Supportive Care in Cancer (2019) 27:2077–2086
https://doi.org/10.1007/s00520-018-4467-8

ORIGINAL ARTICLE

Social correlates of mental health in gastrointestinal cancer patients and their family caregivers: Exploring the role of loneliness

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Received: 7 May 2018 / Accepted: 10 September 2018 / Published online: 17 September 2018

Abstract

Purpose The present study examined the degree to which loneliness mediated the influence of negative (social constraints) and positive (emotional support) relationship qualities on the global mental health of advanced gastrointestinal (GI) cancer patients and their family caregivers.

Methods Fifty patient-caregiver dyads completed measures assessing social constraints (e.g., avoidance, criticism) from the other dyad members, emotional support from others, loneliness, and global mental health. Structural equation modeling was used to examine individual models, and Actor-Partner Interdependence Mediation Modeling was used to examine dyadic associations.

Results Individual path analyses for patients and caregivers demonstrated that emotional support had a significant indirect effect on mental health through loneliness ($Bs = 0.32$ and 0.30, respectively), but no associations were found between social constraints and mental health. In dyadic analyses, participants' loneliness and mental health were not significantly related to their partner's emotional support, loneliness, or mental health ($Bs = -0.18$ to 0.18).

Conclusions Findings suggest that for advanced GI cancer patients and caregivers, emotional support from others alleviates feelings of loneliness, which may lead to better mental health. However, the benefits of emotional support appear to be primarily intrapersonal rather than interpersonal in nature. Additionally, participants endorsed low levels of social constraints, which might explain their lack of relation to loneliness and mental health. Continued examination of interdependence in social processes between cancer patients and caregivers will inform intervention development.

Keywords Emotional support · Family caregivers · Gastrointestinal cancer · Loneliness · Mental health · Social constraints

Introduction

Gastrointestinal (GI) cancers are among the most common cancers affecting both men and women [1]. GI cancers are often diagnosed at advanced stages [1], resulting in high physical and psychological symptom burden [2]. Many patients with GI cancers experience elevated distress, with approximately 30% reporting clinically significant anxiety and depressive symptoms [3, 4]. A similar percentage of caregivers of GI cancer patients report significant anxiety and depressive symptoms [4]. Caregiver distress has been related to role changes, extensive caregiving tasks for which they feel unprepared, and the patient's uncertain or poor prognosis [4, 5]. Indeed, cancer patients' caregivers spend an average of 32.9 hours per week providing care to their loved one, and 43% perform complex medical or nursing tasks without any training [6].

Research suggests that emotionally supportive relationships play a critical role in cancer patients' and caregivers' adjustment to the illness [7, 8]. Emotional support involves having close others who listen to and understand one's disclosures as well as demonstrate care and concern [9]. In research on couples coping with cancer and other chronic illnesses, romantic partnerships involving trust, open communication, and reciprocal support conferred psychosocial benefits [10–12]. Similarly, among cancer patients and family

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caregivers, perceptions of greater emotional support have been associated with better mental health outcomes [7, 8]. However, potential mechanisms underlying this relationship have rarely been studied in cancer patient-caregiver dyads.

One factor that may help explain the positive impact of emotional support on psychological adjustment to cancer is family members' ability to talk openly about their experiences with the disease [13, 14]. According to social-cognitive processing theory [13, 15], disclosure of cancer-related thoughts and feelings to close others may facilitate cognitive processing, defined as the process by which people make sense of their experiences and integrate them into their view of self and the world [15]. Successful cognitive processing with supportive others promotes the formation of a meaningful narrative of experiences and emotional acceptance, resulting in improved mental health outcomes [13].

On the other hand, some patients and caregivers experience social constraints on disclosure. For example, when a patient discusses his or her illness experience, the caregiver might react in an unsupportive manner (e.g., withdraw, criticize, avoid the conversation, or display discomfort) [13, 15]. Subsequently, the patient may refrain from disclosing or modify disclosures. Furthermore, patients and caregivers may avoid or modify their disclosures if they expect their family member to be unsupportive. These social constraints may limit or prolong cognitive processing (i.e., intrusive thoughts and avoidance), leading to greater distress for both dyad members [13, 15]. Indeed, positive correlations among intrusive thoughts, avoidance, and distress have been found in studies of cancer patients and caregivers [16, 17].

