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 correct answers to a previously developed 10-question knowledge test. Due to a
Researchers have documented negative outcomes associated with poor health insurance literacy, such as delaying or avoiding care, difficulty paying medical bills, and reporting difficulty in paying for non-medical needs (e.g., rent, food). 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), 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. 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). Health insurance literacy has been understudied among cancer patients; available studies suggest some adults living with cancer have a limited understanding of health insurance.

Health insurance literacy may be particularly important among head and neck cancer (HNC) patients who experience substantial financial toxicity compared with other cancer patients. The median annual out-of-pocket medical expenses for HNC patients is $8101 compared with $5930 for patients with other cancer types. Expenses may continue well after HNC treatment has ended. The financial toxicity may also affect patients’ family caregivers. For instance, caregiving may impact the ability for caregivers to maintain their employment and income. 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.

## 1 | INTRODUCTION

The United States health insurance market is complex and challenging to navigate for most adults. 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. For instance, within Medicare alone, beneficiaries can select from multiple supplemental insurance plans (e.g., 33 Medicare Advantage plans in 2021). Furthermore, researchers have suggested that the range of options for private insurance plans may exceed those of Medicare or Medicaid plans. This complexity contributes to individuals’ confusion and frustration when selecting a plan for themselves and their families. In addition to plan selection, adults can have difficulty with determining which healthcare services are covered under a given plan. For instance, some patients may not fully understand what services apply toward a deductible and may forgo receiving preventive care. This burden of insurance navigation may fall on patients and their informal caregivers (e.g., family members, friends). 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.” To date, there is only one validated measure of health insurance literacy, the Health Insurance Literacy Measure (HILM). Researchers have documented negative outcomes associated with poor health insurance literacy, such as delaying or avoiding care, difficulty paying medical bills and reporting difficulty in

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**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
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.\(^9\) 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,\(^7\) 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,\(^3\) 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 ≥50% and a data completion rate of ≥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
| Characteristics                      | Patients | Caregivers |
|--------------------------------------|----------|------------|
| **Characteristics**                  |          |            |
| Age, mean (SD)                       | 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                        | 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                     |          |            |
| 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%)   |
| **Cancer type**                      |          |            |
| Laryngeal                            | 3 (6.3%)  | –          |
| Nasopharyngeal                       | 2 (4.2%)  | –          |
| Oral cavity                          | 15 (31.3%) | –          |
| Oropharyngeal                        | 20 (37.5%) | –          |
| Other                                | 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%)  |

*Abbreviations include standard deviation (SD).

*Percentages may not add up to 100% due to rounding.

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

*Respondents could select more than one insurance option.

*Other cancer types include nasopharyngeal, paranasal and nasal cavity, ill-defined sites and unknown.
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

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**TABLE 2** Health insurance literacy measure scores

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

*a Only includes complete responses across HILM instrument (n=)."
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, 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. For instance, only 41% of Federal Exchange Health insurance knowledge test results are comparable or improved. 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,\textsuperscript{57,58} including among cancer populations.\textsuperscript{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.\textsuperscript{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.\textsuperscript{13} Notably, approximately $\leq 10\%$ of claim denials have an appeal attempt.\textsuperscript{60–62} Meanwhile, estimates on the proportion of claim denials that become overturned after appeal range from $39\%$ to $80\%$,\textsuperscript{60–65} with cancer-specific estimates ranging from $45\%$ for general cancer patients to $97\%$ for pediatric blood cancer patients.\textsuperscript{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,\textsuperscript{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.\textsuperscript{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.\textsuperscript{59} For instance, cancer centers could assist patients and their caregivers with interpreting jargon-laden denial letters and facilitating decision-making with whether to appeal.\textsuperscript{62} Although most NCI-designated Cancer Centers offer some form of financial services (e.g., debt management counseling, assistance paying medical bills) to patients,\textsuperscript{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.\textsuperscript{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.\textsuperscript{72}

Although existing studies in the oncology setting highlight opportunities for improvement in improving health insurance literacy among patients,\textsuperscript{18,24} 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.\textsuperscript{73–78} For instance, promising results have been documented from the use of financial navigators and related programs in oncology care.\textsuperscript{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.\textsuperscript{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.\textsuperscript{57} 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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