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Cultural and social barriers to hope in gastrointestinal cancer patients

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Background: Hope is correlated with quality of life and overall survivorship among patients with cancer. We aimed to identify sociodemographic and clinical determinants of hope among patients with gastrointestinal (GI) cancer.

Methods: Patients with GI cancer seen in radiation oncology between 10/2022 and 6/2023 were surveyed with the Adult Hope Scale (AHS) questionnaire, which assesses hope based on goal-setting and goal-striving beliefs. Linear regression and Pearson's/Spearman's correlation coefficients were used to evaluate associations between AHS scores and demographic or disease variables.

Results: One-hundred and forty-five (71.1% response rate) patients were included in the analysis. Most (75%) patients were symptomatic from disease, and Asian American and Pacific Islander (AAPI) patients accounted for 30.3% of our cohort. Identifying as AAPI or needing an interpreter for clinic visits was significantly associated with lower AHS scores, and more AAPI patients required interpreter assistance compared to non-AAPI patients ($P=0.04$). Being divorced, unemployed, or female was also linked to less hope. No other differences in hope were found.

Conclusions: Sociodemographic rather than prognostic clinical factors were predictive of hope among patients with GI cancer. Interventions to contextualize psychosocial risk factors have the potential to improve quality of life and oncologic outcomes.

Keywords: Quality of life; questionnaire; Asian American and Pacific Islander (AAPI); interpreter; social support

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Introduction

Gastrointestinal (GI) cancers represent a heterogeneous spectrum of diseases, each of which require individualized multidisciplinary management. Patients diagnosed with GI cancer often grapple with a unique set of symptoms including abdominal discomfort, nausea, GI bleeding, and altered bowel movements. Coupled with the physical toll, the emotional burden of confronting the diagnosis and navigating the multifaceted treatment modalities can be

overwhelming (1).

For minority and non-English speaking patients, these challenges can be magnified. In addition to language barriers and cultural differences in understanding and addressing illness, potential biases and lack of representation within the healthcare system itself can contribute to heightened vulnerabilities among these patients (2-11). Minority language speakers face barriers to accessing healthcare services, are less likely to use cancer screening

services, and are more likely to experience adverse events, contributing further to the physical and emotional burden of their cancer diagnosis.

Hope has been shown to be directly correlated with patient quality of life, existential and spiritual wellbeing, ability to cope, and overall survivorship in patients with cancer (12-15). Hope has also been inversely linked to physical symptom load and psychological distress (16-20). In patients with GI cancer, depression and anxiety have been associated with poorer functional status and prognosis (21,22). Thus, evaluating the factors that shape hope in the context of cancer care, especially among vulnerable populations, is imperative to improving outcomes and patient quality of life. Snyder's Adult Hope Scale (AHS) is a widely adopted psychological assessment tool that defines hope through the concepts of agency and pathways, where agency refers to the willpower to pursue goals even in the face of adversity and pathways the strategies to achieve those goals (11). In this study, we used AHS to evaluate sociodemographic and clinical determinants of hope among patients with GI cancer seen in radiation oncology clinic. We present this article in accordance with the SURGE reporting checklist (available at <https://jgo.amegroups.com/article/view/10.21037/jgo-23-938/rc>).

Methods

After obtaining approval from our institutional review

Highlight box

Key findings

- This prospective survey study found that needing interpreter assistance or being Asian American and Pacific Islander (AAPI), divorced, unemployed, or female was significantly associated with lower hope among patients with gastrointestinal (GI) cancer.

What is known and what is new?

- In patients with cancer, hope has been linked to less psychological distress and symptom load as well as improved quality of life, wellbeing, and overall survivorship.
- Sociodemographic variables, rather than known prognostic clinical factors, were found to be risk factors for lower hope among patients with GI cancer.

What is the implication, and what should change now?

- Understanding psychosocial predispositions that lower hope may help providers identify at risk patients and provide opportunities to mitigate emotional distress and improve quality of life among subgroups of patients with GI cancer.

board (No. 34990), patients seen in GI cancer radiation oncology clinic between October 2022 and June 2023 were sent the AHS survey electronically via their healthcare portal prior to their new patient consultations or follow-up visits. Patients without access to the healthcare portal were given the survey by medical assistants when they checked into clinic. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). This quality improvement metric did not require informed consent according to our institutional review board. To avoid survey fatigue, patients who completed other surveys within the past three months or were currently participating in interventional clinical trials were excluded from the study. Interpreters helped facilitate survey completion for non-English speaking patients. No monetary incentives were provided for participating.