One factor that may underlie associations between positive (emotional support) and negative (social constraints) relationship qualities and mental health is loneliness. Many cancer patients and caregivers report moderate to high levels of loneliness [18, 19]. Loneliness refers to feeling socially disconnected; it is dissatisfaction with the quantity and quality of one's relationships [20]. Consistent with loneliness theory, higher levels of loneliness have been associated with worse health outcomes and greater distress in cancer patients and caregivers [18–20]. Limited research has linked emotional support and social constraints to loneliness in cancer populations. One study found that greater emotional and informational support from family members was associated with lower loneliness and reduced distress in both cancer patients and caregivers [21]. Another study of hematopoietic stem cell transplant survivors found that greater social constraints were associated with higher loneliness, which, in turn, predicted greater distress [14]. Both studies examined individuals rather than potentially interdependent psychosocial processes within patient-caregiver dyads.

Interdependence theory, adopted by dyadic researchers, suggests that each person functions within a relational system [22, 23]. Thus, each dyad member's behavior is hypothesized to influence the other person's behavior [23]. Consistent with this notion, cancer patients and caregivers have been found to cope with cancer-related challenges together as a unit [11, 12]. Accordingly, each person's perception of the social environment is hypothesized to impact their own as well as their partner's mental health. Indeed, systematic reviews indicate that cancer patients' mental health outcomes, such as anxiety and depressive symptoms, are significantly correlated with their caregivers' mental health outcomes ($rs = 0.23$ to 0.44) [24, 25]. However, relatively few studies have investigated the interdependence of mental health and social processes in patient-caregiver dyads coping with advanced cancer [26, 27].

To advance our understanding of dyadic social processes underlying mental health, the present study examined loneliness as a theory-driven mediator of the impact of social relationship qualities (i.e., social constraints from one another and emotional support from their social network) on global mental health in advanced GI cancer patients and their family caregivers. We investigated these processes for patients and caregivers individually and as a dyad to capture the potential interdependence of these associations. We hypothesized that, individually, cancer patients and their caregivers with either lower emotional support or higher social constraints would report higher loneliness and, in turn, poorer global mental health. We also hypothesized that within dyads, patients' and caregivers' emotional support and social constraints would be associated with their own as well as their partner's loneliness, which would, in turn, be associated with their own and their partner's mental health.

Methods

Participants

Participants were recruited for a telephone-based psychosocial intervention trial between August 2015 and August 2016 at two medical centers in Indianapolis, IN. Eligible patients were diagnosed with stage IV GI cancer at least 8 weeks prior to enrollment and had a consenting family caregiver. Patient exclusion criteria included (1) having severe cognitive impairment (≥ 3 errors on a six-item cognitive screener) [28]; (2) having a self-reported Eastern Cooperative Oncology Group (ECOG) score > 2 (able to do little activity) [29]; or (3) receiving hospice care at the time of enrollment. Caregivers were considered eligible if they lived with the patient or had visited the patient at least twice a week for the past month. Additionally, both patients and caregivers had to be ≥ 18 years of age and fluent in English. Given our interest in intervening with participants with clinical and subclinical levels of distress [30], one or both dyad members had to report a score of 3 or higher on the 0-10 Distress Thermometer scale [31].

Procedures

The trial design and methods have been published previously [30]. Following the Indiana University institutional review board approval, potentially eligible patients were identified via chart review and consultation with the attending oncologist and were approached by a research assistant during an oncology clinic visit. After the research assistant described the study, interested patients were screened for eligibility, including identification of a primary family caregiver, and provided written informed consent. Then, with the patient's permission, a research assistant approached the caregiver in clinic or via telephone to complete an eligibility screening and obtain informed consent. Consenting patient-caregiver dyads completed the study measures reported here during a baseline telephone interview prior to randomization to one of two telephone-based psychosocial interventions. Each participant who completed the baseline interview received a $25 gift card.

