










ORIGINAL RESEARCH

Health insurance literacy among head and neck cancer patients and their caregivers: A cross-sectional pilot study

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Abstract

Objective: Health insurance literacy interventions may reduce financial burden and its effects on cancer patients and their caregivers. However, little is known about the health insurance literacy levels of head and neck cancer (HNC) patients and their caregivers. We assessed the feasibility of screening for health insurance literacy in a pilot study and described the health insurance literacy levels of HNC patients and their caregivers.

Methods: We administered a survey that assessed demographics and subjective and objective health insurance literacy to HNC patients and their caregivers. Subjective health insurance literacy was measured through the Health Insurance Literacy Measure (score range: 0–84). Objective health insurance literacy was measured through correct answers to a previously developed 10-question knowledge test. Due to a

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small sample size, inferential statistics were not used; we instead descriptively reported findings.

Results: The pilot included 48 HNC patients and 13 caregivers. About 44.4% of patients and 30.8% of caregivers demonstrated low health insurance literacy (HILM ≤ 60). On the 10-item knowledge test, patients had an average of 6.8 (SD: 2.3) correct responses and caregivers had 7.8 (SD: 1.1) correct responses. Calculating out-of-pocket costs for out-of-network services was challenging; only 9.5% of patients and 0% of caregivers answered correctly.

Conclusion: Additional outreach strategies may be needed to supplement screening for health insurance literacy. Areas of focus for interventions include improving understanding of how to calculate financial responsibility for health care services and filing an appeal for health insurance claim denial.

Level of Evidence: IV

KEYWORDS

cancer center, caregivers, financial toxicity, head and neck cancer, health insurance literacy

1 | INTRODUCTION

The United States health insurance market is complex and challenging to navigate for most adults.¹⁻⁴ Some complicating factors include a mix of private and public payers and substantial variability in benefit and payment design across plans. Compared with other countries, the US adults reported spending more time appealing health insurance claim denials and having greater difficulty with navigating the health insurance market.⁵ For instance, within Medicare alone, beneficiaries can select from multiple supplemental insurance plans (e.g., 33 Medicare Advantage plans in 2021).² Furthermore, researchers have suggested that the range of options for private insurance plans may exceed those of Medicare or Medicaid plans.⁶ This complexity contributes to individuals' confusion and frustration when selecting a plan for themselves and their families.^{4,7-9} In addition to plan selection, adults can have difficulty with determining which healthcare services are covered under a given plan.¹⁰⁻¹² For instance, some patients may not fully understand what services apply toward a deductible and may forgo receiving preventive care.^{10,11} This burden of insurance navigation may fall on patients and their informal caregivers (e.g., family members, friends).^{12,13} Consequently, interventions targeting health insurance literacy may be warranted to address these challenges.

Health insurance literacy is defined as "the degree to which individuals have the knowledge, ability, and confidence to find and evaluate information about health plans, select the best plan for their own (or their family's) financial and health circumstances, and use the plan once enrolled."¹⁴ To date, there is only one validated measure of health insurance literacy, the Health Insurance Literacy Measure (HILM).^{8,15} Researchers have documented negative outcomes associated with poor health insurance literacy, such as delaying or avoiding care,^{15,16} difficulty paying medical bills^{17,18} and reporting difficulty in

paying for non-medical needs (e.g., rent, food).¹⁹ National data suggest that 53.8% of US adults have low health insurance literacy based on the HILM (defined as having a score of ≤ 60 out of 84),²⁰ suggesting opportunities for improvement. One area where health insurance literacy may be critical is cancer care. Studies demonstrate that cancer patients are subject to higher out-of-pocket expenditures and are more likely to declare personal bankruptcy than adults without cancer.^{21,22} Furthermore, coverage rules are more complex to navigate in cancer care (e.g., different coverage rules based on whether an anticancer drug treatment is administered orally or intravenously).²³ Health insurance literacy has been understudied among cancer patients; available studies suggest some adults living with cancer have a limited understanding of health insurance.^{19,24}

Health insurance literacy may be particularly important among head and neck cancer (HNC) patients who experience substantial financial toxicity compared with other cancer patients.²⁵⁻³⁶ The median annual out-of-pocket medical expenses for HNC patients is \$8101 compared with \$5930 for patients with other cancer types.²⁷ Expenses may continue well after HNC treatment has ended.²⁸ The financial toxicity may also affect patients' family caregivers.³⁷ For instance, caregiving may impact the ability for caregivers to maintain their employment and income.^{37,38} Despite this high financial burden, limited research exists on the state of health insurance literacy among HNC patients and their caregivers.

To address this gap, we used a pilot study design to evaluate the feasibility of assessing health insurance literacy among HNC patients and their caregivers and generate hypotheses for further testing. We also described subjective insurance literacy using a validated measure of health insurance literacy (HILM) and objective insurance literacy by assessing knowledge of insurance terminology among HNC patients and caregivers. The findings can inform future financial navigation interventions for HNC patients and caregivers.

2 | MATERIALS AND METHODS

We reported the design and findings of this cross-sectional survey using the Strengthening the Reporting of Observational Studies in Epidemiology guidelines.³⁹ This study was reviewed and approved by the study site's Institutional Review Board of record, Advarra.

2.1 | Setting and participants

We recruited adult patients (aged 18 years and up) that spoke English and were initiating treatment for HNC at a National Cancer Institute (NCI)-designated Comprehensive Cancer Center in Florida. Patients could also identify a primary caregiver to participate in the study. We contacted available primary caregivers to assess their interest in study participation.

2.2 | Study procedures

We recruited patients and caregivers from the HNC clinics from October 2020 to December 2021. After consenting and recruitment, participants were provided the survey through their preferred mode (electronic or paper). The research team provided up to four reminders through phone calls and emails. Participants were compensated with a \$20 e-gift card.