The AHS is a 12-item measure comprising four agency-thinking items, four pathways-thinking items, and four filler items (23). Participants respond to each item using an eight-point Likert-type scale ranging from definitely false to definitely true. Higher subscale or total AHS scores are representative of higher hope, and total scores can be categorized as hopeful [40-48], moderately hopeful [48-56], and high hope [>56] (24).

Statistical analysis

Univariable linear regression was used to evaluate associations between AHS scores and demographic, disease, and treatment variables. P values <0.05 were considered statistically significant, and Pearson/Spearman's correlation coefficients (PCC/SCC) were calculated for continuous variables. All the analyses were performed in SAS version 9.4 (Cary, NC, USA). Response rate was calculated by dividing the number of fully completed survey responses by the number of patients sent the survey.

Results

We surveyed 204 patients with a survey response rate of 71.1% (145/204). Patients who did not respond were not included in the analysis. Of the 145 patients who responded, demographic and clinical cohort characteristics are summarized in *Table 1*. Most patients were symptomatic (75%) from their disease at the time of survey completion.

Asian American and Pacific Islander (AAPI) patients constitute a substantial portion of our cohort (30.3%). Identifying as AAPI or needing an interpreter for clinic

Table 1 Baseline demographic and clinical cohort characteristics

Characteristic	Data
Age (years)	65.6 (31.1–92.5)
Sex	
Male	89 (61.4)
Female	56 (38.6)
Race	
White	73 (50.3)
AAPI	44 (30.3)
Black/African American	1 (0.7)
Native American	2 (1.4)
Other	23 (15.9)
Unknown/not reported	2 (1.4)
Ethnicity	
Hispanic/Latino	18 (12.4)
Not Hispanic/Latino	126 (86.9)
Unknown/not reported	1 (0.7)
Interpreter needed	
Yes	12 (8.3)
No	133 (91.7)
Marital status	
Single	21 (14.5)
Married	101 (69.7)
Divorced	9 (6.2)
Widowed	10 (6.8)
Unknown/not reported	4 (2.8)
Insurance type	
Private	65 (44.8)
Medicare	60 (41.4)
Medi-Cal	16 (11.0)
Unknown/not reported	4 (2.8)
Occupation status	
Employed	34 (23.5)
Not employed	17 (11.7)
Retired	36 (24.8)
Unknown/not reported	58 (40.0)

Table 1 (continued)**Table 1** (continued)

Characteristic	Data
Symptomatic from disease at time of survey	
Yes	105 (72.4)
No	35 (24.1)
Unknown/not reported	5 (3.5)
Pain level (0–10)	
0	68 (72.3)
1	5 (5.3)
2	5 (5.3)
3	2 (2.1)
4	3 (3.2)
5	3 (3.2)
6	4 (4.3)
7	1 (1.1)
8	2 (2.1)
9	1 (1.1)
10	0 (0)
Disease stage	
Non-metastatic	95 (65.5)
Metastatic	50 (34.5)
Disease subsite	
Colorectal	84 (57.9)
Pancreas	15 (10.3)
Liver	11 (7.6)
Anus	11 (7.6)
Biliary tract	12 (8.3)
Esophagus/stomach	9 (6.2)
Small intestine	2 (1.4)
Appendix	1 (0.7)
Treatment modality	
No treatment yet	33 (22.8)
Monotherapy treatment	30 (20.7)
Bimodality treatment	51 (35.1)
Trimodality treatment	31 (21.4)

Data are presented as n (%) or median (range). AAPI, Asian American and Pacific Islanders.

visits was significantly associated with lower overall, agency, and pathways thinking AHS scores, respectively (Table 2). Being divorced or unemployed was also significantly associated with lower total, agency, and pathways thinking AHS scores. Female patients had lower overall and pathways AHS scores.

There were no other significant differences in hope scores based on sociodemographic or clinical variables. Specifically, symptomatic presentation, pain levels, having metastatic disease, and treatment status were not associated with lower hope.

Significantly more AAPI patients required interpreter assistance compared to non-AAPI patients (16% vs. 5%, $P=0.04$). There were no other differences based on gender, type of medical insurance, marital status, or employment status between AAPI and non-AAPI patients (Table 3).

