1% at T3 reported clinically meaningful levels of depressive symptoms. At T1, all three cases were African American; nonetheless, the prevalence of clinical levels of symptoms did not differ significantly by ethnicity at any time point (T1 p = 0.074, other p values >0.32).

Predictors of depressive symptoms across three assessments during the first year

Hierarchical general linear modeling with repeated measures was used to relate depressive symptoms to predictor variables, in three steps (see Table 2). All predictors were measured at T1 only and depressive symptoms were measured at all three time points that were tested in the same analysis. Table 2 displays the results of each step as it was entered.

No demographic characteristics or care task frequency (step 1) was related systematically to depressive symptoms, with the exception that lower household income was related to higher depressive symptoms at T2. Ethnicity, caregiving stress, and social support were entered in step 2, and their interactions with repeated assessment were entered in step 3. Ethnicity was not related to depressive symptoms at any

Table 1. Sample characteristics and ethnic group differences on caregiving stress, social support, and depressive symptoms

<table>
<thead>
<tr>
<th></th>
<th>Overall (n = 79)</th>
<th>African Americans (n = 39)</th>
<th>Whites (n = 40)</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregivers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (SD)</td>
<td>54.7 (12.8)</td>
<td>55.1 (13.8)</td>
<td>54.3 (11.9)</td>
<td>-0.29</td>
</tr>
<tr>
<td>Gender (female), %</td>
<td>77.2</td>
<td>87.2</td>
<td>67.5</td>
<td>4.35</td>
</tr>
<tr>
<td>Ethnicity (African American), %</td>
<td>49.4</td>
<td>—</td>
<td>—</td>
<td></td>
</tr>
<tr>
<td>Household income (≥$40,000), %</td>
<td>57.0</td>
<td>46.2</td>
<td>67.5</td>
<td>3.69</td>
</tr>
<tr>
<td>Spouse of patient</td>
<td>36.7</td>
<td>30.8</td>
<td>42.5</td>
<td>1.17</td>
</tr>
<tr>
<td>Patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of cancer</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colon, %</td>
<td>73.0</td>
<td>81.6</td>
<td>63.9</td>
<td>3.45</td>
</tr>
<tr>
<td>Rectal, %</td>
<td>25.7</td>
<td>18.4</td>
<td>33.3</td>
<td></td>
</tr>
<tr>
<td>Both, %</td>
<td>1.4</td>
<td>0.0</td>
<td>2.8</td>
<td></td>
</tr>
<tr>
<td>Stage of cancer</td>
<td></td>
<td></td>
<td></td>
<td>0.79</td>
</tr>
<tr>
<td>Localized, %</td>
<td>50.0</td>
<td>50.0</td>
<td>50.0</td>
<td></td>
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<tr>
<td>Regional, %</td>
<td>42.1</td>
<td>39.5</td>
<td>44.7</td>
<td></td>
</tr>
<tr>
<td>Distant, %</td>
<td>7.9</td>
<td>10.5</td>
<td>5.3</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Scale range</th>
<th>Overall Mean (SD)</th>
<th>African Americans Mean (SD)</th>
<th>Whites Mean (SD)</th>
<th>t</th>
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</thead>
<tbody>
<tr>
<td>Care task at T1</td>
<td>1–4</td>
<td>2.17 (0.78)</td>
<td>2.24 (0.89)</td>
<td>2.11 (0.66)</td>
</tr>
<tr>
<td>Caregiving stress at T1</td>
<td>1–4</td>
<td>1.54 (0.72)</td>
<td>1.47 (0.74)</td>
<td>1.61 (0.71)</td>
</tr>
<tr>
<td>Social support at T1</td>
<td>1–4</td>
<td>3.37 (0.62)</td>
<td>3.46 (0.55)</td>
<td>3.28 (0.68)</td>
</tr>
<tr>
<td>CES-D at T1</td>
<td>0–60</td>
<td>8.01 (4.80)</td>
<td>8.03 (6.04)</td>
<td>8.00 (3.24)</td>
</tr>
<tr>
<td>CES-D at T2</td>
<td>0–60</td>
<td>8.65 (5.95)</td>
<td>8.21 (6.41)</td>
<td>9.07 (5.51)</td>
</tr>
<tr>
<td>CES-D at T3</td>
<td>0–60</td>
<td>8.03 (5.05)</td>
<td>7.08 (4.11)</td>
<td>8.95 (5.72)</td>
</tr>
</tbody>
</table>

* p < 0.10.