2.3 | Data collection and survey characteristics

The survey collected demographic information (age, sex, relationship status, insurance type, race/ethnicity, education and household income). Caregivers were also asked about caregiver duration, relation to patient (e.g., spouse, parent), and whether they shared finances with the patient. The survey assessed health insurance literacy using the Health Insurance Literacy Measure.⁸ Although this instrument has not yet been validated among HNC patients and caregivers specifically, there is evidence that supports its validity among diverse US adult populations.⁸ The HILM identifies four domains of health insurance literacy: (1) confidence in choosing plans, (2) comparing plans, (3) using plans and (4) being proactive with plan use.⁸ The HILM presents participants with 21 questions that assess their confidence to complete various health insurance tasks.⁸ The overall score ranges from 0 to 84 with a higher score indicating greater health insurance literacy. Consistent with previous work,²⁰ we used a score of 60 or below to define low health insurance literacy, which has been previously done by another study. The HILM contains four sub-scales: (1) choosing insurance (range: 6–30); (2) comparing health plans (range: 6–30); (3) using insurance (range: 5–25) and (4) being proactive with insurance (range: 4–20). For each item, respondents select from a Likert-type scale ranging from “not at all confident” (1 point) to “very confident” (4 points). Since there may be discrepancies between perceived health insurance literacy and actual health insurance knowledge,¹ participants were also presented with 10 multiple-choice

questions that were developed by Kaiser Family Foundation (KFF) to assess objective health literacy.⁴⁰

We also abstracted patient clinical characteristics (cancer site, stage and treatment) and home address at time of diagnosis from the electronic health record. Extracted addresses were used to assign a 2010 Rural–Urban Community Area Code to determine whether a patient resided in a rural or urban area.⁴¹

Feasibility of health insurance literacy screening was measured through the consent rate and data completion rate. We defined the consent rate as the percentage of participants who consented to the study out of all participants approached. We defined the data completion rate as the percentage of participants who answered questions on health insurance literacy from all participants who consented to the study.

2.4 | Analytic approach

We reported the sample characteristics using mean and SD. We also descriptively summarized the overall and subscale scores for the HILM measure. For the KFF insurance knowledge test, we reported the percentage of correct responses. Using thresholds we set a priori from prior experience and other literature on administering patient-reported outcome instruments in cancer care,^{42–44} we interpreted a consent rate of $\geq 50\%$ and a data completion rate of $\geq 60\%$ “as showing feasibility of screening health insurance literacy outside of the clinic setting” to match the language used throughout the rest of the paper of this screening being conducted outside of the clinic. Due to the small sample size of this pilot study, no inferential testing was conducted. Missing data were coded as such per variable of interest when reporting sample characteristics. Records with missing data for the outcome measure were excluded when reporting health insurance literacy scores. All analyses were conducted with Stata SE 17.0 (StataCorp, LLC, College Station, TX).

3 | RESULTS

3.1 | Feasibility of assessing health insurance literacy in clinic

A total of 174 patients were approached about the study. Of these, 81 patients consented and were sent the survey (consent rate: 46.6%). Among these, 44 completed the health insurance literacy items (completion rate: 54.3%). A total of 24 caregivers were identified by patients and were approached about the study. Of these, 19 (consent rate: 79.2%) were sent the survey, and 15 began the survey (response rate: 78.9%). Among caregivers who started the survey, 13 completed their surveys (completion rate: 86.7%).

3.2 | Sample characteristics

The final sample included 48 patients and 13 caregivers. Most patients had some college education, vocational training, or a

TABLE 1 Sample characteristics (n = 48 patients, 13 caregivers)

Characteristics	Patients n (%)	Caregivers n (%)
Age, mean (SD) ^{a,b}	62.1 (10.7)	52.8 (16.0)
Sex		
Male	28 (58.3%)	1 (7.7%)
Female	20 (41.7%)	12 (92.3%)
Relationship status		
Currently married or in a committed relationship	33 (68.8%)	11 (84.6%)
Widowed	4 (8.3%)	0 (0.0%)
Divorced or separated	7 (14.6%)	1 (7.7%)
Never married	3 (6.3%)	1 (7.7%)
Prefer not to answer or missing data	1 (2.1%)	0 (0.0%)
Ethnicity		
Not Hispanic or Latino	46 (95.8%)	13 (100.0%)
Hispanic or Latino	2 (4.2%)	0 (0.0%)
Race		
White or Caucasian	45 (93.8%)	13 (100.0%)
More than one ^c	2 (4.2%)	0 (0.0%)
Not listed	1 (2.1%)	0 (0.0%)
Education		
Less than high school diploma or equivalent	2 (4.2%)	0 (0.0%)
High school diploma or equivalent	16 (33.3%)	0 (0.0%)
Some college, associate's degree or vocational training	17 (35.4%)	8 (61.5%)
Four-year college degree or bachelor's degree	8 (16.7%)	3 (23.1%)
Postgraduate degree	4 (8.3%)	2 (15.4%)
Other	1 (2.1%)	0 (0.0%)
Urbanicity		
Rural residence	2 (4.2%)	0 (0.0%)
Urban residence	45 (93.8%)	13 (100.0%)
Prefer not to answer or missing data	1 (2.1%)	0 (0.0%)
Household income		
< \$10,000	1 (2.1%)	0 (0.0%)
\$10,001–\$25,000	3 (6.3%)	0 (0.0%)
\$25,001–\$50,000	15 (31.3%)	5 (38.5%)
\$50,001–\$75,000	6 (12.5%)	3 (23.1%)
\$75,001–\$100,000	10 (20.8%)	1 (7.7%)
>\$100,000	10 (20.8%)	6 (30.8%)
Prefer not to answer or missing data	3 (6.3%)	0 (0.0%)
Insurance status ^d		
Uninsured	1 (2.1%)	2 (15.4%)
Employer-sponsored insurance	24 (50.0%)	6 (46.2%)
Privately purchased private insurance	15 (31.3%)	1 (7.7%)

