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Illness perceptions and perceived stress in patients with advanced gastrointestinal cancer

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Abstract

Objective: According to the Common-Sense Model of Self-Regulation, when faced with a health threat, we make cognitive and emotional assumptions about the illness. The aims of this study were to: (1) examine the role of sociodemographic and disease-specific factors on illness perception and perceived stress; and (2) test the association between perceived stress and illness perception in participants diagnosed with gastrointestinal cancer.

Methods: Participants completed a battery of questionnaires including a Sociodemographic and Disease-Specific Questionnaire, the Illness Perception Questionnaire Brief Version (Brief-IPQ), and the Perceived Stress Scale (PSS-14). Descriptive statistics, Pearson correlations, ANOVA, and linear regression were performed to test the hypotheses.

Results: Of the 627 participants, the mean age was 62 years ($SD = 11$); the majority were male (63.3%) and Caucasian (90.9%). Younger [$F(3,625) = 5.80, p < 0.01$] and divorced or never married participants reported higher levels of perceived stress when compared to older and married participants [$F(4,618) = 3.52, p < 0.01$]. Younger participants (18–74 years old) reported more negative illness perceptions than older participants (75 years and older) [$F(3,511) = 4.08, p <$

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0.01]. A weak, positive relationship between perceived stress and illness perceptions was observed ($r = 0.22$, $p < 0.01$) and illness perceptions predicted 36.1% of the variance of perceived stress.

Conclusions: Our findings suggest that participants who negatively perceived their illness experienced greater levels of perceived stress. Interventions that aim to adjust patients' illness perceptions in order to facilitate a reduction of stress and improvement in quality of life are needed.

Keywords

Cancer; gastrointestinal cancer; illness perception; oncology; perceived stress

Background

Over the past two decades, incidence and death rates for pancreatic, hepatocellular carcinoma (HCC), and intrahepatic bile duct carcinoma (cholangiocarcinoma) have increased for both men and women¹. Compared to all other cancer types, liver cancer is the most rapidly increasing cancer diagnosis, and seventy-five percent of all new liver cancer diagnoses are HCC¹⁻². Incidence rates of cancers of the gastrointestinal system have increased due to excessive tobacco and alcohol use, obesity, and the high prevalence of hepatitis C in baby boomers due to intravenous drug use of the 1960s through 1980s³⁻⁴. Although patients with gastrointestinal cancer have numerous treatment options (i.e. surgery, transplantation, ablation, chemotherapy), many participants are not healthy enough for surgery, experience harsh side effects from chemotherapy, or in the case of liver cancer, pass away before receiving an organ for transplantation^{2,5}. As many as one-third of cancer patients have reported experiencing anxiety and one-fourth of patients experienced depression⁷. Previous research has found that stress is a predictor for worse physical and psychological functioning⁸⁻⁹.

According to the Common-Sense Model of Self-Regulation, when diagnosed with cancer, participants make cognitive, emotional, and causal assumptions about the illness¹⁰. These assumptions about the severity of the threat, or illness perceptions, are based on past experiences, symptom severity, and information from others, including the medical team¹¹. Illness perceptions include: (1) *identity*: how a participant describes their illness and the symptoms they experience; (2) *consequences*: anticipated outcomes of the disease; (3) *cause*: personal reasons for the cause of their disease; (4) *timeline*: duration of their illness; (5) *cure or control*: belief that treatments will improve their illness¹¹.

Previous researchers demonstrated that most cancer participants believed they understood their illness well and that their cancer was treatable¹²⁻¹³. However, inconsistent patterns are observed regarding participants' perceived longevity of their illness, beliefs of cancer causation, and their personal control of their illness¹²⁻¹³. One explanation regarding the differences in illness perceptions may be the variations within and across cancer types regarding the cause, prognosis, and health behaviors associated with the development and/or recurrence of cancer^{4,14}. For example, lung cancer participants attributed causation to bad luck and smoking; thus, participant attributed causation is largely dependent upon cancer type¹⁵. Differences between illness perceptions may be due to each cancer type causing

diverse changes in bodily function (e.g. colostomy bag in colon cancer); appearance (e.g. mastectomy surgery for breast cancer); or lack of obvious physical changes (e.g. asymptomatic liver cancer). Due to the discrepancy in illness perceptions between cancer types, the current study aims to specifically examine the perceptions of participants diagnosed with advanced cancers affecting the gastrointestinal system.