Measures

Patients' medical information (e.g., cancer type, time since diagnosis) was retrieved from their medical records. Patients and caregivers completed a demographic questionnaire, and the self-report measures listed below, most of which were from the Patient-Reported Outcomes Measurement Information System (PROMIS). PROMIS measures have been extensively validated, demonstrating adequate reliability and validity in general and cancer populations [32–34].

Global Mental Health was measured with the 4-item Global Mental Health subscale of the PROMIS short-form Global Health measure [32] (e.g., "In general, would you say your quality of life is…"). Responses are rated on a 5-point Likert-type scale from 1 (*poor*/*never*) to 5 (*excellent*/*always*), with higher scores indicating better mental health.

Loneliness was assessed with the 6-item PROMIS short-form Social Isolation measure [34] (e.g., "I feel isolated from others"). Responses are rated on a 5-point Likert-type scale from 1 (*never*) to 5 (*always*), with higher scores indicating greater loneliness.

Emotional support was assessed with the 4-item PROMIS short-form Emotional Support measure [34] (e.g., "I have someone who makes me feel appreciated"). Responses are rated on a 5-point Likert-type scale from 1 (*never*) to 5 (*always*), with higher scores indicating greater emotional support.

Social constraints were measured with the 5-item Social Constraints Scale [13, 35], which assesses perceived barriers to disclosing thoughts and feelings about cancer to the other dyad member (e.g., "In the past week, how often did you feel as though you had to keep your feelings about [name of patient's] cancer to yourself because they made [him/her] uncomfortable?"). Responses are rated on a 5-point Likert-type scale from 1 (*almost never*) to 5 (*almost always*), with higher scores indicating greater social constraints. The scale has shown evidence of good reliability and validity in cancer populations [13].

Statistical methods

First, we conducted bivariate analyses to examine associations between demographic and medical variables and mental health in order to identify potential control variables. Next, we conducted path analyses to test hypotheses regarding individual models using MPlus 6.12. We chose path analyses over alternative methods (e.g., multiple regression) due to its greater accuracy in parameter estimation by using FIML data imputation [36]. Given that all of our models were saturated, we do not report indices of model fit, but instead focus on parameter estimates. Based on previous research and theory [14, 15], a hypothesized model was specified. We estimated parameters of the model using maximum likelihood estimation. We used bias-corrected bootstrapping procedures to test the indirect effects using 5000 bootstrap samples [36]. Power analyses using Monte-Carlo simulations indicated that we had over 70% power to detect indirect effects of loneliness as small as $B = 0.25$ in each model with only patient or caregiver data [37].

Finally, we conducted dyadic analyses using the Actor-Partner Interdependence Mediation Model (APIMeM) as a general analytic strategy [38]. APIMeM models were estimated using MPlus 6.12. In APIMeM, the patient-caregiver dyad is treated as the unit of analysis allowing the effects within and between dyads to be examined. APIMeM tests *actor effects*, which are the relations of a person's characteristics (e.g., loneliness) to their own outcomes (e.g., mental health) and *partner effects*, which are the relations of a person's characteristics to their partner's outcomes. For example, the effect of patient emotional support on caregiver loneliness is the patient-partner effect, and the effect of caregiver emotional support on patient loneliness is the caregiver-partner effect.

Results

Sample characteristics

Of the 130 GI cancer patients approached, 12 were ineligible, 35 declined to participate, and 83 consented. Of the 79 caregivers who were approached, 21 were ineligible and two declined to participate. Thus, 56 patient-caregiver dyads were eligible and consented to participate. However, six dyads withdrew before the baseline assessment, resulting in 50 dyads who completed study measures prior to the intervention. Patients' and caregivers' primary reasons for study refusal included time constraints or lack of interest in the study or talking on the phone.

Sample characteristics are presented in Table 1. The majority of patients were men (62%), and the majority of caregivers were women (66%). The most common diagnoses were colorectal (38%) and pancreatic cancer (26%). Most caregivers were spouses or partners of the patients (76%). Both patients and caregivers were predominantly Caucasian and college-educated.