TABLE 1 (Continued)

Characteristics	Patients n (%)	Caregivers n (%)
Medicare	22 (45.8%)	3 (23.1%)
Medicaid or other government assistance plan	2 (4.2%)	0 (0.0%)
TRICARE	4 (8.3%)	3 (23.1%)
VA	3 (6.3%)	2 (15.4%)
Not listed	7 (14.6%)	0 (0.0%)
Prefer not to answer or missing data	7 (14.6%)	0 (0.0%)
Cancer type		
Laryngeal	3 (6.3%)	—
Nasopharyngeal	2 (4.2%)	—
Oral cavity	15 (31.3%)	—
Oropharyngeal	20 (37.5%)	—
Other ^e	10 (20.9%)	—
Cancer stage		
Stage 1	8 (16.7%)	—
Stage 2	7 (14.6%)	—
Stage 3	12 (25.0%)	—
Stage 4	12 (25.0%)	—
Unknown	9 (18.8%)	—
Time since initial diagnosis		
<1 year ago	41 (85.4%)	—
1 year or more ago	2 (4.2%)	—
Unknown	5 (10.4%)	—
Treatment type		
Chemotherapy or radiotherapy only	22 (45.8%)	—
Surgery only	11 (22.9%)	—
Surgery and adjuvant therapy	9 (18.8%)	—
Unknown	6 (12.5%)	—
Relation to patient		
Spouse or partner	—	10 (76.9%)
Child	—	2 (15.4%)
Not listed	—	1 (7.7%)
Sharing finances with patient		
No finances shared	—	1 (7.7%)
No finances shared, but caregiver contributes financially	—	2 (15.4%)
Some finances shared	—	3 (23.1%)
All finances shared	—	7 (53.9%)

^aAbbreviations include standard deviation (SD).

^bPercentages may not add up to 100% due to rounding.

^cOther races include American Indian or Alaska Native, Asian, Black or African-American, Middle Eastern or North African, and Native Hawaiian or other Pacific Islander.

^dRespondents could select more than one insurance option.

^eOther cancer types include nasopharyngeal, paranasal and nasal cavity, ill-defined sites and unknown.

(Continues)

bachelor's degree (52.1%) and had a household income of \$25,001–\$50,000 (31.3%). Most caregivers had at least some college education, vocational training or a bachelor's degree (84.6%) and had a household income of \$25,001–\$50,000 (38.5%) (Table 1).

3.3 | Subjective insurance literacy

Across completed patient responses, the mean composite HILM score was 42.1 (SD: 27.1) (Table 2). Patients scored a mean of 15.8 (SD: 4.6) out of 30 points on the confidence in choosing an insurance plan domain ($n = 36$ patients), 16.6 (SD: 4.8) out of 30 points on the comparing health plans domain ($n = 41$ patients), 11.8 (SD: 4.4) out of 25 points on the confidence in using the insurance plan domain ($n = 41$ patients), and 10.8 (SD: 3.6) out of 20 points on the being proactive with insurance plan use domain ($n = 41$ patients). Approximately 44.4% of patients reported low health insurance literacy (score ≤ 60).

Among caregivers, the mean composite HILM score was 60.8 (SD: 17.9) (Table 2). Caregivers scored a mean of 17.4 (SD: 5.1) out of 30 points on the confidence choosing an insurance plan domain, 18.4 (SD: 5.1) out of 30 points on the comparing health plans domain, 12.9 (SD: 5.9) out of 25 points on the confidence in using the insurance plan domain, and 12.1 (SD: 3.7) out of 20 points on the being proactive with insurance plan use domain. Approximately 30.8% of caregivers reported low health insurance literacy (score ≤ 60). Full reporting of the performance of each survey item for patients and caregivers is reported in Table 2.

3.4 | Objective insurance literacy

For completed patient responses ($n = 42$), the average number of correct responses was 6.8 (SD: 2.3) on the KFF health insurance knowledge test (Table 3). No patient answered all 10 questions correctly. At