Previous research has demonstrated an association between negative illness perceptions and increased ratings of perceived stress^{8,16}. One study involving participants with Chronic Lymphocytic Leukemia even found that illness perceptions explained as much as 25% of the variance in cancer-related stress¹⁶. However, data is limited in understanding which individual illness perceptions are mainly associated with stress. It is imperative for researchers to understand illness perceptions and their relationship to stress because of their impact on overall quality of life, including physical and mental health, and mortality¹⁷⁻¹⁹. By identifying which illness perceptions are associated with stress, medical professionals can implement targeted interventions to focus on these specific areas and promote quality of life. The current study aimed to describe how gastrointestinal cancer participants perceive their illness in terms of their perceptions about illness identity, consequences, cause, timeline, and cure or control, and how these perceptions influence ratings of perceived stress.

In addition to illness perceptions and perceived stress varying across cancer types, research findings have varied between individual demography^{12-13,20-21}. The current study aimed to examine the role of sociodemographic factors on illness perception and perceived stress to better understand individuals at higher risk for poor physical and psychological outcomes. This approach is in line with the National Institutes of Health goals in Rigor and Reproducibility and their desire for consideration of relevant biological variables (i.e. sex, age, underlying health conditions). By appreciating how participant experience varies between individuals, professionals can implement targeted interventions that are culturally and individually appropriate. In the general population, women and people who are single, younger, and of a minority background reported more perceived stress than individuals who are men, married, older, or of Caucasian descent²²⁻²³. We hypothesize that the current study would parallel these trends, proposing that demographic characteristics will moderate the relationship between illness perceptions and perceived stress, but not necessarily significantly differ from the general population.

Methods

Participants

This study was a secondary data analysis of participants from three studies conducted at the Division of Hepatobiliary and Pancreatic Cancer at the University of Pittsburgh's School of Medicine. This cohort of participants were diagnosed with hepatocellular, cholangio, gallbladder, and pancreatic carcinomas, and other primary tumors that have metastasized to the liver (e.g. colorectal, ovarian, breast). Recruitment of participants occurred from January 2008 through June 2011 (K07CA118576), November 2013 through June 2015 (K07CA118576), and December 2016 through June 2017 (R01CA176809). Response rates were 77%, 56%, and 64% respectively. Treatment options for advanced cancers of the

gastrointestinal system did not radically change between recruitment dates. Inclusion criteria of participants included: (1) biopsy or radiographic-proven diagnosis of advanced cancer affecting the hepatobiliary or pancreatic system; (2) age \geq 21 years; (3) English fluency. Exclusion criteria of participants included: (1) age $<$ 21 years; (2) lack of fluency in English; and (3) evidence of thought disorder, hallucinations, or delusions.

Instruments

Sociodemographic and Disease-Specific Characteristics.—Sociodemographic data (i.e. age, gender, race, and marital status) and disease-specific information (diagnosis and time of diagnosis) were gathered from the participants' electronic medical records.

Perceived Stress Scale (PSS-14).—The PSS is a 14-item scale that measures the degree to which one finds life unpredictable, uncontrollable and overloading; the three central components of the experience of stress²⁴. Participants are asked to rate items on a 5-point Likert Scale of *Never* to *Very Often*, reflecting upon thoughts and feelings during the past month. Cohen, Kamarck, & Mermelstein¹⁴ determined that the scale demonstrated substantial validity, average coefficient alpha reliability as .85, and test-retest reliability as .85.

Illness Perception Questionnaire, Brief Form (Brief IPQ).—The Brief IPQ is a self-report questionnaire designed to measure emotional and cognitive representations of illness. Individual components of consequences, timeline, personal control, treatment control, identity, coherence, emotional representation, and concern are rated on an 8-item continuous linear scale from 0 to 10. Broadbent et al.¹¹ have shown the B-IPQ to have good test-retest reliability and predictive and discriminant validity.

Procedure

The University of Pittsburgh's Institutional Review Board approved all three studies before enrollment commenced. Participants in all studies were referred by a member of the medical team at the tertiary medical center. Prior to consent, each participant spoke with a member of the study team about the risks and benefits of the study. After this discussion, written informed consent was obtained from each participant before they completed the study questionnaires.