T1, initial survey at 2 months post-diagnosis; T2, follow-up assessment at 6 months post-diagnosis; T3, follow-up assessment at 12 months post-diagnosis; CES-D measure of depressive symptoms.
assessment point. In contrast, greater caregiving stress and lower perceived social support at T1 were both significant predictors of greater depressive symptoms at almost all assessment points. There was also an interaction between stress and assessment time points (p = 0.002), with the predictive role of T1 stress diminishing at T3.

Among the two-way interaction effects, the effect between ethnicity and caregiving stress was significant. As shown in Figure 1, at T1, greater caregiving stress was related to higher depressive symptoms among African Americans (B = 5.52, SE = 0.93, t = 5.93, p < 0.001), but not among Whites (B = 1.10, SE = 0.83, t = 1.33, p = 0.19). A similar interaction was observed at T2: greater caregiving stress was related to higher depressive symptoms among African Americans (B = 4.88, SE = 1.14, t = 4.28, p < 0.001) but not among Whites (B = 1.80, SE = 1.12, t = 1.77, p = 0.086).

Another significant two-way interaction at T2 was between caregiving stress and social support. The positive relation between caregiving stress and depressive symptoms was more pronounced among caregivers who perceived less social support (slope = 0.83, p < 0.01) than among those who perceived more social support (slope = 0.63, p < 0.05).

At 12 months post-diagnosis (T3), the two-way interaction effect between ethnicity and social support was significant. As shown in Figure 2, lower social support was associated with greater depressive symptoms among Whites (B = -3.52, SE = 1.33, t = -2.65, p < 0.02) but not among African Americans (B = -0.42, SE = 1.37, t = -0.31, p = 0.76). The three-way interaction was not significant (data not shown).

## Discussion

Greater caregiving stress and lack of social support were significant predictors of depressive symptoms of cancer caregivers during the first year since the diagnosis. Indeed, there was a synergy, such that the adverse impact of caregiving stress was exaggerated among

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### Table 2. Hierarchical general linear modeling analysis predicting depressive symptoms at three assessment points

<table>
<thead>
<tr>
<th>Step</th>
<th>2 months</th>
<th>6 months</th>
<th>12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>SE</td>
<td>t</td>
</tr>
<tr>
<td>Step 1: Covariates</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.07</td>
<td>0.05</td>
<td>-1.34</td>
</tr>
<tr>
<td>Gender (female)</td>
<td>1.18</td>
<td>1.47</td>
<td>-0.80</td>
</tr>
<tr>
<td>Income (≥$40,000)</td>
<td>-1.08</td>
<td>1.38</td>
<td>0.78</td>
</tr>
<tr>
<td>Caregiving frequency</td>
<td>-1.10</td>
<td>0.77</td>
<td>-1.42</td>
</tr>
<tr>
<td>Step 2: Main effects</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity (AA as reference)</td>
<td>0.63</td>
<td>1.00</td>
<td>-0.63</td>
</tr>
<tr>
<td>Caregiving stress</td>
<td>3.96</td>
<td>0.74</td>
<td>5.39***</td>
</tr>
<tr>
<td>Social support</td>
<td>-1.60</td>
<td>0.82</td>
<td>-1.96*</td>
</tr>
<tr>
<td>Step 3: Two-way interactions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AA x CS</td>
<td>4.79</td>
<td>1.34</td>
<td>-3.59***</td>
</tr>
<tr>
<td>AA x SS</td>
<td>-0.36</td>
<td>1.55</td>
<td>0.23</td>
</tr>
<tr>
<td>CS x SS</td>
<td>-1.25</td>
<td>0.75</td>
<td>-1.66</td>
</tr>
</tbody>
</table>

*p < 0.05. **p < 0.01. ***p < 0.001.