TABLE 2 Health insurance literacy measure scores

Construct	Patients Mean (SD)	Caregivers Mean (SD)
<i>Confidence Choosing Insurance Subscale Score (total: 30 points)</i>	15.8 (4.6)	17.4 (5.1)
You understand health insurance terms?	2.7 (0.9)	2.8 (0.8)
You know where to find the information you need to choose a health plan if you were not offered insurance through an employer?	2.9 (0.9)	3.2 (1.1)
You know how to estimate what you have to pay for your health care needs in the next year, not including emergencies?	2.3 (1.1)	2.8 (0.9)
You know where to go for help if you were having trouble affording health insurance outside of an employer?	2.0 (1.1)	2.7 (1.1)
You know what questions to ask so you can choose the best health plan for you?	2.6 (0.9)	2.8 (1.0)
You would choose the health plan that is best for you?	3.0 (0.9)	3.2 (0.8)
<i>Comparing Health Plans Subscale Score (total: 30 points)</i>	16.6 (4.8)	18.4 (5.1)
Understand how the plans differ?	2.7 (0.7)	2.8 (0.8)
Find out if you have to meet a deductible for health care services?	3.0 (0.9)	3.2 (0.9)
Look to see which doctors and hospitals are covered in each plan?	3.0 (1.0)	3.2 (0.8)
Understand what you have to pay for prescription drugs?	2.7 (1.0)	3.2 (0.8)
Understand what you would have to pay for emergency visits?	2.7 (1.1)	3.1 (1.0)
Understand what you would have to pay for specialist visits?	2.6 (1.1)	2.9 (1.0)
<i>Confidence Using Insurance Subscale Score (total: 25 points)</i>	11.8 (4.4)	12.9 (5.9)
You know what to do if your health plan refuses to pay for a service you think should be covered?	2.3 (1.0)	2.8 (1.1)
You know how to figure out your share of the cost for care, after the health plan pays their share?	2.2 (1.0)	2.5 (1.3)
You know what questions to ask your health plan if you have a coverage problem?	2.4 (1.1)	2.5 (1.3)
You know most of the things you need to know about using health insurance?	2.5 (0.9)	2.7 (1.3)
You know how to find out what is and is not covered before you receive a health care service?	2.3 (0.9)	2.5 (1.3)
<i>Being Proactive with Insurance Subscale Score (total: 20 points)</i>	10.8 (3.6)	12.1 (3.7)
Look to member services to tell you what medical services your health plan covers?	2.8 (1.1)	2.8 (0.9)
Look into what your health plan will and will not cover before you get health care services?	2.2 (1.1)	2.9 (1.1)
Review the statements you get from your health plan showing what you owe and what they paid for a service?	2.9 (1.0)	3.2 (1.1)
Find out if a doctor is in-network before you see him/her?	2.9 (1.0)	3.2 (0.9)
<i>Composite Health Insurance Literacy Scores (total: 84 points)^a</i>	42.1 (27.1)	60.8 (17.9)
% with low health insurance literacy (score ≤ 60), n (%)	16 (44.4%)	9 (30.8%)

^aOnly includes complete responses across HILM instrument ($n=$).

TABLE 3 Health insurance knowledge test results

Question	Patients n (% correct)	Caregivers n (% correct)
<i>Health Insurance Knowledge Test</i>		
Average number of correct responses on health insurance knowledge test, mean (SD)	6.8 (2.3)	7.8 (1.1)
Percentage of participants who answered all 10 health insurance knowledge questions correctly	0 (0.0%)	0 (0.0%)
Which of the following is the best definition of the term “health insurance premium”?	36 (85.7%)	12 (100.0%)
Is a health insurance premium something you must pay every month, regardless of whether you use health care services, or do you only have to pay for your health insurance premium during months when you use health care services?	39 (92.9%)	12 (100.0%)
Which of the following is the best definition of the term “annual health insurance deductible”?	34 (81.0%)	11 (91.7%)
Suppose that under your health insurance policy, hospital expenses are subject to a \$1000 deductible and \$240 per day copay. You get sick and are hospitalized for 4 days, and the bill (after insurance discounts are applied) comes to \$6000. How much of that hospital bill will you have to pay yourself?	24 (57.1%)	8 (66.7%)
Which of the following best describes the “annual out-of-pocket limit” under a health insurance policy?	32 (76.2%)	11 (91.7%)
Which of the following best describes a “health insurance formulary”?	17 (40.5%)	8 (66.7%)
Which of the following best describes a health plan “provider network”?	38 (90.5%)	12 (100.0%)
True or false: If you receive inpatient care at a hospital that participates in your health plan's provider network, all the doctors who care for you while you are in the hospital will also be in network.	25 (59.5%)	10 (83.3%)
Suppose your health plan covers lab tests in full if you go to an in-network lab, but only pays 60% of allowed charges if you go out of network. You forget to check and go get your blood test at a lab that turns out to be out of network. The lab bills you \$100 for the blood test. Your health insurance allows only a \$20 charge for that test. How much would you have to pay out of pocket for that lab test?	4 (9.5%)	0 (0.0%)
True or false: If your health insurance or health plan refuses to pay for a service that you think is covered and your doctor says you need, you can appeal the denial and possibly get the insurance company to pay the claim.	36 (85.7%)	10 (83.3%)

the question-level, correct responses ranged from 9.5% (calculating out-of-pocket costs for an out-of-network lab test) to 92.9% (payment schedule for health insurance premiums).

For completed caregiver responses ($n = 12$), the average number of correct responses was 7.8 (SD: 1.1) on the knowledge test. No caregiver answered all 10 questions correctly. However, all caregivers correctly answered questions on the payment schedule for health insurance premiums and the definition of a premium and provider network. None of the caregivers correctly answered the question on calculating out-of-pocket costs for an out-of-network lab test. Detailed performance on each question is reported in Table 3.

4 | DISCUSSION

This study assessed the feasibility of health insurance literacy screening outside of the clinic setting and described health insurance literacy among HNC patients and their caregivers. Overall, our pilot found that administering health insurance literacy screening tools fell slightly below our feasibility targets for both HNC patients and their caregivers, suggesting a need for further outreach strategies to supplement screening outside of the clinic. Notwithstanding, almost half of HNC patients and a third of their caregivers reported low insurance literacy in our sample. HILM sub-scale scores suggest patients and caregivers have similar difficulty with choosing an insurance plan, comparing insurance plans, using health insurance, and being proactive with

insurance. HNC patients and caregivers also demonstrated low objective health insurance literacy, particularly around calculating expected out-of-pocket costs and understanding consumer rights about appealing health claim denials. Similar to studies in adults with cancer,^{19,24} our findings suggest that a considerable proportion of patients and their caregivers may benefit from health insurance literacy interventions. We discuss the implications for clinical practice below.