Preliminary analyses

Table 2 presents descriptive statistics, internal consistency reliabilities, and bivariate correlations among the main study variables. For cancer patients and caregivers, higher emotional support was associated with lower loneliness ($r = -0.56$, $p < .001$; $r = -0.62$, $p < .001$, respectively) and better global mental health ($r = 0.43$, $p = .002$; $r = 0.36$, $p = .010$, respectively). Additionally, for patients and caregivers, lower loneliness was associated with better global mental health ($r = -0.63$, $p < .001$; $r = -0.55$, $p < .001$, respectively). Among patients, social constraints from the caregiver showed small, non-significant associations with emotional support, loneliness, and global mental health. However, among caregivers, lower social constraints from the patient were associated with higher emotional support ($r = -0.50$, $p < .001$), lower loneliness ($r = 0.38$, $p = .007$), and better global mental health ($r = -0.33$, $p = .018$). Regarding partner effects, patients' emotional support was negatively associated with caregivers' loneliness ($r = -0.28$, $p = .048$). Remaining associations between patient and caregiver variables were small and non-significant (see Table 2).

Concerning demographic and medical factors, bivariate analyses revealed that for cancer patients, better mental health was associated with lower ECOG scores ($r = -0.48$, $p < .001$). Other demographic (e.g., age, gender) and medical factors (e.g., cancer treatments) were not correlated with patient or caregiver mental health.

Model testing

Cancer patients

We hypothesized that social constraints and emotional support would be associated with global mental health directly and indirectly via loneliness (Fig. 1a). However, due to the non-significant bivariate correlations between patient social constraints and other patient variables, we excluded social constraints from our hypothesized model for patients, as including this variable would only introduce error into the model. Thus, in this modified model, we examined whether loneliness mediated the relation between emotional support and global mental health (Fig. 1b). Results suggested that emotional support was not directly associated with global mental health. However, bootstrapped 95% confidence intervals (CIs) revealed a significant indirect effect of emotional support ($B = 0.32$; 95% CI, 0.11 to 0.52) on global mental health through loneliness.

Family caregivers

For family caregivers, we estimated the hypothesized model in which loneliness mediated effects of social constraints and emotional support on global mental health (Fig. 1c). Results of the path analysis indicated that social constraints were not significantly associated with loneliness or mental health, but were only associated with emotional support. Additionally, bootstrapped 95% CIs revealed a significant indirect effect of emotional support ($B = 0.30$; 95% CI, 0.11 to 0.49) on global mental health through loneliness.

Dyadic effects

Using APIMeM, we tested whether patient and caregiver emotional support would be associated with their own as well as their partner's global mental health directly and indirectly via each person's loneliness (Fig. 2a). Because bivariate analyses indicated that patient social constraints were not associated with their global mental health, we did not test a dyadic mediation model with social constraints. Results of the path analysis indicated that actor effects were significant; that is, patient and caregiver emotional support predicted their own loneliness ($B = -0.56$, $p < .001$ and $B = -0.59$, $p < .001$, respectively), and patient and caregiver loneliness predicted their own global mental health ($B = -0.59$, $p < .001$ and $B = -0.49$, $p = .001$, respectively). However, partner effects were non-significant. Specifically, patient and caregiver loneliness and mental health were unrelated to their partner's emotional support (Bs $= -0.18$ to 0.15) and loneliness (Bs $= -0.08$ to 0.18). For the indirect pathways involving loneliness, bootstrapped 95% CIs revealed that only actor-actor pathways were significant. We found a significant indirect effect of patient emotional support ($B = 0.33$; 95% CI, 0.08 to 0.58) on their mental health via loneliness as well as a significant indirect effect of caregiver emotional support ($B = 0.29$; 95% CI, 0.11 to 0.47) on their mental health via loneliness.

