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# Patient's informational needs and outreach preferences: A cross-sectional survey study in patients with hepatobiliary malignancies

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# ABSTRACT

*Objective:* Hepatobiliary tumors have evolving management guidelines. Patient educational needs and interest in community engagement are unknown. This study serves as a needs assessment.

*Methods*: A prospective, needs assessment, survey study of hepatobiliary patients was performed (2016–2019). Surveys (n = 169) were distributed covering three domains of interest: informational needs, interest in outreach, and engagement preferences.

*Results*: Seventy patients completed the survey (response rate = 41.4%). Most patients had completed surgical treatment (84.3%). *Cancer treatment* was ranked as their primary topic of interest (n = 39, 55.7bold%), followed by *symptom management*, *nutrition*, and *survivorship*. Most patients did not participate in screening (n = 57, 81.4%), though were interested in learning more about these programs. Thirty-nine patients (55.7%) stated they would want to receive more education. Only 17 (24.3%) were interested in attending in-person events. Patients preferred online methods for education (n = 49, 70%). While patients were aware of their case presentation at tumor board, only 38 (54.3%) felt well-informed about recommendations.

*Conclusion:* Multidisciplinary care is complex and difficult for patients to navigate. Most patients have interest in educational resources and prefer online modalities. Patients understand multidisciplinary tumor boards, but communication could be improved.

Innovation: These data inform a new, innovative, approach to outreach efforts in this population.

# 1. Introduction

The timeline of cancer care is multifaceted from prevention to survivorship. It is critical to empower patients with the appropriate educational tools to optimize health outcomes. With increasing complexity of care, knowledge gaps among patients are becoming more common and relevant. This lack of awareness about the signs, symptoms, and risk factors for cancer combined with inadequate cancer prevention programs at the community level has been documented as an important barrier in different settings [1]. While cancer prevention and screening has been thoroughly investigated in breast, lung, and prostate cancers [2], there is little knowledge about the awareness of and participation in screening programs for hepatobiliary malignancies. Hepatobiliary cancers are one of the top causes of cancer-related

mortality worldwide [3], and it is estimated they represent the sixth leading cancer worldwide when ranked by incidence, with the disease burden of liver cancers continuing to increase over time [4]. In fact, in a recent population-level study [5], hepatocellular carcinoma was found to be among the few cancers with increasing incidence in the United States. As such, there is a critical need to identify and understand deficits in patient knowledge to narrow the informational gaps and improve care across the cancer care continuum.

The concept of evidence-based public health is centered on the process of integrating science-based interventions with community preferences to improve the health of populations. Interventions often include community outreach efforts which are focused on translating knowledge into relevant interventions to enhance health, prevent disease and manage chronic illness [6]. Studies have shown that outreach

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programs can effectively increase cancer screening rates, both within a hospital and community setting [7,8]. Similarly, educational programs have demonstrated the ability to expand overall knowledge about specific cancers and their contributing risk factors, treatment pathways and overall care [9]. Creating a successful outreach program typically begins with strategies that utilize a needs assessment. Conducting community assessments for ascertaining the health and cultural needs is an integral part of the development stage for an outreach intervention that addresses the identified issues [10]. Our institution has been involved in several educational outreach efforts dedicated to improving prevention, treatment, and survivorship in the surrounding community; however, more information is needed to ascertain how to best focus these resources. The goal of this study was to conduct a needs assessment across our community of patients to examine domains relevant to education and outreach, and better understand informational needs relevant to their disease. To our knowledge, there has never been a study that has assessed the educational needs among patients with hepatobiliary malignancies. With this goal in mind, we designed a study using survey methodology to collect information directly from patients.

# 2. Methods

# 2.1. Study design

This was a prospective, cross-sectional, survey study designed as a needs assessment for hepatobiliary patients evaluated at Moffitt Cancer Center. A patient-based survey focused on relevant domains and the field of hepatobiliary tumors was developed and disseminated across patients with history of hepatobiliary tumors, previously treated at Moffitt Cancer Center. Hepatobiliary tumors included all cancers with a primary origin within the liver (i.e., hepatocellular carcinoma, HCC) and bile ducts or gallbladder (i.e., cholangiocarcinoma, CCA; gallbladder cancer, GBC). Survey responses were compiled and analyzed to identify informational needs and patient preferences on outreach interventions. The Moffitt Cancer Center Scientific Review Committee and Institutional Review Board of record, Advarra, reviewed and approved this study.

