Is Health Insurance Literacy Associated With Financial Hardship Among Cancer Survivors? Findings From a National Sample in the United States

Jingxuan Zhao, Xuesong Han, Zhiyuan Zheng, Matthew P. Banegas, Donatus U. Ekwueme, K. Robin Yabroff

See the Notes section for the full list of authors' affiliations.

Correspondence to: Jingxuan Zhao, MPH, Surveillance and Health Services Research Program, American Cancer Society, 250 Williams St, Atlanta, GA 30303 (e-mail: Jingxuan.zhao@cancer.org).

Abstract

Little is known about the association between health insurance literacy and financial hardship among cancer survivors. Using the 2016 Medical Expenditure Panel Survey Experiences with Cancer self-administered questionnaire, we evaluated the associations between health insurance literacy and medical financial hardship and nonmedical financial sacrifices among adult cancer survivors in the United States. Of the survivors, 18.9% aged 18–64 years and 14.6% aged 65 years and older reported health insurance literacy problems. In both age groups (18–64 and ≥65 years), from multivariable logistic regressions, survivors with health insurance literacy problems were more likely to report any material (adjusted odds ratio [AOR] = 3.02, 95% confidence interval [CI] = 1.53 to 5.96; AOR = 3.33, 95% CI = 1.69 to 6.57, respectively) or psychological (AOR = 5.53, 95% CI = 2.35 to 13.01; AOR = 8.79, 95% CI = 4.55 to 16.97, respectively) hardship, as well as all types of nonmedical financial sacrifices than those without these problems. Future longitudinal studies are warranted to test causality and assess whether improving health insurance literacy can mitigate financial hardship.

Rising costs of cancer care result in financial hardship for cancer survivors, even among those with health insurance (1). Growing evidence indicates that many adults have limited knowledge, ability, and confidence to obtain, evaluate, and use health insurance information (health insurance literacy), which may prevent optimal use of health plan benefits and lead to unnecessary medical spending (2). Therefore, health insurance literacy has been proposed as an important, potentially modifiable patient characteristic for preventing financial hardship (3). With growing numbers of newly insured individuals following implementation of the Affordable Care Act, the improvement of health insurance literacy is receiving increasing attention (4,5). To date, however, little is known about the associations between health insurance literacy and medical financial hardship and nonmedical financial sacrifice in cancer survivors.

We identified adult cancer survivors from the 2016 Medical Expenditure Panel Survey (MEPS) Experiences with Cancer self-administered questionnaire CSAQ, a nationally representative household survey (6) addressing financial hardship, health insurance coverage, and access to care related to cancer, its treatment, and lasting effects of treatment. The response rate was 46.0% for the 2016 core MEPS and 81.2% for the cancer self-administered questionnaire among MEPS respondents, resulting in an overall response rate of 37.4% (6). Detailed information on the MEPS is presented in eMethods (available online).

Health insurance literacy was measured by the question, “Did you ever have a problem understanding health insurance or medical bills related to your cancer, its treatment, or the lasting effects of that treatment?” (yes or no). Consistent with earlier studies (1,7), medical financial hardship was categorized into three domains: 1) material (eg, problems paying medical bills); 2) psychological (eg, worry about paying medical bills); and 3) behavioral (eg, delaying or forgoing care because of cost). Nonmedical financial sacrifices were measured by changes in
Descriptive statistics were used to characterize the sample. We used multivariable logistic regressions to separately evaluate the associations between health insurance literacy and medical financial hardship and nonmedical financial sacrifices, adjusted for potential confounders. Analyses were stratified by age group (18–64 years and ≥65 years) by including an interaction term of age group by health insurance literacy in models, because of differences in insurance coverage and financial hardship (1). We also conducted sensitivity analysis to assess whether the associations differ by some important risk factors of financial hardship, including health insurance, family income, time since last cancer treatment, and number of conditions.