Conclusions

The present study investigated the role of loneliness in the impact of the social environment on mental health in advanced GI cancer patient-caregiver dyads. Potential interdependence

Table 1 Sample characteristics (*N* = 50)

	Cancer patients (*N* = 50)	Family caregivers (*N* = 50)
Sex, *n* (%)		
Male	31 (62.0)	17 (34.0)
Female	19 (38.0)	33 (66.0)
Age		
Mean	58.18	53.86
SD	11.48	13.69
Range	33–82	21–83
Race, *n* (%)		
Non-Hispanic White	43 (86.0)	44 (88.0)
Employment status, *n* (%)		
Employed full or part-time	14 (28.0)	29 (58.0)
Retired	18 (36.0)	11 (22.0)
Unemployed	18 (36.0)	10 (20.0)
Household income, *n* (%)		
\$0–\$50,999	17 (34.0)	15 (30.0)
\$51,000–\$99,999	19 (38.0)	20 (40.0)
\$100,000 or more	11 (22.0)	11 (22.0)
Years of education		
Mean	14.62	14.60
SD	2.69	2.15
Range	9–21	11–19
Caregiver relationship to the patient, *n* (%)		
Spouse/partner	–	38 (76.0)
Other family member	–	12 (24.0)
Caregiver lives with the patient, *n* (%)	–	42 (84.0)
Married/living with a partner, *n* (%)	38 (76.0)	46 (92.0)
Type of gastrointestinal cancer, *n* (%)		
Colorectal	19 (38.0)	–
Pancreatic	13 (26.0)	–
Esophageal	6 (12.0)	–
Other	12 (24.0)	–
Years since diagnosis		
Mean	1.53	–
SD	1.74	–
Range	0.18–10.27	–
Treatments received, *n* (%)		
Chemotherapy	47 (94.0)	–
Radiation	6 (12.0)	–
Surgery to remove primary tumor	28 (56.0)	–
Surgery to remove metastases	12 (24.0)	–
Targeted therapy	17 (34.0)	–
Patient ECOG score		
Mean	0.88	–
SD	0.75	–
Range	0.00–2.00	–

SD standard deviation, *ECOG* Eastern Cooperative Oncology Group

Table 2 Zero-order correlations between study variables ($N = 50$ dyads)

	1	2	3	4	5	6	7	Mean	SD	Range	α
1. Patient mental health	–							13.68	3.17	6.00–20.00	0.82
2. Patient loneliness	− 0.63***	–						10.58	3.87	6.00–22.00	0.85
3. Patient social constraints	− 0.14	0.14	–					1.36	0.52	1.00–3.40	0.77
4. Patient emotional support	0.43**	− 0.56***	− 0.25	–				18.52	1.96	12.00–20.00	0.82
5. Caregiver mental health	0.19	− 0.24	− 0.26	0.25	–			12.72	3.19	6.00–20.00	0.83
6. Caregiver loneliness	− 0.20	0.25	0.09	− 0.28*	− 0.55***	–		11.82	4.76	6.00–23.00	0.92
7. Caregiver social constraints	0.17	− 0.14	− 0.09	0.02	− 0.33*	0.38**	–	2.02	0.92	1.00–4.20	0.85
8. Caregiver emotional support	0.16	− 0.06	0.08	0.18	0.36*	− 0.62***	− 0.50***	17.02	3.54	5.00–20.00	0.94

SD standard deviation. *$p < .05$, **$p < .01$, ***$p < .001$

in these associations within dyads was examined. Consistent with loneliness theory [20], findings suggest that for both patients and caregivers, emotional support from others may improve mental health by alleviating feelings of loneliness. However, the benefits of emotional support appear to be primarily intrapersonal rather than interpersonal in nature. That is, patient and caregiver perceptions of having emotionally supportive relationships were associated with their own mental health, not that of their family member. Findings are largely inconsistent with Interdependence Theory, which posits reciprocal influences between dyad members [22–25]. However, our results converge with those of several studies with cancer patient-caregiver dyads suggesting that actor effects on mental health may be stronger than partner effects [26, 27, 39]. For example, one study found that, among cancer patients with young children and their partners, social support from others, including their partner, only impacted their own mental health [39].