We found that HNC patients and caregivers reported difficulty with choosing a health insurance plan (patients: 15.8/30 points; caregivers: 17.4/30 points). This point is particularly salient because some insurance plans do not offer in-network benefits from some oncology clinicians or hospitals.^{45,46} For instance, only 41% of Federal Exchange Plan networks under the Affordable Care Act included at least one NCI-designated Cancer Center,⁴⁶ despite growing research that shows NCI-designated Cancer Centers may offer emerging treatments,⁴⁷ greater adherence to care guidelines,^{48,49} and comparable or improved clinical outcomes (e.g., operative mortality rates) compared with non-NCI-designated centers.^{48,50-55} Furthermore, our study offers preliminary evidence that patients and their caregivers may be unaware of changes to plan networks where the patient's current care team is now out-of-network.⁵⁶ Together, these events can lead to disruptions to continuity of care and higher out-of-pocket expenses for patients and their caregivers. Consequently, patients and their caregivers may benefit from interventions to help them evaluate and select a health plan for themselves. Notably, our sample of HNC patients and their caregivers reported low confidence in knowing what points they should

consider when evaluating a health plan, suggesting that personalized decision aids may facilitate the decision process for selecting a health plan. Decision aids may improve health insurance knowledge and confidence in selecting a health plan,^{57,58} including among cancer populations.⁵⁸ Further research is needed to tailor decision aids to individuals who have low health insurance literacy. Additionally, identification of effective decision aid components (e.g., total cost estimators, quality ratings) can inform future development of decision aids.⁵⁹

Our objective literacy assessment results suggest HNC patients and caregivers had low knowledge in how to file an appeal for claim denial. This finding is consistent with a qualitative study on adolescent and young adult cancer patients.¹³ Notably, approximately <10% of claim denials have an appeal attempt.⁶⁰⁻⁶² Meanwhile, estimates on the proportion of claim denials that become overturned after appealing range from 39% to 80%,⁶⁰⁻⁶⁵ with cancer-specific estimates ranging from 45% for general cancer patients to 97% for pediatric blood cancer patients.^{66,67} These preliminary findings suggest empowering patients and caregivers with the knowledge on the process of claim appeals may lead to lower out-of-pocket expenses for cancer patients and caregivers and bad debt for cancer centers. Although patients can initiate appeals,^{61,68} some appeals may involve the healthcare organization to directly intervene in the form of providing signed paperwork to the insurer or having a peer-to-peer telephone call between the treating care team and a clinical representative from the insurer.^{61,69} Collaborating with the cancer center in filing an appeal may be advantageous since cancer centers may have substantially more experience in navigating the process than patients or their caregivers.⁶⁹ For instance, cancer centers could assist patients and their caregivers with interpreting jargon-laden denial letters and facilitating decision-making with whether to appeal.⁶² Although most NCI-designated Cancer Centers offer some form of financial services (e.g., debt management counseling, assistance paying medical bills) to patients,⁷⁰ it is unclear how often patients receive proactive counseling on appealing claim denials. Additional research is needed to design and implement interventions to improve patient and caregiver confidence in filing appeals for health insurance claim denials. Federal efforts are also being designed and implemented to simplify enrollment and insurance navigation processes, which may hold benefits for cancer populations.^{71,72} For instance, the Centers for Medicare and Medicaid Services is requiring public plans to provide individualized cost-sharing expectations with potential enrollees before they enroll as part of the national price transparency effort.⁷²

Although existing studies in the oncology setting highlight opportunities for improvement in improving health insurance literacy among patients,^{19,24} our study is the first to focus on HNC patients and their caregivers. Findings suggest that while low health insurance literacy is still a notable issue, caregivers may be less likely to report low health insurance literacy compared with patients (30% vs. 44%). A similar finding was observed on the objective insurance literacy questions, where caregivers correctly answered a greater percentage of questions than patients. Together, these data suggest that caregivers may be an important source of support for patients when navigating health insurance and should be included in financial navigation interventions in the

future. Our estimates on the rates of low health insurance literacy were also lower than the US general population (53.8%), suggesting that there may be systematic efforts that are somewhat addressing health insurance literacy among cancer populations. Nonetheless, further work is needed to improve their health insurance literacy. Disease-specific interventions have shown some improvements.⁷³⁻⁷⁸ For instance, promising results have been documented from the use of financial navigators and related programs in oncology care.⁷³⁻⁷⁷ However, research has traditionally targeted only patients and did not include caregivers. Future research should assess the impact of financial navigators on caregivers' health insurance literacy and financial self-efficacy. This is especially critical as our findings suggest that most caregivers were financially involved in their patients' care, which is consistent with other evidence among cancer patients' caregivers.^{12,13}

This pilot's findings come with limitations. First, our sample comes from an NCI-designated Comprehensive Cancer Center, which may limit generalizability to other cancer settings. Second, most study participants were non-Hispanic White and not representative of the diverse population that makes up HNC patients.²⁷ Further research is needed in cancer care settings with greater representation of other racial and ethnic groups. Third, although the responders and non-responders in our sample were comparable by race, ethnicity, and sex, respondents who consented were more likely to be younger. The same pattern was observed for respondents who fully completed the questionnaire compared with non-responders. Accordingly, our results may not generalize to older patients with HNC. Fourth, our low consent and completion rates suggest the need to test additional screening strategies (e.g., in-clinic screening). Lastly, we recruited a small sample size of HNC patients and caregivers. The goal of this study was to pilot data collection for the HILM; in future studies, we intend to expand this health insurance literacy survey to more patients.