Table 1. Characteristics of cancer survivors, Medical Expenditure Panel Survey Cancer Questionnaire, 2016 (n = 914)

| Characteristics | 18–64 y | ≥65 y |
|----------------|--------|-------|
| No.            | Weighted % | χ² P | No.            | Weighted % | χ² P |
| Total cancer survivors† | 389 | 100.0 | 525 | 100.0 |
| Age group, y    |        |       |      |        |       |
| 18–54           | 203    | 50.0  | —    | —      |       |
| 55–64           | 186    | 50.0  | —    | —      |       |
| 65–74           | —      | —     | 255  | 48.6   |       |
| 75–≥85‡         | —      | —     | 270  | 51.4   |       |
| Sex             |        |       |      |        |       |
| Female          | 276    | 68.1  | 297  | 57.2   |       |
| Male            | 113    | 31.9  | 228  | 42.8   |       |
| Race/ethnicity  |        |       |      |        |       |
| Non-Hispanic white only | 233 | 78.0 | 380  | 83.6   |       |
| All other races/ethnicities | 156 | 22.0 | 145  | 16.4   |       |
| Current marital status |        |       |      |        |       |
| Married         | 235    | 64.4  | 259  | 53.7   |       |
| Not married     | 154    | 35.6  | 266  | 46.3   |       |
| Education§      |        |       |      |        |       |
| High school graduate or less/missing | 173 | 35.8 | 269  | 48.6   |       |
| Some college or more | 216 | 64.2 | 256  | 51.4   |       |
| Current family income as percentage of federal poverty line |          |       |      |        |       |
| Low income ≤138% | 109  | 20.2  | 127  | 19.1   | .528 .114 |
| Middle income 139–400% | 137  | 30.2  | 207  | 38.0   |       |
| High income >400% | 143  | 49.6  | 191  | 42.9   |       |
| Current health insurance for age 18–64 y|| |        |       |      |        |       |
| Age 18–64, any private | 251  | 74.9  | —    | —      |       |
| Age 18–64, public only or uninsured¶ | 138  | 25.1  | —    | —      |       |
| Current health insurance for age ≥65 y|| |        |       |      |        |       |
| Age ≥65, Medicare and private* | —    | —     | 270  | 56.5   | <.001 — |
| Age ≥65, Medicare and other public* | —    | —     | 79   | 11.1   |       |
| Age ≥65, Medicare only* | —    | —     | 176  | 32.4   |       |
| Number of current conditions, excluding cancer# |        |       |      |        |       |
| 0–1            | 187    | 49.2  | 84   | 14.2   | <.001 .001 |
| 2–8            | 202    | 50.8  | 441  | 85.8   |       |
| Years since last cancer treatment§ |        |       |      |        |       |
| <5             | 188    | 44.8  | 210  | 40.6   | <.001 .282 |
| ≥5 or never treated/missing | 201  | 55.2  | 315  | 59.4   |       |
| Ever had problem understanding health insurance or medical bills | |       |      |        |       |
| Yes            | 83     | 18.9  | 79   | 14.6   | <.001 .196 |
| No             | 306    | 81.1  | 446  | 85.4   |       |