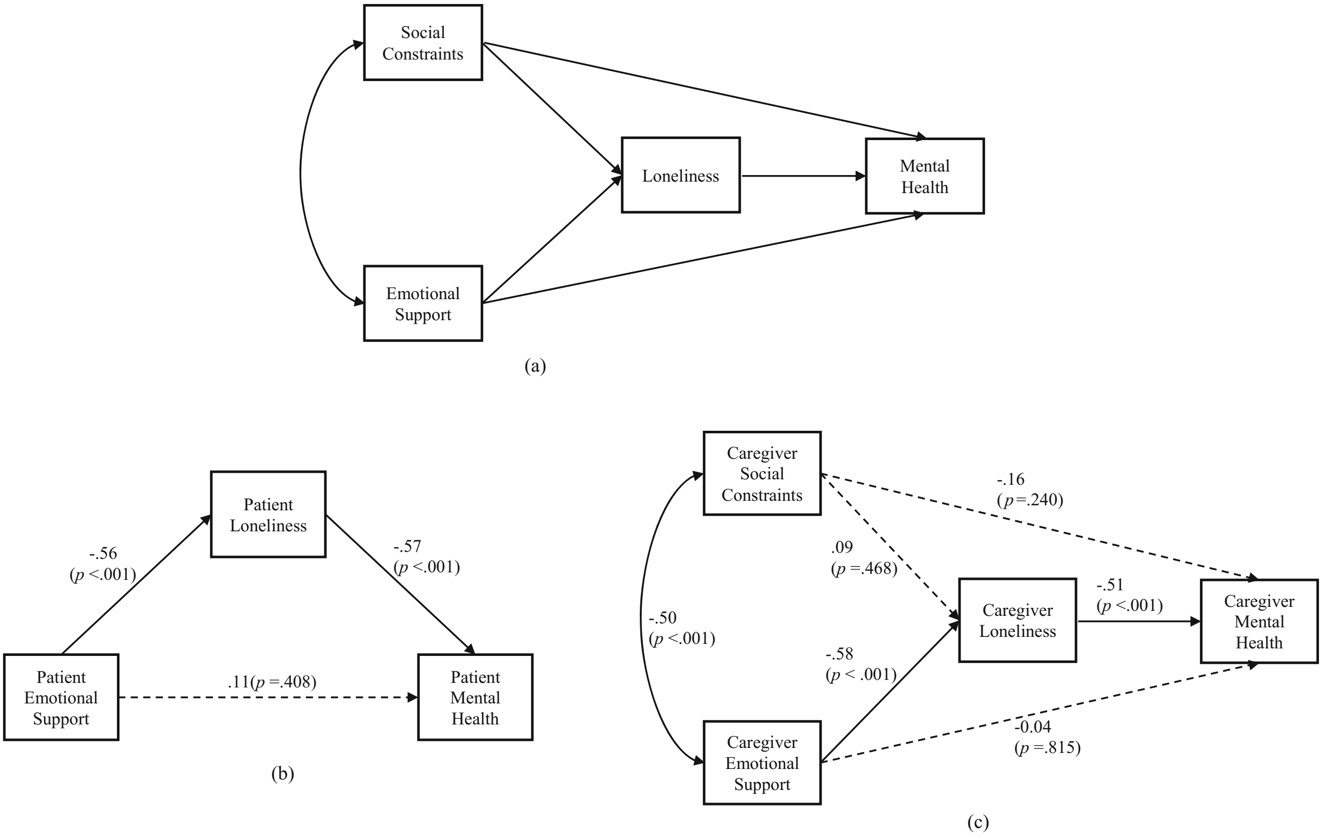

Fig. 1 **a** Hypothesized model for patients and caregivers. **b** Results of the modified model for cancer patients. **c** Results of the hypothesized model for family caregivers. Parameter estimates are standardized. The dashed lines represent hypothesized but non-significant paths, and solid lines represent the significant paths