# 2.2. Study population

Patients were identified from a prospectively collected database including all new patients with hepatobiliary tumors evaluated and treated by the Hepatobiliary Section at Moffitt Cancer Center and presented in the weekly hepatobiliary tumor board. Patients were identified from an institutional database of patients with hepatobiliary cancers evaluated and treated by the Hepatobiliary Section at Moffitt Cancer Center. Using a purposeful random sampling strategy, investigators (DAA and MH) randomly selected patients with the following characteristics: i) confirmed pathologic or radiologic diagnosis of liver, bile duct, and gallbladder tumors, ii) presented to the weekly tumor board, and iii) underwent surgical procedure between 2016 and 2019. Patients who did not have a valid address or listed a P.O. Box were excluded from the study. This was to ensure equal sampling from multiple diagnoses and time periods (by year). A waiver of HIPAA authorization and consent was requested to utilize this database as all survey responses were anonymous. For the consent process, each participant received a study informational sheet that provided instructions and additional study details, which included required elements of consent.

### 2.3. Survey development

The survey was designed to encompass the entire continuum of cancer care, including prevention, diagnosis, access, treatment, and survivorship. Survey content was informed by three a priori domains of interest: 1) Informational Needs: assessed educational needs of patients; 2) Interest in Participation: focused on motivators, facilitators, and barriers for active participation in different outreach formats; and 3) Community engagement: assessed opportunities for implementation of initiatives within the community. The treatment of liver tumors is a multidisciplinary field and several questions assessed perception of tumor board in cancer care. Survey items were created by the authors and reviewed by a psychometrician for appropriateness. The survey was pilot tested in a small sample of patients (n = 3) and adjustments were made accordingly. The final survey included 43 items (demographics = 7 items, informational needs = 16 items, interest in participation = 11 items, community engagement = 9 items). The final survey is available upon request.

# 2.4. Survey administration

The administration strategy utilized Dilman's Tailored Design Method (TDM), which was developed to reduce errors related to survey coverage, sampling, measurement, and nonresponse [11]. TDM recommends multiple contacts with at least one "special" mailing (i.e. envelope/package sent via FedEx). This included a mailed package with a personally addressed introductory letter, \$10 gift card incentive, survey, and paid return envelope. Opt-out postcards were also included in the mailing packet. Three scheduled reminders with replacement surveys were mailed at intervals of 2 weeks. No personal health information was recorded as the survey was anonymous.

# 2.5. Data collection and analysis

Survey responses were compiled into a secured, password-protected project database, and 10 % of surveys were randomly selected to be checked for scanning errors. Quantitative analyses included collating survey items and using descriptive statistics to summarize findings. The analysis was descriptive as there was no control group used, thus, data variables were summarized based on counts and percentages.

# 3. Results

#### 3.1. Overview of cohort

A total of 169 patients were identified as our study sample from the database. Seventy patients completed the survey, resulting in a response rate of 41.4%.

Table 1 summarizes reported characteristics of surveyed participants. The average age of respondents was  $69.3 \pm 9.9$  years old. Most patients were male (n = 42, 60%). Forty-six patients responded with a diagnosis, 25 with HCC (35.7%) and 21 with CCA/GBC (30%). There were twenty-four patients (34.3%) who were either unsure or did not respond when asked about their diagnosis. The population was predominantly white (94.3%) and non-Hispanic (84.2%). Most patients had surgery as the first treatment (n = 59, 84.3%), followed by other initial treatments including liver-directed therapies (n = 5, 7.1%), radiation (n = 4, 5.7%), and systemic therapy (n = 2, 2.9%).

# 3.2. Informational needs

When assessing informational needs, more than half of the full cohort (n = 39, 55.7%) ranked *cancer treatment* as the primary topic of interest closely followed by *symptom management* (n = 34, 48.6%), *nutrition* (n = 29, 41.4%), and *survivorship* (n = 24, 34.3%), with *physical activity*, *emotional well-being* and other topics ranking lower in priority. Fig. 1A shows the interests in educational topics by cancer diagnosis.