Discussion

In this prospective survey study, we assessed hope among patients with GI cancer seen in a single radiation oncology clinic and found sociodemographic variables, rather than known prognostic clinical factors, to be more associated with hope. Our study showed that requiring an interpreter for clinic visits or being AAPI, divorced, or unemployed were risk factors for lower total and subscale AHS scores. Female patients also had lower total and pathways thinking AHS scores. Interestingly, there were no associations between hope and treatment status or presence of metastatic disease, symptoms, or pain. These results underscore the importance of sociodemographic factors in the context of cancer care, providing opportunities to mitigate emotional distress and improve quality of life among subgroups of patients with GI cancer.

One of the strengths of our study is the substantial representation of AAPI patients, which account for 30.3% of our study cohort and allowed us to evaluate the relationship between race, interpreter use, and hope. Patients needing interpreter assistance were found to have lower levels of hope. Non-English speaking patients have had limited access to healthcare services, been less likely to receive standard care for chronic conditions, and experienced reduced quality of care in acute clinical settings (2-5). Especially in cancer care, difficulty navigating multidisciplinary care can lead to delays in diagnosis, treatment initiation, and recurrence detection (6). Although patients may greatly benefit from modern translation services, studies have demonstrated less optimal

information exchange between patients and physicians even in the presence of interpreters, predisposing patients with language barriers to greater psychological distress, poorer prognoses, and therefore less hope (7,8). Offering interpreter assistance for completing the English version of this survey may have exacerbated this effect and contributed to a lower AHS score. Providing the survey in patients' native languages may have more adequately addressed needs and improved their sense of hope. While AAPI patients were more likely to require an interpreter than non-AAPI patients, only 16% of AAPI patients needed interpreter assistance, suggesting that language barriers may only partially explain the hope disparity observed among AAPI patients. Cultural processes—such as cancer fatalism, medical mistrust, and emotional reservedness around medical professionals—have also been shown to be more prominent in AAPI and other minority populations, which may affect hope and quality of life (9,10). Chen *et al.* notes that many AAPI patients believe increasing pain to be indicative of disease progression, yet they are more likely to be apprehensive about biomedical pain management and to purposely withhold information about the extent of their symptoms in the name of being a 'good' patient (11). Thus, the mounting emotional and physical suffering that ensues in this patient population could also account for a diminished sense of hope and lower AHS scores.

Social support, which encompasses the emotional, informational, and practical assistance provided by one's social network, helps patients cope with their diagnosis and increase hope. Cancer patients with greater social support have been reported to have better quality of life, treatment adherence, and overall survival outcomes (25,26). Bou-Samra *et al.* found that among patients specifically with GI cancer, low social support was associated with higher incidences of depression and mortality, and identified marital status to be a predictor of social support even after controlling for other sociodemographic and disease factors (27). Our findings were similar to those of existing studies in that divorced patients were found to have lower AHS scores, but unlike these studies, we did not see this trend with single or widowed patients (21,27-29). In addition to the lack of spousal support, divorced patients may also face increased financial challenges from being a single income household. Lower levels of hope among patients facing unemployment may similarly be ascribed to decreased social support, financial insecurity, and increased symptom burden (30,31). Unemployment limits opportunities for socialization with colleagues and has been

Table 2 Associations between Adult Hope Scale (AHS) scores and sociodemographic and clinical variables

Characteristic	Overall AHS scores		Agency AHS scores		Pathways AHS scores	
	Mean (SD)	P value	Mean (SD)	P value	Mean (SD)	P value
Sex		0.04		0.06		0.04
Male	53.4 (8.1)		26.4 (4.2)		27.0 (4.3)	
Female	50.0 (11.5)		24.8 (6.0)		25.2 (6.1)	
Race		<0.001		<0.001		0.001
White	54.5 (7.0)		27.1 (3.4)		27.3 (4.0)	
AAPI	46.8 (11.7)		23.0 (6.1)		23.8 (6.4)	
Black/African American	63.0		32.0		31.0	
Native American	54.5 (10.6)		26.5 (6.4)		28.0 (4.2)	
Other	55.0 (6.7)		27.1 (4.0)		28.0 (3.4)	
Unknown/not reported	41.5 (24.7)		20.0 (12.7)		21.5 (12.0)	
Ethnicity		0.32		0.39		0.33
Hispanic/Latino	54.9 (6.8)		27.1 (4.3)		27.8 (3.3)	
Not Hispanic/Latino	51.7 (9.9)		25.6 (5.1)		26.1 (5.3)	
Unknown/not reported	59.0		29.0		30.0	
Interpreter needed		<0.001		<0.001		0.002
Yes	42.7 (13.4)		20.7 (7.0)		22.0 (7.1)	
No	60.0 (8.8)		26.3 (4.6)		26.7 (4.8)	
Marital status		0.01		0.009		0.04
Single	54.9 (8.7)		27.3 (5.1)		27.5 (3.9)	
Married	52.6 (8.9)		26.1 (4.5)		26.5 (5.0)	
Divorced	43.7 (14.4)		21.6 (7.1)		22.1 (7.4)	
Widowed	52.5 (7.9)		25.7 (5.1)		26.8 (3.1)	
Unknown/not reported	43.0 (13.8)		20.5 (6.8)		22.5 (7.9)	
Insurance type		0.06		0.06		0.06
Private	53.7 (9.1)		26.4 (4.9)		27.3 (4.9)	
Medicare	52.2 (8.5)		26.2 (4.2)		24.1 (6.9)	
Medi-Cal	47.3 (13.4)		23.2 (6.9)		26.0 (4.7)	
Occupation status		<0.001		<0.001		<0.001
Employed	55.4 (7.8)		27.5 (3.8)		27.9 (4.4)	
Not employed	43.9 (13.7)		21.5 (7.6)		22.4 (6.9)	
Retired	53.1 (7.1)		26.2 (3.8)		26.9 (3.6)	
Symptomatic at time of survey		0.18		0.21		0.20
Yes	51.4 (10.3)		25.4 (5.4)		26.0 (5.5)	
No	53.9 (7.4)		26.7 (3.6)		27.3 (4.1)	