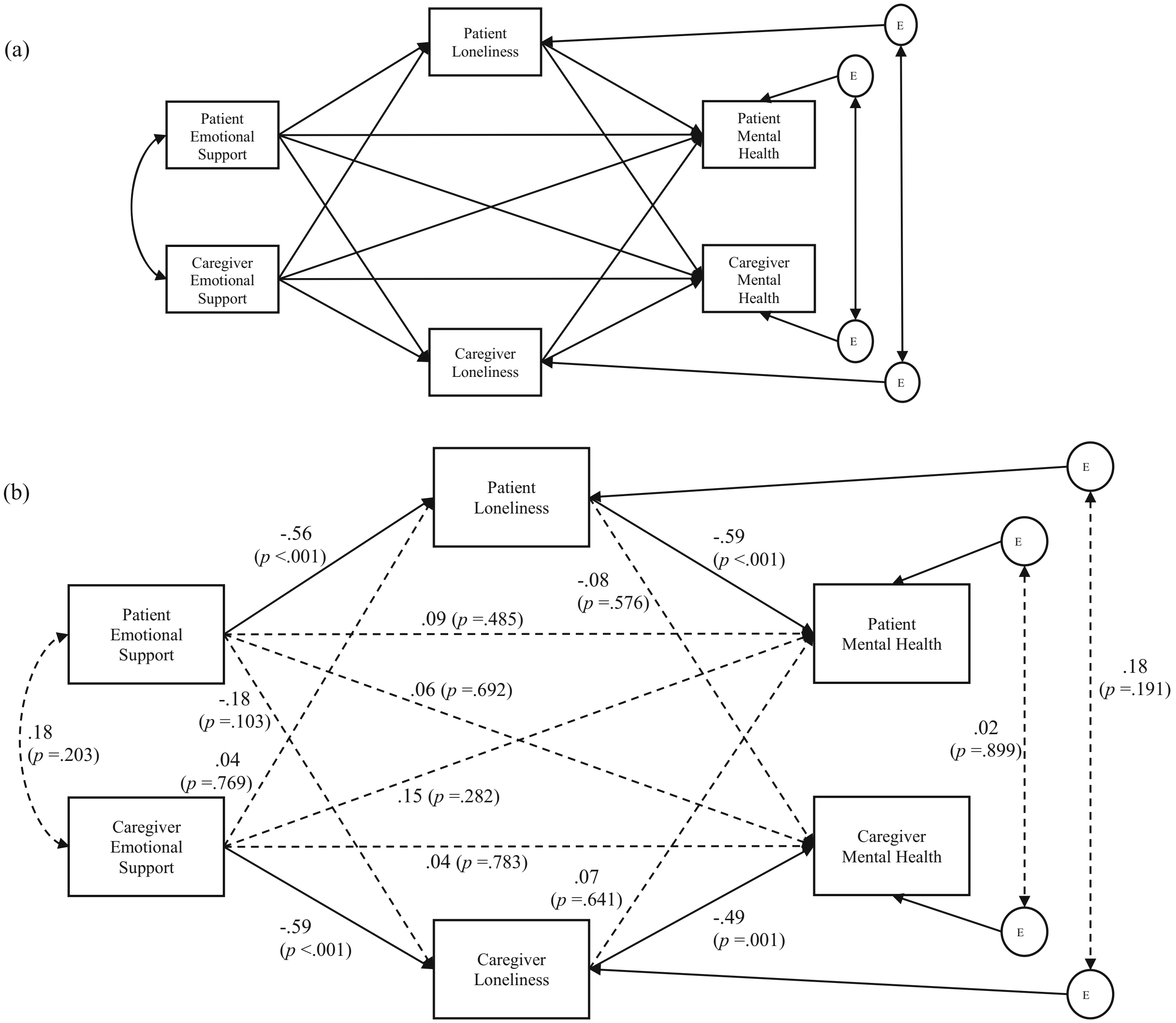

Fig. 2 **a** Hypothesized dyadic model. **b** Results of the dyadic model. Parameter estimates are standardized. The dashed lines represent hypothesized but non-significant paths, and solid lines represent the significant paths

Regarding the current study, other explanations for the lack of interdependence within dyads warrant mention. First, the emotional support measure was not restricted to support from partners, and dyad members may have been rating different confidants. Caregivers in our study were predominantly women, and patients were primarily men. Men tend to rely on their romantic partner as their main source of emotional support, whereas women tend to have larger support networks [11, 40]. Perhaps partner effects would have emerged if the emotional support measure had focused on the relationship between dyad members. Additionally, literature with healthy couples suggests that interdependence might be observed to a greater extent in relationship outcomes (e.g., relationship quality) than individual mental health outcomes [41]. Further, given that associations between patient and caregiver psychosocial outcomes are generally small to moderate [24, 25], it is possible that our sample size limited our statistical power to detect significant associations.