Table 2 summarizes survey responses by survey domain from the full cohort (N = 70). Most patients expressed informational needs related to screening programs. Twenty-three (32.9%) patients reported agreement in receiving education about risk factors leading to liver tumors and 22 patients (31.4%) reported education about screening guidelines. In addition, most patients (n = 57, 81.4%) could not confirm participation in a screening program prior to their diagnosis of liver cancer. Thirty-

#### Table 1

Summary of surveyed patient characteristics (N = 70).

CHARACTERISTICS	FREQUENCY (N $=$ 70)		
Age (mean $\pm$ SD)	$69.3 \pm 9.9$		
Reported Gender			
Male	42 (60.0%)		
Female	28 (40.0%)		
Race			
White	66 (94.3%)		
Black	4 (5.7%)		
Ethnicity			
Hispanic	9 (12.9%)		
Non-Hispanic	59 (84.3%)		
Prefer not to say	1 (1.4%)		
Missing	1 (1.4%)		
Diagnosis			
Hepatocellular Carcinoma (HCC)	25 (35.7%)		
Cholangiocarcinoma (CCA)	21 (30.0%)		
Not Sure	12 (17.1%)		
Missing	12 (17.1%)		
Primary Treatment for Cancer			
Surgery	59 (84.3%)		
Medication	2 (2.9%)		
Radiation	4 (5.7%)		
Liver-directed Therapy	5 (7.1%)		
Missing	1 (1.4%)		
Initial Cancer Diagnosis Made by:			
Primary Care Provider	24 (34.3%)		
Gastroenterology	19 (27.1%)		
Emergency Room Provider	11 (15.7%)		
Other	14 (20.0%)		
Missing	2 (2.9%)		
Referral after Initial Diagnosis			
Surgery	27 (38.6%)		
Gastroenterology	12 (17.1%)		
Medical Oncology	16 (22.9%)		
Radiation Oncology	4 (5.7%)		
Liver Transplant Program	2 (2.9%)		
Other	9 (12.9%)		
Origin of Referring Practice			
Academic/University Hospital	42 (60.0%)		
Community-based Hospital	6 (8.6%)		
Outpatient setting	13 (18.6%)		
Other	6 (8.6%)		
Missing	3 (4.3%)		

Where SD = standard deviation.

nine (55.7%) patients stated that they would want to receive more patient-centered education about their cancer diagnosis. Only 10 patients (14.3%) were not interested in receiving additional education.

Concerning multidisciplinary care and presentation at tumor boards, 48 patients (68.6%) stated they were informed that their case would be or had been presented at multidisciplinary tumor board (MDT), while a smaller sample stated they were not informed (n = 9, 12.9%). Most patients (n = 65, 92.9%) stated that they understood the role of each doctor involved in their multidisciplinary team and knew what MDT were (n = 49, 70%). Most also agreed that they understood the role of MDT (n = 48, 68.6%) and believed it to be beneficial to cancer care (n =49, 70%). Regarding their own case presentation, 43 (61.4%) patients knew that their case had been presented at MDT, while 35.7% were unsure. Of the patients who were presented at MDT, 38 patients (54.3%) stated they had been informed of MDT recommendations, 35.7% were unsure, and 7.1% stated they were not informed. Less patients were informed about controversies discussed at tumor board (n = 12, 17.1%), with the majority not being informed (n = 25, 35.7%) or unsure (n = 30, 42.9%).

# 3.3. Interest in participation

While most patients stated they wanted to receive more information about their type of cancer, only 17 (24.3%) stated they would be interested in attending a meeting or conference as an educational opportunity (Table 2). Educational resource utilization was variable across respondents. Most patients used online resources (n = 49, 70%), followed by brochures (n = 26, 37.1%), and meetings/symposiums (n = 3, 4.3%) (Fig. 1B). Twelve patients (17.1%) used no educational resources. The online resources found to be most useful were those from the American Cancer Society (n = 25, 35.7%), Mayo Clinic (n = 20, 28.6%), National Cancer Institute (n = 18, 25.7%), WebMD (n = 12, 17.1%), and other online resources (n = 15, 21.4%). In terms of dissemination of educational content, most patients preferred online methods. Of the online modalities, emailed articles/videos and websites were the most popular preferred formats (Fig. 1C). There was variable interest regarding access to additional resources such as social work, nutrition, psychology, etc. (Table 2).

