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The association of health insurance literacy and numeracy with financial toxicity and hardships among colorectal cancer survivors

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Abstract

Purpose—In this study, we examined the association of financial hardship measured by material financial burden and financial toxicity with health insurance literacy and numeracy among colorectal cancer survivors. The lack of evidence on the impact of cost-related health literacy, specifically health insurance literacy and numeracy, on financial toxicity among cancer survivors warrants further research.

Methods—Between January and November 2019, we used a cross-sectional research design to collect surveys from 104 colorectal cancer survivors (diagnosed within last 5 years) from the Kentucky Cancer Registry. Survey items assessed health insurance literacy (measured by confidence and behaviors in choosing and using health insurance), numeracy, material financial burden, and financial toxicity, in addition to socio-demographic variables. Survey data were subsequently linked to the participant's cancer registry record. Data were analyzed using descriptive, bivariate, and multiple linear regression analyses.

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Author contribution All authors had full access to the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. Conceptualization, JE and RV; methodology, JE, MK, and RV; investigation, JE, XZ, and RV; formal analysis, JE, MK, and RV; resources, JE and RV; writing - original draft, JE, MK, XZ, and RV; writing - review and editing, JE, MK, XZ, and RV; visualization, JE and MK; supervision, RV; and funding acquisition, JE and RV.

Conflict of interest The authors declare no competing interests.

Data availability The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Ethics approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Consent to participate Informed consent was obtained from all individual participants included in the study.

Consent for publication The authors affirm that human subject research participants provided informed consent for publication of their de-identified data.

Results—The mean financial toxicity score was 24.5, with scores ranging from 3 to 43 (higher scores indicating greater financial toxicity). Eighty percent of participants indicated they had experienced one or more material burdens related to their cancer. The majority had adequate health insurance (79%); however, the majority also had low numeracy (84%). After controlling for socio-demographic covariates, significant predictors of greater financial toxicity were high material burden scores, low health insurance literacy, and low numeracy.

Conclusions—Findings indicate the need to develop programs and interventions aimed at improving health insurance literacy and numeracy as a strategy for reducing financial toxicity and hardships among colorectal cancer survivors.

Keywords

Cost-related health literacy; Health insurance literacy; Numeracy; Financial toxicity; Colorectal cancer

Introduction

Cancer survivors have a higher risk of experiencing increased financial burden compared to those with other chronic illnesses [1–7]. Much of this burden results from higher out-of-pocket costs for cancer care and loss of income due to inability to work [8, 9]. This adverse impact of out-of-pocket healthcare costs—a combination of actual financial costs and the financial distress or hardship associated with those costs—on the health and wellbeing of cancer survivors is referred to as financial toxicity (FT) [10].

Financial toxicity is associated with clinically relevant patient outcomes, including poorer health-related quality of life [11], decreased survival [12], increased symptom burden [13], and decreased treatment compliance [14]. Despite growing research in this area, there is a lack of evidence on the impact of cost-related health literacy, specifically health insurance literacy (HIL) and numeracy, on FT among cancer survivors [15, 16]. HIL 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 based on their financial and health circumstances, and use the plan once enrolled to access care [17]. Numeracy is closely linked to HIL as it influences an individual's ability to calculate out of pocket costs and make appropriate decisions on selecting insurance plans that meet their financial needs. Evidence is growing on the relationship between low consumer HIL and higher use of emergency services and delayed or forgone use of preventive services [18–20]. As cancer is one of the costliest health conditions in the USA (US), continued research on establishing a link between cost-related health literacy and FT among cancer survivors is needed [16].

In this study, we examined the relationships among financial hardship, HIL, and numeracy in a sample of colorectal cancer survivors in Kentucky. We selected Kentucky for this study as the state leads the nation in cancer incidence and mortality, specifically new cases of colorectal cancer [21, 22]. Between 2012 and 2017, colorectal cancer was the third leading cause of cancer and cancer deaths among Kentuckians [23]. Greater disparities in cancer incidence and mortality exist in Kentucky as a result of 42% of its population residing in rural areas and 17% living under the federal poverty level [24, 25]. Several studies have specifically documented the FT and burden of colorectal cancer especially since the standard treatments of chemotherapy and surgery place prohibitively high costs and financial burden on patients [11, 26–29]. To our knowledge, this is the first study to examine the association between financial hardship or FT and cost-related health literacy among colorectal cancer survivors.

