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Research paper

Fatalism and educational disparities in beliefs about the curability of advanced cancer



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ABSTRACT

Objective: Understanding socioeconomic disparities in the care of patients with incurable cancer is a high priority. We hypothesized that patients without a high school education are more likely to believe that they could be cured and we explored the role of fatalism.

Methods: We studied 977 patients with advanced, incurable cancer. Two logistic regression analyses were conducted. Model One examined the effect of education on beliefs about curability. Model Two added fatalism.

Results: The significant association between having less than a high school education and the belief that advanced cancer can be cured (OR = 2.55; 95% CI: 1.09–5.96) in Model One was attenuated by 39% and rendered nonsignificant in Model Two. Fatalism was associated with the belief that advanced cancer can be cured. Whites were less likely to believe they could be cured than Blacks and Asians/Pacific Islanders. Beliefs about curability were not associated with income or insurance status.

Conclusions: People who do not complete high school are more likely to believe that their advanced cancer is curable, in part because they are more likely to hold fatalistic worldviews.

Practice implications: Interventions to help oncologists care for patients with fatalistic beliefs could mitigate socioeconomic disparities in end-of-life care.

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1. Introduction

Individuals who receive fewer years of education and those with lower incomes are more likely to be hospitalized weeks before death, less likely to be referred for palliative care or hospice, and more likely to receive chemotherapy at the end of life (EoL) [1–4]. Interventions to improve EoL care ought to be informed by research on why these socioeconomic disparities exist [5]. Drawing from the literature on education-related health disparities [6,7],

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we report secondary analyses of data gathered in the Cancer Care and Outcomes Research and Surveillance Consortium (CanCORS) to test the hypothesis that patients with lower levels of education are more likely to believe that their incurable colorectal or lung cancer can be cured. Although research has been conducted to understand ethnic and racial disparities in EoL care [8–10], we are aware of no comparable research on socioeconomic disparities.

Beliefs about curability are clinically important. For example, patients with advanced cancer who believe they could not be cured are more likely to enter hospice [11]. Prior studies have explored the relationship between education and beliefs about curability [12–14]. Weeks et al. [14] reported no relationship between education and curability beliefs in their main analyses, but their sensitivity analyses (using a more relaxed definition of perceived incurability) showed that patients who did not complete high school were more likely to believe that their Stage IV cancer could

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be cured. No study has explored the effects of education independent of economic indicators of socioeconomic status, and no study has attempted to explain why people who do not go very far in school are more likely to believe that they can be cured.

Patients with lower educational attainment may be more likely to believe they can be cured for several reasons (e.g., greater physician-patient communication challenges, poor patient health literacy, etc). This study focuses on the role of fatalism, as assessed by the Fatalism Scale (FS) [15] and by responses to an open-ended question about expected lifespan. The FS assesses the extent to which 'the individual accepts whatever happens to him or her in life as his or her just fate [and that] one can do little about the events that happen to them" [15,pg.12]. For the lifespan question, fatalism was operationalized as any response that invoked God (e.g., "it's in God's hands"). Intuitively, to many in societies that place a premium on personal agency and perceived control, a fatalistic attitude may seem unhelpful, bad for one's health, perhaps even an instrument of self-oppression [16]. However, as a socially-constructed [17,18] worldview that is cultivated by identity-conferring institutions (e.g., families, schools, churches), fatalism is neither inherently bad nor inherently good. In some contexts, fatalism may convey denial, resignation, or passivity [19], and may indeed have damaging consequences. In other situations, particularly those characterized by uncertainty [20], fatalism "may not be as much an indication of pacifism as hope" [15,pg. 18].

Fatalism has been shown to differ by race and religious affiliation [15,21], presumably reflecting the importance of different identity-conferring institutions across demographic groups. Insofar as educational institutions not only shape people's understanding of who they are but also increase their sense of control over life circumstances [7,22], it is not surprising that prior studies have shown that levels of fatalism are higher among individuals with fewer years of formal education [15,23]. If patients with fewer years of education are more likely to believe that incurable cancer can be cured, and if this belief can be partially explained by their higher levels of fatalism, then interventions to address fatalism in cancer communication interventions might be warranted.

In this study, we hypothesized that, independent of economic indicators of socioeconomic status (e.g., income, insurance status) and other potential confounds such as race and ethnicity, patients who did not complete high school would be more likely to believe they could be cured. Further, we explored whether patients with lower levels of education would be more fatalistic, and whether their higher levels of fatalism would partially account for their belief that they could be cured.

2. Methods

2.1. Overview of CanCORS

CanCORS was a prospective observational study of outcomes for patients with lung and colorectal cancer. From 2003 to 2005, patients were enrolled from five integrated health care delivery systems in the NCI-funded Cancer Research Network (northern California, Los Angeles County, North Carolina, Iowa, Alabama) or 15 VA Health Care Systems. Staff interviewed participants using computer-assisted telephone interview software four to six months following diagnosis.