For individual advanced GI cancer patients and caregivers, emotional support appeared to positively impact mental health by decreasing a sense of loneliness. Results are similar to those found in post-treatment cancer survivors [14] and are consistent with theory suggesting that emotional support helps protect against loneliness and its negative mental health consequences [19, 42]. For example, emotional support may reduce loneliness by increasing an individual's sense of belongingness [19] and feelings of self-worth [42] and by providing opportunities for meaningful social interactions [42].

In contrast to findings involving emotional support, each person's perceived social constraints from the other dyad member did not impact their own loneliness or mental health. Findings did not support hypotheses derived from social-cognitive processing theory linking higher social constraints to poor mental health [13, 20]. However, among caregivers, perceiving greater social constraints from the patient was moderately associated with lower levels of emotional support. The primarily null findings might be explained by the low levels of social constraints endorsed by participants (i.e., $M = 1.69$, $SD = 0.82$ on a 1–5 scale). In addition, cancer patients reported significantly lower levels of social constraints than caregivers ($t = 4.22$, $p < .001$). Given that the majority of our participants were romantic partners and most caregivers were women, the higher social constraints reported by caregivers might be related to gender differences. Specifically, research suggests that women tend to be more sensitive to emotional cues and more aware of negative interactions than men, especially in the marital relationship [12, 43]. Therefore, increased sensitivity to emotional cues might explain caregivers' endorsement of greater social constraints.

Study limitations and directions for future research should be noted. First, given the cross-sectional design of the study, the directionality of relationships cannot be inferred. Longitudinal research is necessary to clarify the directions of relationships between social factors and mental health. Second, the sample size was relatively small, and the majority of participants were Caucasian, middle-aged, married, and middle-to-upper class. This limited variance in certain demographic and medical variables may help explain their lack of association with mental health. Further research with large, diverse samples is needed to determine the generalizability of the findings. Third, participants were recruited for a psychosocial intervention trial and, thus, may differ from other patient-caregiver dyads given the eligibility criteria of the study. However, most screened patients and caregivers were eligible for this study, and average patient and caregiver distress levels in this study were comparable to prior studies with advanced cancer patients and caregivers [4]. Finally, emotional support from the other dyad member as well as family and friends should be assessed separately in future research to examine the effects of the source of support.

Our findings have important implications for future research to address prevalent mental health needs of advanced GI cancer patients and caregivers [1, 2, 4]. Most dyadic research in cancer has focused on those coping with early-stage disease [44]. This study extends dyadic research on mental health and its social correlates to an advanced cancer context. Our results suggest that patients' and caregivers' perceptions of the social environment have a greater impact on their mental health than their partner's perception of it. In the general cancer literature, dyad members' reciprocal influence on quality of life, mental health, marital satisfaction, and coping is often small to moderate [25]. Furthermore, effect sizes for couple-based interventions in psycho-oncology have been relatively small (Hedges $gs = 0.21$ to 0.31) [44]. To inform clinical care, future research should compare the mental health effects of dyadic versus individual interventions designed to improve perceptions of the social environment and coping.

Our results also suggest that targeting loneliness in advanced GI cancer patients and caregivers might mitigate the negative mental health effects of decreased emotional support. In the general population, loneliness-reduction interventions focused on reducing maladaptive social cognitions have been found to be most effective relative to other types of interventions (e.g., increasing social support) [45]. However, loneliness-reduction intervention research with cancer patients and caregivers is limited [45]. Based on evidence with general populations, clinicians might target loneliness in cancer patients and caregivers using a cognitive-behavioral approach. Interventions might involve identifying automatic maladaptive thoughts about others and social interactions and considering these thoughts as potential faulty hypotheses to be challenged rather than as facts. Given the well-established detrimental impact of loneliness on health and well-being [20], developing efficacious interventions to reduce loneliness in advanced GI and other cancer patients and caregivers should be a high priority for future research and clinical care.

Acknowledgements We would like to thank the study participants, and Kelly Chinh, Susan Daily, and Danielle B. Tometich for assisting with this study.

Funding information This study was supported by the National Cancer Institute under Grants K05CA175048 (Shelley A. Johns and Catherine E. Mosher) and K07CA168883 (Catherine E. Mosher).

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflicts of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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