Methods

Study procedures

Colorectal cancer survivors residing in Kentucky were recruited from January to November 2019 through the population-based Kentucky Cancer Registry. Recruitment of participants was initiated after Kentucky Cancer Registry staff identified survivors that met our inclusion criteria: (1) diagnosed with colorectal cancer in the past 5 years, (2) resided in Kentucky, (3) between the ages of 18 and 64, and (4) able to read and write in English. The Kentucky Cancer Registry helped identify a representative sample of cancer survivors stratified by rural and urban geographic regions and stage of colorectal cancer. Informational letters were sent to 420 eligible colorectal cancer survivors informing them of their eligibility for the research study and obtaining permission to release their contact information for research purposes. A total of 212 survivors agreed to be contacted; 104 completed mailed surveys. In addition to obtaining informed consent to collect and analyze survey data, respondents provided consent for the release of individual, record-level data from the Kentucky Cancer Registry. This study was approved by the University of Kentucky Institutional Review Board.

Measures

Individual-level characteristics were ascertained from each survivor’s Kentucky Cancer Registry record, including sex; date of birth; race/ethnicity; county of residence; date of diagnosis; health insurance coverage; and stage of colorectal cancer at diagnosis. County of residence was scored as urban or rural based on the 2013 rural-urban continuum codes (USDA, 2013) [30]; counties with codes from 1 to 3 were considered urban, while those in the 4–9 range were scored as rural. Similarly, the Appalachian county status—as defined by the Appalachian Regional Commission—was also evaluated for each survivor. Participants completed a descriptive survey, which included items about their education, income, and number of people living in their household, which was used to evaluate their federal poverty level.

Financial hardship among cancer survivors is typically measured using both objective (material) and subjective (psychological) measures, as each of these aspects may be affected by a disease diagnosis differentially [31]. A material burden total score was formed by summing seven indicator variables derived from the Medical Expenditure Panel Survey - Experiences with Cancer Survivorship Supplement, each related to the financial burden of cancer or to the more global assessment of the ability to live on the income of the household. One item of the former type is “Did you or your family every file for bankruptcy because of your cancer, its treatment, or the lasting effects of that treatment?” (yes/no response). The other five cancer-specific burden items asked about borrowing money or going into debt, making financial sacrifices, being worried about having to pay large medical bills, being unable to cover treatment costs, and not being able to receive care because of costs. The item used to assess the global assessment of income is “Which one of these comes closest to your own feelings about your household’s income these days?” (responses include “living comfortably,” “getting by,” “finding it difficult,” and “finding it very difficult” on present income). The total score for the material burden scale was the number of “yes” responses to either of the “difficult on present income” options. The total score had a 0 to 7 range with higher scores indicating greater material burden reported.

Psychological aspects of financial hardship, known as *financial toxicity* (FT), were measured using the 11-item Comprehensive Score for Financial Toxicity (COST) tool (scored from 0 to 44, with higher scores indicating worse FT). Sample items include “My cancer treatment has reduced my satisfaction with my present financial situation” and “I am frustrated that I cannot work or contribute as much as I usually do;” response options for all items ranged from “not at all (0)” to “very much (4).” The COST scale is a valid and reliable patient-reported outcome measure of FT (Cronbach’s $\alpha = .92$) [10].