N = 79.

AA, African American; CS, caregiving stress; SS, social support.
caregivers who reported lower levels of social support. These findings replicate those from an existing caregiving literature that examines primarily caregivers of dementia patients [18], but this is the first study, to our knowledge, to make these points among caregivers of colorectal cancer survivors.

The substantial effects of the stress from providing care to a relative or friend with cancer on caregivers’ psychological adjustment have been well documented in the broader caregiving literature [18]. Perhaps the most important contribution of our study is to provide evidence about possible differential effects of caregiving stress as a function of the caregivers’ ethnicity. Specifically, the adverse effect of caregiving stress proved to be significantly stronger among African American than among White caregivers. This was particularly evident during the early phase of the survivorship period. Given the limited variables under study in this project, we can only speculate about why caregiving stress was particularly pernicious among African Americans.

One possibility is that the daily travails of being an ethnic minority in America already drains people’s ability to function via perceived or actual discrimination, and that further stress from the cancer caregiving role increases their depression more compared with people of other ethnic backgrounds. Our findings, however, were not attributable to ethnic group differences in caregiving stress, depression scores, or socioeconomic status per se. Although there were more female participants in the African American group than in the White group in our sample, gender was not a significant factor in depressive symptoms across assessments. Psychosocial factors that are embedded in social norms related to caregiving in a certain culture and ethnic group may be responsible for this aggravating effect of caregiving stress on that ethnic group. One factor pertaining specifically to this concern is familism, which refers to ‘strong identification and attachment of individuals with their families (nuclear and extended) and strong feelings of loyalty, reciprocity and solidarity among members of the same family’ [19]. Familism is a motivating factor for providing care [20]; it conveys the expectation that extended family will assist with the care of relatives who are ill [21,22]. It is widely argued that minorities are especially likely to have high levels of familism [23,24]. Consequently, greater caregiving responsibilities among ethnic minorities that also create demands may make family caregivers vulnerable to psychological distress [23,24]. This idea and the extent to which this idea applies to caregiving-specific stress as opposed to general stress await exploration in future research.

Another interesting finding pertains to the effect of social support. On the basis of the suggestions from previous literature, we had expected that the benefits of social support would be more pronounced among African American caregivers, but this was not the case. Instead, we found the beneficial effects of social support among Whites. Because our sample reported high levels of social support overall, the findings might have been constrained by a ceiling effect. It will be important to investigate the effects of ebbs and flows of social support across the illness trajectory and whether the impact of such effects might potentially differ by ethnicity. Furthermore, investigations of the other aspects of social support, such as network size, sources of support, centrality, enacted (actual) support [12,25–30], as well as social integration, such as access to health care and medical mistrust [31–34], may be fruitful in advancing our knowledge about the differential effect of social support on caregivers’ depression by ethnicity.

Limitations and directions for future studies

Several limitations of this study should also be noted. First, all variables were self-reported, and therefore may be affected by social desirability or defensive reactions [35]. Second, we examined only basic demographic and caregiving experiences. Third, the effect sizes in the general linear models were small to modest. Future research should further investigate other factors that may affect the caregiving experience, such as the cancer survivors’ objective functional status and the presence of other caregiving help. Fourth, we were not able to assess minority groups other than African American, and all participants lived in a metropolitan area. It will be important to replicate these findings with diverse ethnic minorities, individuals living in rural areas, and persons of lower socioeconomic status. Fifth, our investigation is limited to the first year since the diagnosis, and thus it will also be important to replicate our findings in other phases of cancer survivorship.

Conclusion

Despite these limitations, this study makes an important contribution to the cancer caregiver literature by providing the first evidence that caregiving stress plays a different role among members of two ethnic groups in predicting depressive symptoms during the first year after the survivor’s diagnosis. These findings suggest that programs designed to reduce caregiving stress may be particularly beneficial for African Americans during the first year after the relative’s cancer diagnosis.

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