Data Analysis

All data were entered, verified, and analyzed with SPSS version 21 (IBM Corp, Armonk, NY). Using Pearson correlation, there was a linear relationship between participant age and stress ($r = -0.164$, $p < .000$) and no relationship between illness perceptions and age ($r = -0.054$, $p = 0.212$). To explore these trends further and understand age data in a clinically meaningful manner, age of participants was recoded into categories recommended by the United States Department of Health and Human Services in the 2016 National Health Interview Survey: 18–24 years, 25–44 years, 45–64 years, 65–74 years, and 75 years and older. However, due to a limited number of participants in the 18–24 age group, categories 18–24 years and 25–44 years were combined to create an 18–44 years of age category. Participant diagnoses were categorized based on type of cancer: 1) hepatocellular carcinoma

or cholangiocarcinoma; 2) cancer of the appendix, gallbladder, stomach, or pancreas; 3) neuroendocrine tumors; and 4) primary cancers (e.g., breast, ovarian, or colorectal cancer) that had metastasized to the liver.

Descriptive statistics were performed to provide information regarding demographic and disease-specific characteristics. Analysis of Variance (ANOVA) with pairwise comparisons were performed to test associations between demographic and disease-specific variables with illness perception and perceived stress. Linear regression was also performed to test the predictors of perceived stress and determine the amount of variance in which illness perception contributed to perceived stress.

Results

Sociodemographic and Disease-Specific Characteristics

Of the 627 participants enrolled in the study, the mean age was 62 years ($SD = 11$); the majority were male ($n = 397$; 63.3%) and Caucasian ($n = 569$; 90.9%). The majority of participants in our sample were married ($n = 391$; 63.2%), had been diagnosed with cancer within the past month ($n = 223$; 35.6%), and were most often diagnosed with HCC or cholangiocarcinoma ($n = 264$; 48.3%) (see Table 1).

Demographic and Disease-Specific Predictors of Perceived Stress

Utilizing Analysis of Variance (ANOVA), we did not find a significant difference between perceived stress by gender, $F(1,626) = 0.27$, $p = 0.60$; race, $F(4,625) = 0.83$, $p = 0.50$; diagnosis, $F(3,546) = 0.13$, $p = 0.94$; or timing of assessment after diagnosis (or > 1 month), $F(1,626) = 0.52$, $p = 0.47$. Using ANOVA, we observed a significant relationship between age and perceived stress, $F(3,625) = 5.80$, $p < 0.01$. Computing pairwise comparisons, results indicated that participants in age category 18–44 years reported the highest level of perceived stress ($M = 25.39$, $SD = 8.96$) and were significantly different from age categories 65–74 years ($M = 20.72$, $SD = 8.01$), $p < 0.01$, and 75 years and older ($M = 19.94$, $SD = 7.79$), $p < 0.01$. Participants in age category 45–64 years reported the second highest level of perceived stress ($M = 22.62$, $SD = 8.35$) and were also significantly different from age categories 65–74 years, $p < 0.05$, and 75 years and older, $p < 0.01$.

Using ANOVA, we observed a significant association between marital status and perceived stress, $F(4,618) = 3.52$, $p < 0.01$. Pairwise comparisons indicated that married participants ($M = 20.98$, $SD = 7.93$) reported significantly lower perceived stress total scores compared to divorced ($M = 23.44$, $SD = 8.29$), $p < 0.01$ and never married participants ($M = 23.82$, $SD = 9.01$), $p < 0.05$. Separated ($M = 25.27$, $SD = 11.09$) or widowed ($M = 21.53$, $SD = 7.75$) individuals were not significantly different from other marital status categories.

Demographic and Disease-Specific Predictors of Illness Perception

Using ANOVA, we did not find a significant difference between illness perception and gender, $F(1,512) = 0.04$, $p = 0.85$; race, $F(4,510) = 0.11$, $p = 0.98$; marital status, $F(4,504) = 0.75$, $p = 0.56$; diagnosis, $F(3,538) = 0.93$, $p = 0.43$; or timing of assessment after diagnosis, $F(1,512) = 1.38$, $p = 0.24$. Using ANOVA, we found a significant difference between age

category and illness perception total score, $F(3,511) = 4.08, p < 0.01$. Pairwise comparisons revealed that age category 75 years and older ($M = 19.94, SD = 7.79$) reported the least perceived threat and significantly differed from age categories 18–44 years ($M = 25.39, SD = 8.96, p < 0.05$), 45–64 years ($M = 22.62, SD = 8.35, p < 0.01$), and 65–74 years ($M = 20.72, SD = 8.01, p < 0.01$). Age categories 18–44 years, 45–64 years, and 65–74 years did not significantly differ from one another.