*Weighted percentages were calculated based on the Medical Expenditure Panel Survey (MEPS) design and sample weight. The SUDAAN “subpop” command was used to form the analytic sample and keep the weight information.
†Adult cancer survivors were defined as those aged 18 years or older reported ever being told by a doctor or other health professional that they had cancer or a malignancy of any kind. Individuals diagnosed only with nonmelanoma skin cancer and/or skin cancer with unknown kind (n = 267), aged 65 years or older without Medicare coverage (n = 6), or who did not respond to the health insurance and financial literacy question (n = 49) were excluded from this study.
‡Age top-coded 85 years or older by the MEPS.
§Consistent with earlier studies (8), cancer survivors with missing information on educational attainment (<0.5%) were combined with high school graduate or less; cancer survivors who did not respond to the time since last cancer treatment question (<1%) were combined with the more than 5 years or never treated group.
¶Public insurance included Medicare, Medicaid, State Children’s Health Insurance Program, and/or other public hospital and physician coverage. TRICARE/CHAMPVA was treated as private coverage, as were employer-based, union-based, and other private insurance.
||For age 18–64 years, uninsured adults were also included because they were likely to be covered in the past and respond to the health insurance literacy question based on earlier experience. Public only or uninsured were combined because of the small sample size for the uninsured (n = 20).
#Conditions include arthritis, asthma, diabetes, emphysema, heart disease (angina, coronary heart disease, heart attack, other heart condition and/or disease), high cholesterol, hypertension, and stroke. Consistent with earlier studies (8), cancer survivors with missing information on angina history (<0.5%) were categorized as no angina history.
reported more health conditions (both 65 years and older were less likely to have attended college and ancestry. Compared with survivors aged 18–64 years, those aged 65 years and older were less likely to have attended college and reported more health conditions (both P < .01). Of the survivors, 18.9% (18–64 years) and 14.6% (≥65 years) reported having problems understanding health insurance or medical bills. Survivors aged 18–64 years with only public insurance or uninsured treatment (P = .011), with family income no more than 400% of the federal poverty line (P = .027), and less than 5 years since last cancer treatment (P = .004) were more likely to report health insurance literacy problems among cancer survivors, by age group, Medical Expenditure Panel Survey Cancer Questionnaire, 2016 (n = 914)

| Characteristics | 18–64 y AOR (95% CI)† | ≥65 y‡ AOR (95% CI)‡ | Wald F P‡ |
|-----------------|------------------------|----------------------|-----------|
| **Material financial hardship§** | | | | |
| Had to borrow money or go into debt | 4.04 (2.07 to 7.88) | 2.51 (0.97 to 6.50) | .414 |
| Unable to cover share of the costs of medical care | 1.81 (0.89 to 3.67) | 3.15 (1.49 to 6.64) | .263 |
| Any material financial hardship¶ | 3.02 (1.53 to 5.96) | 3.33 (1.69 to 6.57) | .836 |
| **Psychological financial hardship** | | | | |
| Worried about paying large medical bills | 4.79 (2.32 to 9.89) | 8.85 (4.66 to 16.82) | .174 |
| Worried about family’s financial stability | 6.36 (3.00 to 13.48) | 9.35 (4.78 to 18.30) | .443 |
| Concerned about keeping job and income or earnings | 4.56 (2.45 to 8.48) | 3.71 (1.76 to 7.83) | .669 |
| Any psychological financial hardship¶ | 5.53 (2.35 to 13.01) | 8.79 (4.55 to 16.97) | .372 |
| **Behavioral financial hardship** | | | | |
| Delay or forgo cancer care because of cost of prescription medicine | 3.70 (1.45 to 9.48) | 3.44 (1.38 to 8.60) | .910 |
| Visit to specialist | 2.22 (0.82 to 5.98) | 3.59 (0.90 to 14.31) | .586 |
| Follow-up care | 1.71 (0.80 to 3.64) | 2.92 (1.12 to 7.64) | .378 |
| Any behavioral financial hardship# | 1.96 (0.96 to 4.02) | 1.09 (0.57 to 2.09) | .209 |
| **Nonmedical financial sacrifices§** | | | | |
| Reduce spending on vacation or leisure activities | 3.57 (1.78 to 7.16) | 2.51 (1.51 to 4.17) | .421 |
| Delay large purchases (eg, car) | 3.98 (1.95 to 8.13) | 3.18 (1.55 to 6.55) | .657 |
| Reduce spending on basics (eg, food and clothing) | 4.59 (2.32 to 9.09) | 2.71 (1.40 to 5.24) | .240 |
| Use savings set aside for other purposes (eg, retirement, educational funds, family support) | 6.89 (3.19 to 14.90) | 5.03 (2.54 to 9.94) | .532 |
| Make a change to living situation (eg, sold, refinanced, or moved to a smaller residence) | 3.04 (1.27 to 7.29) | 3.68 (1.64 to 8.24) | .748 |
| Any financial sacrifices** | 9.90 (3.77 to 26.00) | 2.12 (1.20 to 3.75) | .010 |