5 | CONCLUSION

HNC patients and their caregivers often experience financial hardship as a result of the complex care that HNC patients receive. Health insurance literacy may help patients with navigating their insurance plans and reduce financial hardship. We found that some HNC patients and their caregivers reported low health insurance literacy, especially when calculating personal financial responsibility for receiving a health care service. Future research should use larger sample sizes to identify potential differences in health insurance literacy between HNC patients and their caregivers. Further work is also needed to test decision aids on cancer patients and their caregivers.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

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REFERENCES

- Loewenstein G, Friedman JY, McGill B, et al. Consumers' misunderstanding of health insurance. *J Health Econ*. 2013;32(5):850-862.
- Biniek JF, Freed M, Damico A, Neuman T. *Medicare Advantage 2021 Spotlight: First Look*. Kaiser Family Foundation, 2020. <https://www.kff.org/medicare/issue-brief/medicare-advantage-2021-spotlight-first-look/>. Accessed March 19, 2022.
- Sommers BD, Rosenbaum S. Issues in health reform: how changes in eligibility may move millions back and forth between medicaid and insurance exchanges. *Health Affairs*. 2011;30(2):228-236.
- Heiss F, McFadden D, Winter J. Who failed to enroll in Medicare Part D, and why? Early results. *Health Affairs*. 2006;25(5):w344-w354.
- Schoen C, Osborn R, Squires D, Doty MM. Access, affordability, and insurance complexity are often worse in the United States compared to ten other countries. *Health Affairs*. 2013;32(12):2205-2215.
- Adepoju O, Mask A, McLeod A. Factors associated with health insurance literacy: proficiency in finding, selecting, and making appropriate decisions. *J Healthc Manag*. 2019;64(2):79-89.
- Ali NM, Combs RM, Muvuka B, Ayangeakaa SD. Addressing health insurance literacy gaps in an urban African American population: a qualitative study. *J Community Health*. 2018;43(6):1208-1216.
- Paez KA, Mallery CJ, Noel H, et al. Development of the health insurance literacy measure (HILM): conceptualizing and measuring consumer ability to choose and use private health insurance. *J Health Commun*. 2014;19(Suppl 2):225-239.
- Abaluck J, Gruber J. Heterogeneity in choice inconsistencies among the elderly: evidence from prescription drug plan choice. *Am Econ Rev*. 2011;101(3):377-381.
- Reed ME, Graetz I, Fung V, Newhouse JP, Hsu J. In consumer-directed health plans, a majority of patients were unaware of free or low-cost preventive care. *Health Affairs*. 2012;31(12):2641-2648.
- Smith KT, Monti D, Mir N, Peters E, Tipirneni R, Politi MC. Access is necessary but not sufficient: factors influencing delay and avoidance of health care services. *MDM Policy Pract*. 2018;3(1).
- George N, Grant R, James A, Mir N, Politi MC. Burden associated with selecting and using health insurance to manage care costs: results of a qualitative study of nonelderly cancer survivors. *Med Care Res Rev*. 2021;78(1):48-56.
- Waters AR, Mann K, Warner EL, et al. "I thought there would be more I understood": health insurance literacy among adolescent and young adult cancer survivors. *Support Care Cancer*. 2022;30:4457-4464. doi: [10.1007/s00520-022-06873-2](https://doi.org/10.1007/s00520-022-06873-2)
- Consumers Union, University of Maryland College Park, American Institutes for Research. Measuring health insurance literacy: A call to action. <https://www.air.org/sites/default/files/Health-Insurance-Literacy-Roundtable.pdf>. Accessed March 19, 2022.
- Yagi BF, Luster JE, Scherer AM, Farron MR, Smith JE, Tipirneni R. Association of health insurance literacy with health care utilization: a systematic review. *J Gen Intern Med*. 2022;37(2):375-389.
- Call KT, Conmy A, Alarcón G, Hagge SL, Simon AB. Health insurance literacy: how best to measure and does it matter to health care access and affordability? *Res Social Adm Pharm*. 2021;17(6):1166-1173.
- Dean CA, Wiltshire J, Liu E, Amamoo MA, Garcia Colato E, Elder K. Confidence in understanding health insurance and challenges paying medical bills among men in the United States. *Am J Mens Health*. 2020;14(4).
- Wiltshire J, Liu E, Dean CA, Colato EG, Elder K. Health insurance literacy and medical debt in middle-age Americans. *Health Lit Res Pract*. 2021;5(4):e319-e332.
- Williams CP, Pisu M, Azuero A, et al. Health insurance literacy and financial hardship in women living with metastatic breast cancer. *JCO Oncol Pract*. 2020;16(6):e529-e537.
- Tipirneni R, Politi MC, Kullgren JT, Kieffer EC, Goold SD, Scherer AM. Association between health insurance literacy and avoidance of health care services owing to cost. *JAMA Netw Open*. 2018;1(7):e184796.
- Ramsey S, Blough D, Kirchhoff A, et al. Washington state cancer patients found to be at greater risk for bankruptcy than people without a cancer diagnosis. *Health Affairs*. 2013;32(6):1143-1152.
- Bernard DSM, Farr SL, Fang Z. National estimates of out-of-pocket health care expenditure burdens among nonelderly adults with cancer: 2001 to 2008. *J Clin Oncol*. 2011;29(20):2821-2826.
- Centers for Medicare & Medicaid Services. Medicare coverage of cancer treatment services. <https://www.medicare.gov/Pubs/pdf/11931-Cancer-Treatment-Services.pdf>. Accessed April 3, 2022.
- Edward JS, Rayens MK, Zheng X, Vanderpool RC. The association of health insurance literacy and numeracy with financial toxicity and hardships among colorectal cancer survivors. *Support Care Cancer*. 2021;29(10):5673-5680.
- Coughlan D, Yeh ST, O'Neill C, Frick KD. Evaluating direct medical expenditures estimation methods of adults using the medical expenditure panel survey: an example focusing on head and neck cancer. *Value Health*. 2014;17(1):90-97.
- Mady LJ, Lyu L, Owoc MS, et al. Understanding financial toxicity in head and neck cancer survivors. *Oral Oncol*. 2019;95:187-193.
- Massa ST, Osazuwa-Peters N, Adjei Boakye E, Walker RJ, Ward GM. Comparison of the financial burden of survivors of head and neck cancer with other cancer survivors. *JAMA Otolaryngol Head Neck Surg*. 2019;145(3):239-249.
- Baddour K, Fadel M, Zhao M, et al. The cost of cure: examining objective and subjective financial toxicity in head and neck cancer survivors. *Head Neck*. 2021;43(10):3062-3075.
- Lu L, O'Sullivan E, Sharp L. Cancer-related financial hardship among head and neck cancer survivors: risk factors and associations with health-related quality of life. *Psychooncology*. 2019;28(4):863-871.
- Wissinger E, Griebisch I, Lungershausen J, Foster T, Pashos CL. The economic burden of head and neck cancer: a systematic literature review. *Pharmacoeconomics*. 2014;32(9):865-882.
- Pearce A, Timmons A, O'Sullivan E, et al. Long-term workforce participation patterns following head and neck cancer. *J Cancer Surviv*. 2015;9(1):30-39.
- Buckwalter AE, Karnell LH, Smith RB, Christensen AJ, Funk GF. Patient-reported factors associated with discontinuing employment following head and neck cancer treatment. *Arch Otolaryngol Head Neck Surg*. 2007;133(5):464-470.
- Beeler WH, Bellile EL, Casper KA, et al. Patient-reported financial toxicity and adverse medical consequences in head and neck cancer. *Oral Oncol*. 2020;101:104521.