Additional analyses using pairwise comparisons identified which individual IPQ scales differed between age category 75 years and older and other age categories. Age categories differed on individual IPQ components of *consequences*, *concern*, and *emotional representation*. Age category 75 years and older perceived less serious consequences from their illness (*consequences*), $F(3, 559) = 6.02, p < .01$, and were less concerned about their illness (*concern*), $F(3, 559) = 7.16, p < .01$, compared to all other age groups. Participants within age category 75 years and older believed their illness did not affect them as much emotionally (*emotional representation*) than participants within age categories 18–44 years and 45–64 years, $F(3,56) = 4.25, p < .01$ (see Table 2).

Perceived Stress and Illness Perception

Means and standard deviations of the PSS-14 and Brief-IPQ can be found on Table 3. Using partial correlation, there was a weak, positive relationship between perceived stress and illness perception scores after controlling for age, gender, race, and marital status ($r = 0.22, p < 0.01$). The PSS total score was also associated with each component on the IPQ scale including: effect of cancer on the participant's life (*consequences*), $F(1,534) = 0.40, p < .01$; how long the illness will continue (*timeline*), $F(1,531) = 0.22, p < .01$; *personal control*, $F(1,534) = 0.16, p < .01$; *treatment control*, $F(1,533) = 0.19, p < .01$; concern over their cancer (*coherence*), $F(1,534) = 0.24, p < .01$; experience of symptoms (*identity*), $F(1, 516) = 0.26, p < .01$; understanding of cancer (*emotional representation*), $F(1,534) = -0.23, p < .01$; and emotional impact of the disease (*concern*), $F(1,533) = -0.54, p < .01$ (Table 3).

Illness perceptions predicted 36.1% of the variance in perceived stress, $F(1,512) = 37.17, p < 0.01$. Using linear regression analysis, individual IPQ components of effect of cancer on the participant's life (*consequences*), $p < 0.01$, understanding of cancer (*coherence*), $p < 0.01$, emotional impact (*emotional representation*), $p < 0.01$, and experience of symptoms (*identity*), $p < 0.01$, predicted the greatest amount of the variance of perceived stress. (see Table 4).

Conclusions

The current study aimed to describe how patients with gastrointestinal cancer perceived their illness and how these perceptions influenced ratings of perceived stress. Participants who were never married or divorced reported experiencing more perceived stress than married participants. Perceived stress findings reflect patterns found in prior research in that participants who were single and/or living alone reported greater perceived stress and greater negative effects related to their illness than their married peers^{23,25-26}. These findings may be attributed to the additional stressors of singlehood, including loneliness, maintaining social commitments, and financial hardships²⁶. When managing a diagnosis of cancer,

participants who lived alone reported unmet needs for patient care, including emotional support, and these needs increased over time²⁷. These additional stressors may put single individuals at an increased risk for mental health problems^{26,28}. These findings suggest that social support during cancer treatment is valuable for maintaining quality of life and reducing stress²⁹⁻³⁰.

Consistent with the Common-Sense Model of Self-Regulation, negative illness perceptions were associated with increased ratings of perceived stress. Previous research on illness perceptions and perceived stress within the cancer population often include stress under the term “distress”, often lumping together anxiety, depression and stress^{8,31}. Future researchers would benefit from examining stress separate from other psychological variables due to the relationship between stress and physical and psychological outcomes⁸⁻⁹.

Older participants of the current study reported lower levels of perceived stress and endorsed more positive illness perceptions when compared to their younger counterparts. Our findings suggested that older individuals reported less severe consequences from their illness, were less concerned about their illness, and believed their illness did not affect them as much emotionally than participants within younger age categories. Zhang et al.²³ reported consistent findings, yet additionally found that younger participants reported more personal control and understanding of their illness. The additional findings may be due to the previous study including multiple cancer diagnoses wherein the current study only looked at gastrointestinal cancers. This theory is only an assumption and the underlying cause for differences in illness perceptions between individuals remains unclear.

Patients living with cancer would benefit from interventions designed to explore perceptions about their illness and manage stress. Group interventions incorporating stress management, illness education, coping skills, and challenging poor thought patterns have been effective in reducing negative illness perceptions and stress³²⁻³³. Researchers should continue efforts to develop interventions that explore illness perceptions and either challenge maladaptive thought processes or facilitate acceptance of their new reality. Patients would benefit from having these interventions readily accessible at medical centers where they already seek treatment and are in close contact with their medical team.