*Age top-coded 85 years or older by the Medical Expenditure Panel Survey. AOR = adjusted odds ratio; CI = confidence interval.†Reference group was cancer survivors who had no problems understanding health insurance or medical bills. Multivariable models adjusted for age group, sex, race and ethnicity, educational attainment, years since last cancer treatment, and current marital status, family income, health insurance coverage, and number of conditions. The SUDAAN “subpop” command was used to form the analytic sample and keep the weight information.‡Wald F P tested the differences in the associations between health insurance literacy and financial hardship by age group (18–64 years, ≥65 years).¶Any financial hardship was defined as having responded yes to one or more of the individual financial hardship measures, including ever having to borrow money or go into debt because of cancer, being unable to cover share of the cost of medical care visits for cancer, and/or file for bankruptcy because of cancer. Filing for bankruptcy because of cancer was not shown as an individual measure because of the small number of observations and wide confidence interval.††Any behavioral financial hardship was defined as having responded yes to one or more of the individual material financial hardship measures, including ever having to reduce spending on vacation or leisure activities, delay large purchases, change basic spending, such as food and clothing, use savings set aside for other purposes, change living situation, and/or other sacrifice because of cancer. Other sacrifice was not shown as an individual measure because of the small number of observations and wide confidence interval.

Table 2. Associations of health insurance literacy problems and financial hardship and financial sacrifices among cancer survivors, by age group, Medical Expenditure Panel Survey Cancer Questionnaire, 2016 (n = 914)

J. Zhao et al. | 3 of 4

Downloaded from https://academic.oup.com/jncics/article-abstract/3/4/pkz061/5586974 by guest on 15 November 2019
We observed a higher likelihood of reporting all measures of financial sacrifices among those who had health insurance literacy problems in both age groups (all $P < .05$). Compared with survivors aged 65 years and older, a stronger association between health insurance literacy and financial sacrifices were observed among those aged 18–64 years ($P = .010$).

Among survivors aged 65 years and older, the associations between health insurance literacy and material and psychological financial hardship were stronger among survivors with at least 5 years since last cancer treatment than those within 5 years of treatment (Supplementary Table 7, available online).

In this study, we found health insurance literacy problems were associated with multiple domains of medical financial hardship and nonmedical financial sacrifices among cancer survivors in the United States. With accumulating evidence about the adverse effects of medical financial hardship (10) and rising costs of cancer care (11), financial burden of cancer is receiving increasing attention. As a potentially modifiable patient characteristic, health insurance literacy may be an important intervention lever for addressing financial problems.

Growing evidence suggests that health insurance literacy is a nationwide problem in the United States (12,13) and is associated with adverse effects (2,14,15). An earlier study found that Medicare beneficiaries who were not aware of the Part D donut hole (coverage gap) were more likely to report material and behavioral hardships (14). This study suggested that health insurance literacy problems could cause financial hardship by limiting the ability to avoid higher drug costs and navigate options in the health system. However, no specific interventions have been developed to address health insurance literacy so far. Interventions such as financial and health insurance navigation, decision aids, and more user-friendly and easier-to-read medical bills (13,16), which improve patients’ understanding of health insurance and medical costs, could potentially be applied to improve health insurance literacy and benefit cancer survivors.

Our study is limited by the relatively small sample size, low response rate, and cross-sectional design. We were not able to evaluate other aspects of health insurance literacy, including information seeking, documentation, and self-efficacy (17,18), because of the unavailability of these data. We were also not able to control for cancer treatment or stage at diagnosis because of lack of data. We may have also underestimated the prevalence of health insurance literacy with self-reported data because of the gap in survivors’ self-estimates and their actual knowledge (19). Despite these limitations, we used national data to quantify the associations between health insurance literacy and financial hardship and financial sacrifices among cancer survivors. Future longitudinal studies are warranted to assess whether improving health insurance literacy can mitigate financial hardship.