2.2. Participants

CanCORS enrolled a demographically and clinically representative cohort of adults recently (\leq 3 months) diagnosed with lung and colorectal cancer. African American/Black, Hispanic, and Asian or Pacific Islander patients were oversampled. Our analytic sample was confined to patients with advanced (Stage IV or distant metastases) lung (n=646) or colorectal (n=452) cancer who completed the full patient survey at study entry and had opted to receive chemotherapy, radiation, or surgery. Participants were excluded if they had missing data on the outcome variable (n=56), fatalism (n=9) or covariates (financial worry [n=54], depression [n=2]). The sample size was 977. IRB approval was received for these secondary analyses (RSRB00058964).

2.3. Assessments

2.3.1. Patient beliefs about cure

Patients were asked three questions about what they "thought about the possible results and side effects of (surgery, radiation therapy, chemotherapy) after talking with your doctor. If you have not thought about or discussed the issue, just answer that you do not know. After talking with your doctors about (surgery, radiation therapy, chemotherapy), how likely do you think (surgery, radiation therapy, chemotherapy) would cure your cancer?" Response options were very likely, somewhat likely, a little likely, not at all likely as well as don't know, refused, and not applicable. Whereas prior studies examined predictors of beliefs about the curative potential of just chemotherapy [14] or just radiation [13], we combined responses to all three items (surgery, chemotherapy, radiation) and thus examined predictors of the beliefs about whether any treatment can cure advanced cancer. For example, if a participant stated that chemotherapy was not curative and that surgery was curative, that participant was coded as believing that advanced cancer is curable. Consistent with prior studies, we defined beliefs in curability as believing that it was very likely, somewhat likely, or a little likely that Stage IV lung or colorectal cancer could be cured. This is the study's main outcome variable. Sensitivity analyses were conducted using different operational definitions of beliefs about curability, described in the analytic plan.

2.3.2. Education

This was the main independent variable. It was coded as absence of a high school diploma or equivalent, completed high school or equivalent, some college or vocational school, college, and more than college.

2.3.3. Income

Income was coded as <20,000, 20,000-339,999, 40,000-559,999, \geq 60,000, and missing. We ran sensitivity analyses defining low income as annual household income of less than 20,000 for a household of three or more people, consistent with the 2010 Census Bureau definition of poverty [24].

2.3.4. Insurance

We contrasted those who reported being insured vs. those who reported being uninsured or insured by Medicaid or a state-specific plan (e.g., Oregon Health Plan).

2.3.5. Self-reported fatalism

Fatalism was assessed using four items ($\alpha = 0.79$) developed for the Americans Changing Lives Panel Study [15] and used in prior studies [9,19,25]: "When bad things happen, we are not supposed to know why; we are just supposed to accept them," "People die when it is time to die and nothing can change that," "Everything that happens is a part of God's plan," and "If bad things happen it is because they were meant to be."

2.3.6. Open-ended fatalism – belief that life expectancy is "in god's hands"

Participants were asked an open-ended question about their expected lifespan, as follows: "We would like to try to understand

how serious a threat cancer is to your health. Based on your understanding about what your doctors have told you about your cancer, your health in general, and the treatments you are receiving, how long do you think you have to live?" Rather than offer a numeric response, some respondents (\sim 11%) offered a response that reflected a fatalistic worldview saying, for example, "It's in God's Hands." Responses to this item were coded categorically as fatalistic, expected life span <5 years, expected lifespan \geq 5 years, and don't know/refused.

2.3.7. Comorbidity

We used the validated Adult Comorbidity Evaluation-27 (ACE-27) [26].

2.3.8. Depressive symptoms

Symptoms over the past four weeks were assessed via eight binary CES-D items [27]. Respondents were asked if they felt depressed, happy, sad, lonely, everything was an effort, their sleep was restless, they enjoyed life, and could not get going.

2.4. Statistical methods

Bivariate correlations between key variables were examined. Two multivariate logistic regression analyses were conducted examining the independent effects of education on beliefs about cure. Model 1 examined the effects of education, adjusting for demographic covariates (age, gender, race/ethnicity, marital status) as well as cancer type, days between diagnosis and survey completion, ACE-27 and CES-D. Model 2 was identical to Model 1 except fatalism was included as well. In addition to reporting Odds Ratios for all variables in Model I and Model 2, we calculated the extent to which the association between education and the outcome variable was attenuated by the inclusion of fatalism [28].