34. Jacobson JJ, Epstein JB, Eichmiller FC, et al. The cost burden of oral, oral pharyngeal, and salivary gland cancers in three groups: commercial insurance, medicare, and medicaid. *Head Neck Oncol.* 2012;4:15.
35. Ma SJ, Iovoli AJ, Attwood K, et al. Association of significant financial burden with survival for head and neck cancer patients treated with radiation therapy. *Oral Oncol.* 2021;115:105196.
36. de Souza JA, Kung S, O'Connor J, Yap BJ. Determinants of patient-centered financial stress in patients with locally advanced head and neck cancer. *J Oncol Pract.* 2017;13(4):e310-e318.
37. Balfe M, Butow P, O'Sullivan E, Gooberman-Hill R, Timmons A, Sharp L. The financial impact of head and neck cancer caregiving: a qualitative study. *Psychooncology.* 2016;25(12):1441-1447.
38. Baddour K, Fadel MA, Kudrick LD, Neopaney A, Ferris RL, Mady LJ. Caregiver experience throughout head and neck cancer survivorship: longitudinal study. *Otolaryngol Head Neck Surg.* 2021;165(1 SUPPL):P99-P100.
39. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. Strengthening the reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies. *BMJ.* 2007;335(7624):806-808.
40. Kaiser Family Foundation. Assessing Americans' familiarity with health insurance terms and concepts. <https://files.kff.org/attachment/assessing-americans-familiarity-with-health-insurance-terms-and-concepts-topline-methodology>. Accessed March 22, 2022.
41. United States Department of Agriculture. Rural-urban commuting area codes. <https://www.ers.usda.gov/data-products/rural-urban-commuting-area-codes.aspx>. Accessed October 31, 2021.
42. Penedo FJ, Medina HN, Moreno PI, et al. Implementation and feasibility of an electronic health record-integrated patient-reported outcomes symptom and needs monitoring pilot in ambulatory oncology. *JCO Oncol Pract.* 2022;18(7):e1100-e1113.
43. Mouillet G, Falcoz A, Fritsch J, et al. Feasibility of health-related quality of life (HRQoL) assessment for cancer patients using electronic patient-reported outcome (ePRO) in daily clinical practice. *Qual Life Res.* 2021;30(11):3255-3266.
44. Smith AB, Samuel CA, McCabe SD, et al. Feasibility and delivery of patient-reported outcomes in clinical practice among racially diverse bladder and prostate cancer patients. *Urol Oncol.* 2021;39(1):77.e1-77.e8.
45. Schleicher SM, Mullangi S, Feeley TW. Effects of narrow networks on access to high-quality cancer care. *JAMA Oncol.* 2016;2(4):427-428.
46. Kehl KL, Liao KP, Krause TM, Giordano SH. Access to accredited cancer hospitals within federal exchange plans under the affordable care act. *J Clin Oncol.* 2017;35(6):645-651.
47. National Cancer Institute. NCI-designated cancer centers. <https://www.cancer.gov/research/infrastructure/cancer-centers>. Accessed April 14, 2022.
48. Bristow RE, Chang J, Ziogas A, Campos B, Chavez LR, Anton-Culver H. Impact of National Cancer Institute Comprehensive Cancer Centers on ovarian cancer treatment and survival. *J Am Coll Surg.* 2015;220(5):940-950.
49. In H, Neville BA, Lipsitz SR, Corso KA, Weeks JC, Greenberg CC. The role of National Cancer Institute-designated cancer center status. *Ann Surg.* 2012;255(5):890-895.
50. Onega T, Duell EJ, Shi X, Demidenko E, Gottlieb D, Goodman DC. Influence of NCI cancer center attendance on mortality in lung, breast, colorectal, and prostate cancer patients. *Med Care Res Rev.* 2009;66(5):542-560.
51. Birkmeyer NJO, Goodney PP, Stukel TA, Hillner BE, Birkmeyer JD. Do cancer centers designated by the National Cancer Institute have better surgical outcomes? *Cancer.* 2005;103(3):435-441.
52. Friese CR, Earle CC, Silber JH, Aiken LH. Hospital characteristics, clinical severity, and outcomes for surgical oncology patients. *Surgery.* 2010;147(5):602-609.
53. Friese CR, Silber JH, Aiken LH. National cancer institute cancer center designation and 30-day mortality for hospitalized, immunocompromised cancer patients. *Cancer Invest.* 2010;28(7):751-757.
54. Paulson EC, Mitra N, Sonnad S, et al. National Cancer Institute designation predicts improved outcomes in colorectal cancer surgery. *Ann Surg.* 2008;248(4):675-686.
55. Wolfson JA, Sun CL, Wyatt LP, Hurria A, Bhatia S. Impact of care at comprehensive cancer centers on outcome: results from a population-based study. *Cancer.* 2015;121(21):3885-3893.
56. Volk J. Enrolled in coverage that just got harder to use: consumer options when the network changes mid-year. <http://chirblog.org/enrolled-in-coverage-that-just-got-harder-to-use-consumer-options-when-the-network-changes-mid-year/>. Accessed April 14, 2022.
57. Politi MC, Kuzemchak MD, Liu J, et al. Show me my health plans: using a decision aid to improve decisions in the Federal Health Insurance Marketplace. *MDM Policy Pract.* 2016;1. doi:10.1177/2381468316679998
58. Politi MC, Grant RL, George NP, et al. Improving cancer Patients' Insurance choices (I can PIC): a randomized trial of a personalized health insurance decision aid. *Oncologist.* 2020;25(7):609-619.
59. Wong CA, Kulhari S, McGeoch EJ, et al. Shopping on the public and private health insurance marketplaces: consumer decision aids and plan presentation. *J Gen Intern Med.* 2018;33(8):1400-1410.
60. Pollitz K, McDermott D. Claim denials and appeals in ACA marketplace plans. <https://www.kff.org/private-insurance/issue-brief/claims-denials-and-appeals-in-aca-marketplace-plans/>. Accessed April 15, 2022.
61. Office of Inspector General. Beneficiary appeals in medicare advantage. <https://oig.hhs.gov/oei/reports/oei-01-08-00280.pdf>. Accessed April 15, 2022.
62. Office of Inspector General. Medicare advantage appeal outcomes and audit findings raise concerns about service and payment denials. <https://oig.hhs.gov/oei/reports/oei-09-16-00410.pdf>. Accessed April 15, 2022.
63. The Advisory Board. Early impressions: 2017 hospital revenue cycle benchmarks. https://www.advisory.com/-/media/Project/AdvisoryBoard/shared/Research/FLC/White-Papers/2017/Research-note-quarterlies/Q3-2017-Revenue-Cycle-First-Look.pdf?WT.ac=Inline_FLC_Resource_x_x_x_ATM_2019Mar01_Eloqua-RMKTG+Blog. Accessed April 15, 2022.
64. California Nurses Association. 60-80% of insurance denials overturned or reversed when taken to independent medical review - New data. <https://www.nationalnursesunited.org/press/60-80-insurance-denials-overturned-or-reversed-when-taken-independent-medical-review-new-data>. Accessed April 15, 2022.
65. Government Accountability Office. Private health insurance: data on application and coverage denials. <https://www.gao.gov/assets/gao-11-268.pdf>. Accessed April 15, 2022.
66. Ojerholm E, Hill-Kayser CE. Insurance coverage decisions for pediatric proton therapy. *Pediatr Blood Cancer.* 2018;65(1):e26729. doi:10.1002/pbc.26729
67. Helms L, Werblun J. California independent medical review results. <https://www.californiachronicare.org/wp-content/uploads/2019/03/california-independent-medical-review-results.pdf>. Accessed April 15, 2022.
68. Centers for Medicare & Medicaid Services. Appealing health plan decisions. <https://www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/appealing-health-plan-decisions>. Accessed April 15, 2022.
69. Espinosa JF. Strengthening appeals rights for privately insured patients: the impact of the patient protection and affordable care act. *Public Health Rep.* 2012;127(4):460-463.
70. de Moor JS, Mollica M, Sampson A, et al. Delivery of financial navigation services within National Cancer Institute-designated cancer centers. *JNCI Cancer Spectr.* 2021;5(3). doi:10.1093/jncics/pkab033