Table 2 (continued)

Table 2 (continued)

Characteristic	Overall AHS scores		Agency AHS scores		Pathways AHS scores	
	Mean (SD)	P value	Mean (SD)	P value	Mean (SD)	P value
Disease stage		0.27				0.65
Non-metastatic	51.4 (10.5)		25.2 (5.6)	0.10	26.1 (5.4)	
Metastatic	53.3 (7.9)		26.7 (3.8)		26.5 (4.7)	
Treatment modality		0.58				0.56
No treatment yet	51.7 (9.2)		25.2 (5.1)	0.55	26.5 (3.8)	
Monotherapy treatment	52.6 (9.1)		26.1 (4.8)		26.4 (4.9)	
Bimodality treatment	51.0 (11.6)		25.4 (5.9)		25.5 (6.2)	
Trimodality treatment	53.9 (6.8)		26.8 (3.4)		27.2 (4.7)	
Disease subsite		0.75				0.81
Colorectal	52.0 (10.4)		25.7 (5.5)	0.69	26.3 (5.4)	
Pancreas	54.1 (6.2)		26.7 (3.8)		27.4 (3.0)	
Liver and biliary tract	50.5 (8.4)		24.9 (4.6)		25.6 (4.4)	
Anus	51.2 (9.9)		25.7 (4.2)		25.5 (6.5)	
Other (esophagus, stomach, small intestine, appendix)	54.4 (10.6)		27.4 (4.7)		27.0 (6.0)	
Age	PCC 0.04174	0.62	PCC 0.09291	0.27	PCC 0.01243	0.88
Pain	SCC 0.07332	0.48	SCC 0.09218	0.38	SCC 0.04890	0.64

AAPI, Asian American and Pacific Islanders; PCC, Pearson's Correlation Coefficient; SCC, Spearman's Correlation Coefficient.

Table 3 Sociodemographic differences between AAPI and non-AAPI patients

Characteristic	AAPI (n=44)	Non-AAPI (n=101)	P
Female	19 (43%)	37 (37%)	0.46
Interpreter used	7 (16%)	5 (5%)	0.04
Had medical insurance	6 (14%)	10 (10%)	0.52
Divorced	1 (2%)	8 (8%)	0.27
Unemployed	7 (16%)	10 (10%)	0.40

Data are presented as n (%). AAPI, Asian American and Pacific Islanders.

linked to reduced coping abilities in cancer patients, which can manifest as less hope. Many unemployed patients in this cohort also reported being disabled by their disease.

Finally, gender differences in hope may be attributed to various psychological, biological, and sociocultural factors that render female cancer patients more susceptible to psychological distress. Current literature has consistently observed higher rates of internalizing disorders such as

depression and anxiety in women than in men (32,33). A prospective cohort study of patients with gastric cancer concluded that female patients were at greater risk of developing postoperative depression and anxiety, resulting in worse prognoses (21). Body image and sexual wellbeing are also important quality-of-life measures with proven gender disparities (34). Female patients who underwent cancer treatments have reported greater body dissatisfaction

than their male counterparts, citing appearance-related side effects such as hair loss, weight and skin changes, and surgical disfigurement as significant sources of psychosocial stress (35-38). It is important to acknowledge that traditional gender norms manifest differently in men, and men may oftentimes feel discouraged to express emotion, resulting in underreporting of poor mental health.