# 3.4. Community engagement

Patients stated they would be more likely to attend meetings or conferences which included expert speakers in their field (n = 43, 61.4%) (Table 2). They were less likely to attend if the speakers or panelists were patients (n = 27, 38.6%). Thirty-nine patients (55.7%) did not endorse the ability to connect with other patients or support groups as a main driver to attend conferences. The majority (n = 48, 68.6%) of participants expressed no interest in attending a conference and only a few would engage as speakers (n = 4, 5.7%) or panelists (n = 4, 5.7%) within a conference format. In terms of schedule, the frequency of outreach was noted to be preferred on a quarterly or annual basis. If a conference were to be planned, most patients (n = 56, 80.0%) preferred it to last 1–2 h on a weekday rather than an extended weekend event.

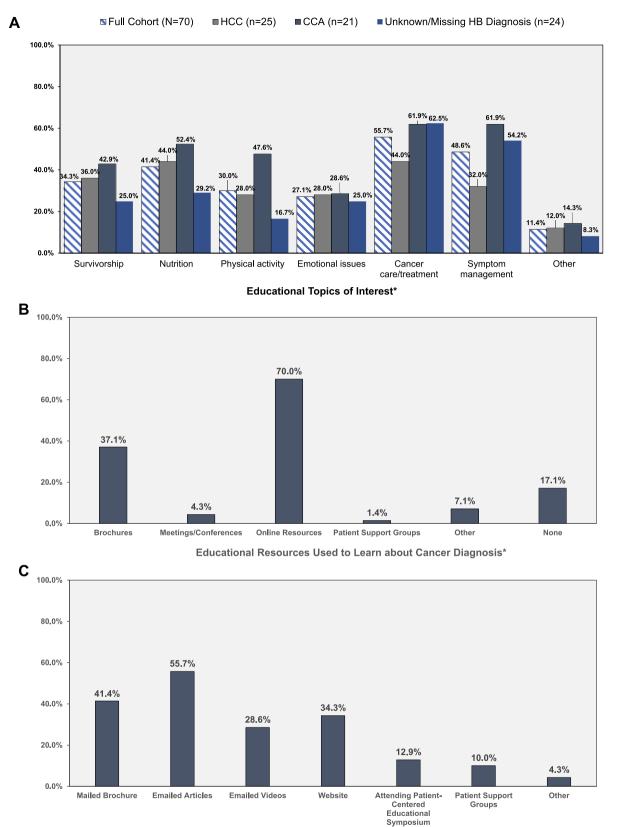
#### 4. Discussion and conclusion

#### 4.1. Discussion

This cross-sectional survey study reveals the educational needs of patients affected by hepatobiliary malignancies related to screening, diagnosis, and multidisciplinary treatment in our community. We also describe patient preferences for outreach efforts to address these deficits. In our institution, educational efforts are provided mostly in-person with education provided during clinic visits as well as during outreach seminars and conferences to engage patients in the community. We are hopeful that these data may provide insight into the best way to address educational needs for patients with hepatobiliary tumors due to the complex nature of their disease and its management. To our knowledge, this is the first study that has investigated patient knowledge and preferences regarding hepatobiliary cancer screening, diagnosis, and information dissemination. From these data, we offer three salient findings: 1) patient education regarding hepatobiliary malignancy risk factors and screening is lacking, 2) patients understand the importance of multidisciplinary care in their treatment but were not always informed of the resulting recommendations, and 3) designing outreach programs should focus on dissemination of electronic resources and education.

Risk factors for hepatobiliary malignancies are well-established and are typically related to chronic insult to the liver parenchyma leading to cirrhosis and eventual progression to cancer. These etiologies include viral hepatitis, alcohol abuse, steatosis, among others [12,13]. There are well developed screening guidelines for at risk individuals by multiple expert societies [14]. This study identified a gap in patient perception or education about risk factors and their participation in a screening program. This offers possibilities for collaboration within the medical community to expand formal patient education and implementing surveillance programs. It is notable that while patients may be appropriately enrolled in a screening program, they could be unaware that they were receiving the proposed standard of care for disease screening as most patients in our study responded that they did not participate in one.