Notes

Affiliations of authors: Surveillance and Health Services Research Program, American Cancer Society, Atlanta, GA (JZ, XH, ZZ, KRY); The Center for Health Research, Kaiser Permanente, Portland, OR (MP8); Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Atlanta, GA (DUE).

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention. Dr Matthew P. Banegas has received research grants from AstraZeneca for projects outside the scope this research project. The other authors have nothing to declare.

References

1. Zheng Z, Jemal A, Han X, et al. Medical financial hardship among cancer survivors in the United States. Cancer. 2019;125(10):1737–1747.

2. McCormack L, Ban C, Ulhaq J, Berkman N, Rudd R. Health insurance literacy of older adults. J Consumer Affairs. 2009;43(2):223–248.

3. Yabroff KR, Zhao J, Zheng Z, Rai A, Han X. Medical financial hardship among cancer survivors in the United States: what do we know? What do we need to know? Cancer Epidemiol Biomarkers Prev. 2018;27(12):1389.

4. Balogh E, Patlak M, Nass SJ. Institute of Medicine. Delivering Affordable Cancer Care in the 21st Century. Washington, DC: The National Academies Press; 2013.

5. Kim J, Braun B, Williams AD. Understanding health insurance literacy: a literature review. Fam Consum Sci Res J. 2013;42(1):3–13.

6. Agency for Healthcare Research and Quality. MEPS HC-192 2016 Full Year Consolidated Data File. August 2018. https://meps.ahrq.gov/data_stats/download_data/pufs/hc192/hc192doc.shtml. Accessed February 15, 2019.

7. Altice CK, Banegas MP, Tucker-Seeley RD, Yabroff KR. Financial hardships experienced by cancer survivors: a systematic review. J Natl Cancer Inst. 2017;109(2):djw025.

8. Yabroff KR, Dowling EC, Guy GP Jr, et al. Financial hardship associated with cancer in the United States: findings from a population-based sample of adult cancer survivors. J Clin Oncol. 2016;34(3):259–267.

9. Research Triangle Institute. SUDAAN Language Manual, Release 11, Vols. 1 and 2. Research Triangle Park, NC: Research Triangle Institute; 2012.

10. Zafar SY, McNeil RB, Thomas GM, Lathan CS, Ayanian JZ, Provenzale D. Measuring Health Insurance Literacy: A Call to Action. A Report from the Health Insurance Literacy Expert Roundtable. Washington, DC: The National Academies Press; 2013.

11. Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. Projections of the cost of cancer care in the United States: 2010-2020. J Natl Cancer Inst. 2011;103(2):117–128.

12. Institute of Medicine. Implications of Health Literacy for Public Health. Workshop Summary. Washington, DC: The National Academies Press; 2014.

13. The National Academies of Sciences, Engineering, and Medicine. Health Insurance and Insights from Health Literacy: Helping Consumers Understand: Proceedings of a workshop. Washington, DC: The National Academies Press; 2017.

14. Hsu J, Fung V, Price M, et al. Medicare beneficiaries’ knowledge of Part D prescription drug program benefits and responses to drug costs. JAMA. 2008;299(16):1929–1936.

15. Tipiemeni R, Politi MC, Kullgren JT, Kieffer EC, Goozd SD, Scherer AM. Association between health insurance literacy and avoidance of health care services owing to cost. JAMA Netw Open. 2018;1(7):e184796.

16. 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.

17. Quincy L. Measuring Health Insurance Literacy: A Call to Action. A Report from the Health Insurance Literacy Expert Roundtable. Yorkers, NY: Consumers Union; 2012.

18. Faez 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.

19. Faez KA, Mallery CJ. A little knowledge is a risky thing: Wide gap in what people think they know about health insurance and what they actually know. American Institutes for Research Issue Brief. 2014;1–6.