Cost-related health literacy was primarily measured using HIL, a commonly used method for assessing cost-related health literacy in cancer care research [16]. HIL was measured using two scales: the 21-item Health Insurance Literacy Measure (HILM) [32] and the 7-item Health Insurance Knowledge Measure (HIKM) [33]. The HILM is a reliable and valid tool (Cronbach’s $\alpha = .90$) that measures confidence and behaviors in the selection and use of health insurance and has been effectively used to assess HIL among the insured and uninsured [32]. It has four domain scores and also yields two subscales: the confidence and behavior subscales relative to choosing and using health insurance. Participants who scored at or above 80% on the HILM, which is an average of the confidence and behavior subscales, were deemed to have adequate HIL. As the HILM does not objectively measure knowledge of health insurance terms, the HIKM [33] was used to test knowledge of key health insurance terms and served as a cognitive measure of HIL. Participants who scored at or above 80% on the HIKM were deemed as having adequate HIL. General numeracy was measured using the 3-item Schwartz numeracy scale [34]. This was scored by summing the three items, each with a potential range from 0 to 2, and determining whether the total score was at least 5, indicating high numeracy.

Data management and analysis

The data from all returned surveys were manually entered into an electronic database and merged with respondents’ individual, record-level data from the Kentucky Cancer Registry. The variables in this combined dataset were summarized using descriptive statistics, including means and standard deviations or frequency distributions. Bivariate evaluation of the associations of FT with the other variables in the study was done using two-sample *t*-tests and Pearson’s product moment correlation. Finally, multiple linear regression was used to assess the demographic, material burden, HIL, and numeracy variables that were most strongly associated with FT. The socio-demographic variables chosen for inclusion in this model were sex, age, federal poverty level, employment status, rural residence, and private insurance status. We included socio-demographic factors that minimized redundancy while still accounting for all measured aspects of participant characteristics in the regression model. Variance inflation factors were evaluated to check for multicollinearity in the model; since all variance inflation factors were less than 2, there was no evidence that multicollinearity caused distortion in regression parameters. All analysis was done using SAS, v. 9.4; an alpha level of .05 was used for inferential tests.

Results

Most of the sample of colorectal cancer survivors were male (57%), had at least some post-secondary education (59%), had public health insurance plans (53%), and resided in rural (56%) and Appalachian-designated (58%) counties with an average age of 57 years (Table 1). The majority were White, non-Hispanic (92%), were unemployed (62%), and had a localized or regional cancer at diagnosis (83%). Half the sample had an annual family income at or above $35,000. As presented in Table 1, the average material burden score was 1.9, with a range of scores from 0 to 5. Among all participants, 80% had a score of 1 or more, 55% had a score of 2 or greater, and 17% had a score of 4 or 5. About one-fifth had a high HILM score (HIL confidence and behaviors; 21%), while more than half had high HIKM score (HIL knowledge; 54%). Only 16% of the participants exhibited high numeracy. The average COST score was 24.5, with a range from 3 to 43.

Table 2 represents findings from our bivariate analysis testing for associations between FT and the other study variables. While there were no differences in FT related to sex, race/ethnicity, or education, income was significantly associated with FT. Those with more limited income had significantly greater FT scores than those with greater household income ($p = .003$). Consistent with this, those who were at or below the federal poverty level had significantly larger FT scores than those who were above this cutoff ($p = .047$). There was also a significant difference in FT between those who were employed and not, with higher scores among those in the latter group ($p = .048$). Private insurance holders had significantly lower FT scores than those who did not have private health insurance ($p = .038$). Financial toxicity was greater among those with low HILM scores (confidence/behaviors; $p < .001$) and those with low numeracy ($p < .001$), but FT was not associated with high HIKM scores (knowledge). The correlation analysis revealed that FT was associated with material burden score ($r = 0.62$, $p < .001$), but not with age ($r = 0.047$, $p = .65$) or years since diagnosis ($r = -0.089$, p = .38).

The regression of FT on socio-demographics, material burden, HIL indicators (HILK and HIKM), and numeracy was significant overall ($F = 10.2$, $p <. 001$; $R^2 = 0.56$). As shown in Table 3, with sex, age, federal poverty level status, employment status, location (rural vs. urban), and private insurance status included in the model, material burden score, high HIL (confidence and behaviors), and high numeracy were significant predictors of FT scores. On average, for every 1-point increase in the number of applicable material burdens endorsed, the FT score increased by 3.7 points. Compared with those having low HILM scores, those with high HILM scores had FT scores that averaged 6.2 points lower. Similarly, compared with those having low numeracy, those with high numeracy averaged 6.9 points lower on their FT scores.