Multidisciplinary care in the management of liver tumors is essential. Due to the complexity of treating liver tumors, it is well established that



Preferred Method to Receive Educational Information\*

**Fig. 1.** Patient's responses regarding educational needs, used resources and preferences for outreach/engagement opportunities. 1A. Patients' Interests in Educational Topics (N = 70). \*Participants instructed to "select all that apply"; categories not mutually exclusive. Where HB = hepatobiliary cancer. 1B. Patients' most used educational resources to learn about cancer diagnosis (N = 70). \*Participants instructed to "select all that apply"; categories not mutually exclusive. 1C. Patients' preferences regarding mode of education delivery (N = 70). \*Participants instructed to "select all that apply"; categories not mutually exclusive.

#### Table 2

Summary of select survey results from patients (N = 70).

Survey items Survey Domain: Informational Needs	Survey responses (%)						
	Strongly Agree	Somewhat Agree	Neither	Somewhat Disagree	Strongly Disagree	No Response	
Educated about risk factors prior to diagnosis	18.6	14.3	22.9	10.0	32.9	1.4	
Educated about screening guidelines	15.7	15.7	25.7	11.4	28.6	2.9	
Want to receive more patient-centered education about cancer diagnosis	34.3	21.4	28.6	7.1	7.1	1.4	
Understand the role of each doctor involved in patient care?	71.4	21.4	1.4	4.3	1.4	0.0	
Understand the role of tumor board?	35.7	32.9	18.6	2.9	8.6	1.4	
Believe tumor board is beneficial to care	51.4	18.6	24.3	0.0	4.3	1.4	
Survey Domain: Informational Needs	Yes	No	Unsure	Missing			
Participated in a screening program due to a risk factor	5.7	81.4	12.9	0.0			
Informed that case would be reviewed by tumor board	68.6	12.9	18.6	0.0			
Interested in learning more about							
Role of the surgical oncologist	50.0	37.1	7.1	5.7			
Role of the medical oncologist	45.7	35.7	10.0	8.6			
Role of the radiation oncologist	27.1	37.1	20.0	15.7			
Role of the interventional radiologist	27.1	32.9	25.7	14.3			
Do you know what tumor boards are?	70.0	15.7	14.3	0.0			
Was your case presented at tumor board?	61.4	2.9	35.7	0.0			
Informed about tumor board recommendations*	54.3	7.1	35.7	0.0			
Informed about controversies that were discussed at tumor board? <sup>†</sup>	17.1	35.7	42.9	0.0			
Survey Domain: Interest in Education	Yes	No	Missing				
Want to attend meetings/conferences to learn about cancer	24.3	68.6	7.1				
Healthcare facility currently offers educational events meeting my							
preferences and needs	40.0	25.7	34.3				
Access to the following resources: <sup>§</sup>							
Social worker	22.9	1.4	_				
Psychologist	15.7	7.1	_				
Nutritionist	38.6	10.0	_				
Patient Support Group	15.7	10.0	_				
Support Groups for Caregiver	11.4	5.7	_				
Spiritual Support	22.9	1.4	_				
Emotional Support	24.3	10.0	_				
Other	12.9	5.7	_				
Survey Domain: Community Engagement	Yes	No	Missing				
More likely to attend conferences with							
Speakers who are experts in the field	61.4	30.0	8.6				
Opportunities to meet other patients and support groups	37.1	55.7	7.1				
Speakers/panelists are patients	38.6	51.4	10.0				
Interested in becoming a speaker at a conference/educational event	5.7	90.0	4.3				
Interested in becoming a panelist at a conference/educational event	5.7	88.6	5.7				

 $^{\ast}\,$  N = 2 (2.9%) reported their case was not presented to tumor board.

 $^{\dagger}$  N = 3 (4.3%) reported their case was not presented to tumor board.

<sup>§</sup> Participants instructed to "select all that apply"; categories not mutually exclusive.

high volume centers report better outcomes and earlier interventions for these patients [15]. Multidisciplinary tumor boards are critical in facilitating these improved outcomes. The VOCAL study group reported that sub-specialist care within 30 days of HCC diagnosis, in conjunction with review by a multidisciplinary tumor board, were associated with reduced mortality (HR, 0.83; 95% CI, 0.77–0.90) [16]. Our own center's experience demonstrated the median time to treatment initiation was lower for patients reviewed at a tumor board compared to patients treated prior to the tumor board implementation (17 vs 24 days; P <0.01) [17]. This study illustrates that patients are aware of the benefit of multidisciplinary care and its implementation in the form of a multidisciplinary tumor board. However, there was a deficit in communication of tumor board results. This highlights the opportunity to optimize communication of tumor board recommendations and incorporating these discussions into the decision-making process for patients.