71. Keohane LM, Hwang A. Congress considers strategies to improve Medicare and Medicaid integration for dual-eligible individuals. <https://www.healthaffairs.org/content/forefront/congress-considers-strategies-improve-medicare-and-medicaid-integration-dual-eligible>. Accessed August 28, 2022.
72. Centers for Medicare & Medicaid Services. Plans and issuers. <https://www.cms.gov/healthplan-price-transparency/plans-and-issuers>. Accessed September 15, 2022.
73. Rocque GB, Pisu M, Jackson BE, et al. Resource use and Medicare costs during lay navigation for geriatric patients with cancer. *JAMA Oncol*. 2017;3(6):817-825.
74. Shankaran V, Leahy T, Steelquist J, et al. Pilot feasibility study of an oncology financial navigation program. *J Oncol Pract*. 2018;14(2):e122-e129.
75. Yezefski T, Steelquist J, Watabayashi K, Sherman D, Shankaran V. Impact of trained oncology financial navigators on patient out-of-pocket spending. *Am J Manag Care*. 2018;24:S74-S79.
76. Kircher SM, Yarber J, Rutsohn J, et al. Piloting a financial counseling intervention for patients with cancer receiving chemotherapy. *J Oncol Pract*. 2019;15(3):e202-e210.
77. Campbell C, Craig J, Eggert J, Bailey-Dorton C. Implementing and measuring the impact of patient navigation at a comprehensive community cancer center. *Oncol Nurs Forum*. 2010;37(1):61-68.
78. McManus KA, Killelea A, Honeycutt E, An Z, Keim-Malpass J. Assistants succeed in insurance navigation for people living with HIV and people at increased risk of HIV in a complex coverage landscape. *AIDS Res Hum Retroviruses*. 2020;36(10):842-851.

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