Discussion

Findings from this study indicate that our sample of colorectal cancer survivors in Kentucky had low cost-related health literacy, and many reported high material burdens particularly as it related to financial costs of cancer care. Most respondents had low numeracy and low confidence and behaviors in selecting and using health insurance as measured by the HILM (confidence/behaviors). Participants with low HIL (confidence and behaviors) and low numeracy had higher FT scores. Financial toxicity was not associated with HIKM scores (knowledge) in this sample. This may be because the HIKM instrument was not able to discern nuances in insurance-specific knowledge given that about half the sample scored at or above 80% on this measure. These findings contribute to gaps in evidence on understanding the relationship between cost-related health literacy and financial hardship in cancer patients.

In general, participants in this study experienced moderate levels of psychological FT with an average COST score of 24.5. However, most participants indicated they had experienced one or more financial burdens related to their cancer and/or they were experiencing difficulty living on their present income. Even while having some type of health insurance coverage, a substantial number of participants indicated that they had to borrow money to cover treatment-related costs, were unable to cover their share of medical costs, and/or had to make some type of financial sacrifice as a result of their cancer. These findings correspond with existing studies on the psychological and material FT of colorectal cancer. Shankaran et al. reported that 38% of a sample of 284 colon cancer survivors experienced at least one financial burden related to their treatment, even with health insurance coverage [26]. In a study with 125 colorectal cancer and 122 neuroendocrine tumor patients, roughly 81% reported having higher out-of-pocket costs related to cancer care; high financial loss related to cancer was significantly associated with lower quality of life and higher distress in these patients [29].

Cancer is one of the costliest health conditions and survivors spend roughly 10–20% of their annual income on out-of-pocket healthcare expenses, not accounting for other spending related to having a cancer diagnosis [35]. In a study of insured cancer survivors, Zafar et al. [36] reported an alarming 24% of participants avoided filling prescriptions to mitigate FT. Additional mitigation strategies included applying for drug copayment assistance and reducing spending on food and clothing [36]. Participants in our study had to make financial sacrifices as a result of their cancer diagnosis and treatment. This indicates that regardless of these spending reduction methods, cancer survivors are overburdened by healthcare costs as the price of most cancer treatments continue to rise, even for the insured [37]. However, growing trends in cancer costs present insurmountable barriers to obtaining high quality care, leaving patients vulnerable to the toll of FT.

In our study, participants who lived at or below the federal poverty level had lower annual income, were unemployed, and did not have private insurance coverage reported higher FT. Loss of employment and income related to cancer is well-documented as a source of FT, especially as they are known risk factors for debt and bankruptcy [38]. In a study with stage III colorectal cancer patients, 45% of employed individuals lost their job as a result of their cancer diagnosis and treatment [39]. Similarly, Apostolidis found that 37% of 125 colorectal cancer and 122 neuroendocrine tumor patients reported job loss following their cancer diagnosis [29]. In a national study with colorectal cancer and lung cancer survivors, Zafar et al. found that higher financial burden was associated with lower household income, poorer QOL, and younger age [11]. Although age was not correlated with FT in our sample, studies have shown that the younger cancer survivor population is more susceptible to experiencing FT as a result of limited savings and assets, other financial responsibilities, and not having adequate health insurance coverage or being enrolled in high-deductible health plans [40, 41].