Finally, these findings are valuable in understanding community needs and patient preferences related to educational content and mode of delivery. Patients were generally motivated to learn about their disease and desired additional resources to better their understanding. Regarding the requested information, there was a broad interest in selected topics (Fig. 1A). Overall, there was a focus on learning about upto-date treatments as well as tools to assist in empowering patient independence (i.e., symptom management, disease education, etc.). Historically, the format for education relied on in-person participation with organized events such as conferences, symposia, or meetings. In our survey, participants strongly favor receiving information in an electronic format, with very low interest in live attendance (Fig. 1C). These points may inform design of an outreach program to best serve the educational needs of our community. We conclude that information should be primarily in the electronic format through emails, websites, and online modules. While there may still be a role for in-person meetings, this role is diminishing, or should be supplemented with electronic materials.

There are several limitations in this study. First, there is an inherent selection bias related to the type of patient who would respond to the survey. In theory, patients who responded would be more likely to engage in further education than their non-responding counterparts. This selection bias extends into the other domains as well as there are likely differences between responders and non-responders. Second, the sampling strategy used in this study was through an existing patient database from those who received care at our institution. As noted by the demographics of our cohort, this may not include all socioeconomic backgrounds of patients diagnosed with liver malignancies. Thus, the results should only be hypothesis-generating regarding their external validity. Third, our sample size is limited. However, we feel there are clear trends within the data from which reasonable conclusions can be drawn to inform our future patient and community outreach and education efforts. Fourth, our study focused on informational needs and

format to gain knowledge and empower patients through the course of their disease, however it did not include needs or preferences from a patient psychosocial support standpoint and as such the preferred formats apply to means for education and cannot be extrapolated to other patient needs, including support groups. Finally, this survey was meant to be an investigational study, thus was not designed to measure the effects of interventions. While certain conclusions can be drawn from the data, further work is necessary to test these assumptions within the field of hepatobiliary malignancies to determine if the patient-reported and treatment outcomes would improve with more informed outreach efforts. As such, our data provides a counterfactual to which future interventions may be compared.

### 4.2. Innovation

These data provide novel information regarding patient needs to inform educational interventions in the hepatobiliary population. The patient preferences identified in this article may help define innovative approaches for information delivery to better meet the needs of hepatobiliary patients. Applying these results for community outreach can be done by creating online educational resources and improving overall communication regarding the patient's care. Education should include topics that range from risk factors, resources for treatment, and screening programs. Based on patient preferences, in-person events should be held infrequently, and education modules should be provided primarily online. Implementation of an electronic format will allow educational materials to be on demand by a wide audience. Finally, communication about multidisciplinary care conferences should be improved and documented to include the patient in the decision-making regarding the treatment plan.

### 4.3. Conclusion

This study illustrates a community's needs for informing the design of an engaging outreach program for treatment and screening of patients with complex hepatobiliary cancers. We propose future quality improvement studies to further engage patients with outreach education about screening programs and communication of information. Additionally, the unexpected findings of patient awareness and communication of multidisciplinary tumor board results creates opportunities for investigating patient perceptions and communication needs relating to multidisciplinary care.

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#### **CRediT** authorship contribution statement

Sean M. Stokes: Formal analysis, Validation, Writing – original draft, Writing – review & editing. Mintallah Haider: Conceptualization, Investigation, Methodology, Project administration, Supervision, Validation, Visualization, Writing – review & editing. Susan T. Vadaparampil: Conceptualization, Investigation, Methodology, Project administration, Supervision, Validation, Writing – review & editing. Catherine Levitt: Investigation, Visualization, Writing – review & editing. Olivia Hardy: Investigation, Visualization, Writing – review & editing. Richard Kim: Conceptualization, Resources, Validation, Writing – review & editing. Diana L. Castillo: Formal analysis, Investigation, Project administration, Resources, Visualization, Writing – review & editing. Jason Denbo: Resources, Writing – review & editing. Jason B. Fleming: Resources, Writing - review & editing. Daniel A. Anaya: Conceptualization, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Writing – original draft, Writing – review & editing.

# **Declaration of Competing Interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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