Clinical Implications

By understanding the association between illness perceptions and perceived stress, medical professionals can provide education about a patient’s diagnosis and develop interventions that challenge unrealistic illness perceptions or cultivate acceptance of their reality. Patients may also benefit from referrals to support groups or at-home services to help them cope with their illness. Future research should investigate targeted intervention strategies that help participants cope with an advanced cancer diagnosis and reduce negative psychological symptoms.

Study Limitations

The cross-sectional design of the study was a limitation in that causation could not be assumed. The study presented a relationship between participants’ perceptions about their illness and perceived stress; however, additional factors that help explain this relationship

were not assessed. Additional factors commonly associated with an advanced cancer diagnosis that may induce stress include: loss of employment, additional appointment times for testing and treatments, role and identity changes, and loss of social support³⁴⁻³⁵.

The current study did not assess participants' knowledge of their longevity of survival. Some medical professionals decline to inform participants of their prognosis unless the participant asks³⁶. Participant understanding of their illness, including projected longevity and treatment options, may influence perceptions about their illness³⁷. This may also further explain the lack of significance between cancer diagnoses because participants may not understand the nuances between pancreatic cancer or HCC regarding treatment options, associated symptoms, and survival rates.

The current study did not find a significant difference between participants diagnosed within the past month versus those diagnosed greater than one month from the time of assessment. One-month was an arbitrary timepoint and therefore future research should consider examining illness perceptions over the treatment span. Analyzing how illness perceptions change over time and what factors may have contributed to these changes can inform treatment interventions.

Conclusion

Illness perceptions can influence perceived stress in patients living with advanced gastrointestinal cancers and there may be differences between patient characteristics and cancer types. Fortunately, illness perceptions are malleable and through education, psychological treatment, and social support, patients can learn to cope with their illness and maintain a fulfilling life.

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Table 1.

Sociodemographic and disease-specific characteristics of participants (n = 627)

Variable	n (%)
Age Category (n, %)	
18-44	36 (5.8)
45-64	341 (54.5)
65-74	162 (25.9)
>75	87 (13.9)
Gender (n, %)	
Male	397 (63.3)
Female	230 (36.7)
Race (n, %)	
White	569 (90.9)
Black	48 (7.7)
Asian	3 (0.5)
American Indian	1 (0.2)
Other	5 (0.8)
Marital Status (n, %)	
Married	391 (63.2)
Widowed	49 (7.9)
Divorced	107 (17.3)
Separated	11 (1.8)
Never Married	61 (9.9)
Time of Diagnosis (n, %)	
<1 month	223 (35.6)
>1 month	404 (64.4)
Diagnosis	
Cholangiocarcinoma and HCC	264 (48.3)
Neuroendocrine tumor with liver metastases	49 (9.0)
Gallbladder, appendix, stomach, and pancreas cancers	31 (5.7)
Other primary cancers with liver metastases	203 (37.1)

Table 2.

Summary of pairwise comparisons of age categories and illness perception components

	18-44 years	45-64 years	65-74 years	75+ years	F	p
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)		
Consequences	6.91 (2.94)	6.34 (2.90)	6.01 (3.03)	4.88 (2.63)	6.02	<.000
Concern	8.26 (2.80)	8.46 (2.18)	8.27 (2.44)	7.03 (2.88)	7.16	<.000
Emotional representation	3.63 (3.32)	4.10 (2.91)	4.64 (3.12)	5.30 (2.99)	24.25	.006

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Table 3.

Means and standard deviations of PSS-14 and Brief-IPQ

Scale item	Mean (SD)
PSS Total	21.81 (7.83)
IPQ Total	46.24 (7.84)
IPQ component Consequences	6.13 (2.92)
IPQ component Timeline	6.69 (3.01)
IPQ component Personal control	5.80 (3.05)
IPQ component Treatment control	2.18 (2.36)
IPQ component Identity	4.78 (1.92)
IPQ component Concern	8.23 (2.38)
IPQ component Coherence	8.11 (2.06)
IPQ component Emotional Representation	4.37 (3.02)

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Table 4.

Summary of linear regression analysis and beta coefficients of Brief-IPQ components and perceived stress

Component	Unstandardized B	Standard Error	Standardized B	t	p
Consequences	0.368	0.125	0.136	2.947	.003
Coherence	-0.673	0.137	-0.176	-4.897	<.000
Emotional representation	-1.092	0.117	-0.413	-9.306	<.000
Identity	0.449	0.157	0.107	2.856	.004

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