In our multiple regression model, none of the socio-demographic variables included as covariates was significant. This underscores that the strongest predictors of FT in this study were material burdens, HIL (confidence and behaviors), and numeracy. It is important to note that these observed relationships were significant even when controlling for socio-demographic differences among participants. This key finding on HIL and numeracy being strong predictors of FT should be considered in future interventional studies aimed at improving cost-related health literacy to mitigate the impact of financial toxicity on cancer survivors. However, other upstream factors must also be considered such as promoting access to sufficient sources of income and adequate health insurance coverage and reducing costs of cancer care. Addressing the impact of cost-related health literacy on FT of cancer is a burgeoning area with a limited number of studies. In a national sample of breast cancer survivors, Zhao et al. found that survivors with HIL problems were more likely to report experiencing material and psychological financial hardship when compared to those not experiencing HIL issues [42]. In another study, metastatic breast cancer patients with low HIL were more likely to report having to borrow money, being unable to pay for basic needs, and forgoing medical tests, procedures, and treatment compared to patients with high HIL [43]. Evidence supports the need for continued investigation on the impact of HIL and other cost-related health literacy measures on mitigating the experiences and impact of FT among cancer survivors [44]. Further research to examine the root cause of financial hardship among cancer survivors and how to accommodate their unique needs is needed.

The majority of our participants had low numeracy, which serves as a substantial barrier to being able to understand and make simple calculations related to out-of-pocket costs. Participants also had low HIL as measured by confidence and behaviors related to selecting and using health insurance. These findings are represented in national HIL trends which show that over half of the American population does not understand basic health insurance terms and a significant portion struggle with numeracy [11, 20, 45, 46]. Limitations in HIL and numeracy impact consumers' abilities to understand financial and health implications of enrolling in certain health insurance plans, often leading to delayed or foregoing needed care. Additional research is needed to understand the extent of the impact of FT on access to healthcare, especially regarding forgoing or delaying medications, therapies, and healthcare visits as a result of high costs.

Findings from our study should be interpreted cautiously as there were several limitations. Our cross-sectional design and lack of longitudinal data does not allow us to fully understand the experiences of financial burden among colorectal cancer survivors across the trajectory of their cancer experience. We were not able to recruit the number of participants we originally planned to include, which may have limited the ability to identify demographic factors that influence FT in the regression. Most of our sample had health insurance coverage, which limits our understanding of FT experiences among uninsured cancer survivors. Our use of a non-randomized sample limits generalizability of findings to other colorectal cancer survivors and survivors of other cancer types. Additional studies with larger sample sizes and a more diverse participant recruitment frame will add to our ability to more completely identify those who may be most at risk for experiencing FT. Despite these limitations, the use of the Kentucky Cancer Registry data allowed us to recruit a geographically diverse population to represent cancer survivors residing in both urban and rural counties. Furthermore, the use of validated tools to measure HIL, numeracy, and FT added to the credibility of our study findings.

Findings from this study indicated that colorectal cancer survivors with low HIL and low numeracy were more likely to experience FT. Therefore, improving cost-related health literacy has the potential to promote better understanding of cancer care costs and self-efficacy in managing costs for survivors, consequently helping prevent financial hardship. Evidence gained from this study is crucial to advancing programs promoting cost-related health literacy of cancer survivors. For example, solutions could lie in educating cancer survivors on healthcare costs using decision aids and outreach efforts or by mobilizing financial counselors and other financial navigation resources at the community level. Additional research is needed to help identify if improvements in HIL can mitigate experiences of FT among cancer survivors.

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Table 1

Descriptive summary of the sample ($N = 104$)