Thus, given the complex interplay between hope and cancer, healthcare providers must contextualize psychosocial determinants of hope for each unique patient and tailor interventions appropriately to alleviate psychological and physical anguish as well as improve quality of life and survivorship. Minority patient populations with limited English proficiency may feel a reduced sense of autonomy even with interpreter assistance, and cultural nuances may get lost in translation (7). These findings highlight the importance of cultural sensitivity training for healthcare providers to be able to effectively communicate to a patient the extent of their disease and available treatment options. Providers who are cognizant of patients' psychoemotional needs can also initiate conversations surrounding sensitive topics such as mental health or refer patients for appropriate quality-of-life, specialist-led interventions. In a cohort of patients with GI cancer undergoing chemoradiation, Cheville *et al.* found that multidisciplinary interventions helped reduce symptom load and unplanned hospital admissions while also improving treatment adherence (39). These included social courses in communication strategies, body image and sexuality, and interpersonal relationships; cognitive courses in coping, healthy lifestyle choices, and taking charge; and emotional courses in stress management, irrational thoughts, and assertiveness. Finally, providers can recommend patients with limited social support to support groups or social workers. A prospective study found that unemployed patients were more likely to participate in self-help groups when given the opportunity (40). It is important to recognize that limited access to specialist-led resources, financial and time constraints, and other logistical challenges may impede delivery of additional psychosocial support. The nuanced nature of individual psychological differences—such as the cultural impact on AAPI patients to be less vocal about their concerns and the increased susceptibility to internalizing disorders and negative body image among female patients—may also be difficult to address. Additionally, patients facing physical and emotional distress may be too preoccupied with immediate concerns of disease progression and treatment side effects to fully

engage in such interventions. Nonetheless, given the potential impact of hope on quality of life, wellbeing, and overall survivorship among patients with cancer, healthcare teams must make concerted efforts to identify possible risk factors for low hope and offer holistic care when possible.

This survey study had several limitations. Patients completed the AHS survey at only one point during their disease course and were not followed for consecutive clinic visits. This may have led to biases, as patients may have greater uncertainty and lower hope at the time of their first visit prior to a treatment plan being discussed and explained, whereas patients on treatment with a clear oncologic plan may have greater hope. The sample sizes of certain race, marital status, and occupation status subcohorts were too small for analysis, and employment status was missing for 40% of the cohort. The findings of low hope among patients requiring interpreter assistance will need to be validated in broader populations. Translated versions of AHS have been validated, but the use of an interpreter for completing the English version of the survey has not been. Therefore, the method by which the survey was delivered to patients who required interpreter assistance itself may have led to lower AHS scores. While this study included a substantial number of AAPI patients, AAPI is a broad term that encompasses many patients with diverse cultural backgrounds and health experiences, and improper aggregation can mask Native Hawaiian and other Pacific Islander disparities; however, further information for disaggregating this population in our study was not available (41). Limited English proficiency may not have been accurately captured for patients whose family members translated during clinic visits, and additional forms of social support other than marital and occupation status were not evaluated. Education level was also not available, and this may be related to employment status and to hope, irrespective of employment. Future work in prospectively following these patients throughout the course of their disease as well as defining specific risk factors for lower hope and opportunities for respective interventions are warranted.

Conclusions

In this prospective survey study, needing interpreter assistance or being AAPI, divorced, unemployed, or female was associated with lower AHS scores in patients with GI cancer. Understanding psychosocial predispositions that

lower hope may help providers identify at risk patients and inform the development of interventions to better quality of life, reduce psychological distress and symptom load, and improve oncologic outcomes.

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Footnote

Reporting Checklist: The authors have completed the SURGE reporting checklist. Available at <https://jgo.amegroups.com/article/view/10.21037/jgo-23-938/rc>

Data Sharing Statement: Available at <https://jgo.amegroups.com/article/view/10.21037/jgo-23-938/dss>

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Conflicts of Interest: All authors have completed the ICMJE uniform disclosure form (available at <https://jgo.amegroups.com/article/view/10.21037/jgo-23-938/coif>). E.L.P. reports receiving honorarium from Varian Clinical School, consulting fees from Vysioneer, and GT Medical Technologies. The other authors have no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013) and has obtained approval from our institutional review board (No. 34990). This quality improvement metric did not require informed consent according to our institutional review board.

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