Characteristic	***N* (%) or mean (standard deviation); range**
Sex	
Male	59 (56.7%)
Female	45 (43.3%)
Age	56.8 (7.6); 34–68
Race/ethnicity	
White, non-Hispanic	96 (92.3%)
Other race/ethnicity	8 (7.7%)
Education	
At most high school	42 (40.8%)
At least some college	61 (59.2%)
Annual family income	
< $35,000	51 (50.5%)
≥ $35,000	50 (49.5%)
Family income above federal poverty level*	
Yes	75 (74.3%)
No	26 (25.7%)
Employed	
Yes	40 (38.5%)
No	64 (61.5%)
Location	
Rural	58 (55.8%)
Urban	46 (44.2%)
Appalachian	
Yes	60 (57.7%)
No	44 (42.3%)
Private insurance	
Yes	48 (47.1%)
No	54 (52.9%)
Cancer stage at diagnosis	
Non-invasive malignant tumor (I)	1 (1.1%)
Localized (II)	39 (42.9%)
Regional (III)	36 (39.6%)
Distant metastasis (IV)	15 (16.4%)
Years since diagnosis	2.8 (1.3); 0.4–5.5
Number of material burden items endorsed	1.9 (1.5); 0–5
High health insurance literacy (HILM - confidence and behaviors)	
Yes	21 (21.4%)
No	77 (78.6%)
High health insurance literacy (HIKM - knowledge)	

Characteristic	***N* (%) or mean (standard deviation); range**
Yes	56 (53.9%)
No	48 (46.2%)
High numeracy	
Yes	17 (16.4%)
No	87 (83.7%)
Financial toxicity score	24.5 (10.4); 3–43

Table 2

Two-sample t-test comparisons of financial toxicity scores between demographic subgroups ($N = 104$)

Characteristic	Mean (SD) for FT^	$\lvert t \rvert$ (p value)
Sex		
Male	24.2 (11.3)	0.4 (.73)
Female	25.0 (9.2)	
Race/ethnicity		
White, non-Hispanic	24.5 (10.6)	0.3 (.79)
Other race/ethnicity	25.5 (7.9)	
Education		
At most high school	25.8 (9.8)	1.0 (.34)
At least some college	23.8 (10.9)	
Annual family income		
< $35,000	27.8 (9.9)	3.1 (.003) *
≥ $35,000	21.4 (10.3)	
Family income above federal poverty level		
Yes	23.4 (10.7)	2.0 (.047) *
No	28.3 (9.0)	
Employed		
Yes	22.0 (10.2)	2.0 (.048) *
No	26.2 (10.2)	
Location		
Rural	26.3 (11.0)	1.9 (.059)
Urban	22.4 (9.3)	
Appalachian		
Yes	23.5 (10.0)	1.2 (.25)
No	26.0 (10.9)	
Private insurance		
Yes	22.1 (10.1)	2.1 (.038) *
No	26.5 (10.3)	
Cancer stage at diagnosis		
I or II	23.0 (10.7)	0.4 (.69)
III or IV	24.1 (10.4)	
High health insurance literacy (confidence and behaviors, HILM)		
Yes	17.7 (9.0)	3.6 (<.001) *
No	26.5 (10.1)	
High health insurance literacy (knowledge, HIKM)		
Yes	23.3 (10.4)	1.3 (.19)
No	26.1 (10.4)	
High numeracy		
Yes	16.3 (9.9)	3.8 (<.001) *

Characteristic	**Mean (SD) for FT**^	**|*t*| (*p* value)**
No	26.2 (9.7)	

^ *FT* financial toxicity

* $p < .05$

Table 3

Multiple linear regression to assess factors related to financial toxicity ($N = 92$)

Variable	***b* (SE *b*)**	**Standardized *β***	**|*t*| (*p* value)**
Male	−1.22 (1.61)	−.058	0.76 (.45)
Age	0.013 (0.12)	< .01	0.11 (.91)
Above federal poverty level	0.93 (2.29)	.038	0.41 (.68)
Employed	−3.42 (2.02)	−.16	1.70 (.094)
Rural location	2.37 (1.70)	.11	1.40 (.17)
Private insurance	0.46 (2.17)	.022	0.21 (.83)
Material burden score	**3.66 (0.55)**	**.54**	6.65 (<.001)*
High health insurance literacy (HILM - confidence and behaviors)	**−6.24 (1.99)**	**−.25**	3.14 (.002*
High health insurance literacy (HIKM - knowledge)	1.49 (1.79)	.071	0.84 (.41)
High numeracy	**−6.85 (2.17)**	**−.26**	3.16 (.002)*

[*] for the last value 3.8 (<.001)

[*] $p < .05$