Four sensitivity analyses were conducted. In two analyses, different operational definitions of the outcome variable were used. In one, only those who reported very likely, don't know, or refused in response to the item "... how likely do you think (treatment) would cure your ... cancer?" were classified as believing they could be cured. In another, only those who responded very likely were classified as such. Additional sensitivity analyses a) replaced the income variable with an indicator of household poverty, b) added self-reported reading frequency (never or less than once a week (n = 70) vs. once a week, a few times a week, every day (n = 907)) as a crude indicator [29] of literacy, and c) replaced the income variable with an indicator of financial worry. Patients were asked to report their levels of worry about treatment costs, taking time away from family, and transportation to treatment. Response options were not at all worried, a little worried, somewhat worried, and very worried. Prior analyses [30] have shown that these items ($\alpha = 0.63$) are associated inversely with income. All models used robust standard errors.

3. Results

Table 1 reports data on demographics and other key covariates. Our main outcome variable is the belief that one's incurable cancer is curable. Most (81.7%) believed they could be cured. Education was significantly associated with both self-reported fatalism (r = -0.32, p < 0.0001) as well as open-ended fatalism (r = -0.23, p < 0.001). The correlation between beliefs about cure and self-reported fatalism was statistically significant (r = 0.10, p < 0.005); the correlation with open-ended fatalism (r = 0.08, p = 0.06) was not.

Table 2 presents two regression models predicting beliefs about cure. Model 1 reports the findings for education when only the demographic variables and covariates are entered in the model. For

Table 1

Descriptive Statistics (n = 977).

Variable	N	9/
Variable	N	%
Belief about cure		
Probably incurable	179	18.3
Probably curable	798	81.7
Education		
< High school	155	15.9
High school or GED	289	29.6
Some college or vocational school	314	32.1
College graduate	121	12.4
> College	97	9.9
DK/refuse/NA	1	0.1
Appual household income (US\$)		
Annual household income (US\$) <\$20,000	284	29.1
\$20,000-\$39,999	261	26.7
\$40,000-\$59,999	144	14.7
≥ \$60,000	219	22.4
Missing	69	7.1
Insurance		
Insured	869	88.9
Uninsured or receiving Medicaid	105	10.7
Missing	3	0.3
Age		
<65	548	56.1
≥ 65	429	43.9
Gender		
Male	566	57.9
Female	411	42.1
Race		
White	659	67.5
Black	139	14.2
Asian/Pacific Islander	56	5.7
Other	51	5.2
Hispanic	72	7.4
Marital status Married or cobabiting	601	C1 E
Married or cohabiting Divorced/separated/widowed	601 311	61.5 31.8
Single/never married	63	6.4
DK/refuse/NA	2	0.2
Cancer type		
Colorectal	417	42.7
Lung	560	57.3
Comorbidity		
Comorbidity	250	26.4
None Mild	258 310	26.4 31.7
Moderate	141	14.4
Severe	113	11.6
Missing	155	15.9
-		
Depressive symptoms (mean, SD)	3.07	2.36
Days between diagnosis and baseline survey (mean, SD)	144.15	57.58
Self-reported fatalism (mean, SD)	10.84	2.61
Open-ended fatalism		
Open-ended fatalism No, perceived survival < 5 years	222	22.7
No, perceived survival \geq 5 years	292	29.9
Yes, survival is in God's hands	108	11.1
DK/refuse/NA/missing	355	36.3

Note: DK = don't know; GED = did not complete high school, but passed a series of General Educational Development tests certifying the attainment of high school levels skills; NA = Not Applicable.

patients who did not complete high school, there was a 155% increase in the odds of believing that they could be cured compared to those with more than a college education (OR = 2.55; 95% CI:1.09–5.96), supporting our hypothesis.

Table 2

Predictors of Beliefs about Cure: Multivariate Regressions).

	Model 1				Model 2			
	OR	95% CI	Robust SE	р	OR	95% CI	Robust SE	р
Education								
<high school<="" td=""><td>2.55</td><td>1.09-5.96</td><td>1.10</td><td>0.03</td><td>1.95</td><td>0.79-4.85</td><td>0.91</td><td>0.15</td></high>	2.55	1.09-5.96	1.10	0.03	1.95	0.79-4.85	0.91	0.15
High school/GED	1.38	0.68-2.80	0.50	0.37	1.12	0.53-2.34	0.42	0.77
Some college or vocational school	1.64	0.82-3.29	0.58	0.16	1.40	0.68-2.88	0.52	0.36
College graduate	1.12	0.53-2.37	0.43	0.76	1.14	0.53-2.45	0.45	0.74
>College	1.00				1.00			
Annual household income (US \$)								
<\$20,000	0.81	0.42-1.56	0.27	0.54	0.82	0.42-1.59	0.28	0.56
\$20,000-\$39,999	0.84	0.48-1.45	0.24	0.53	0.84	0.48-1.49	0.24	0.55
\$40,000-\$59,999	0.95	0.51-1.75	0.30	0.86	1.01	0.53-1.89	0.32	0.99
>\$60,000	1.00				1.00			
Missing	1.95	0.67-5.64	1.06	0.22	1.94	0.68-5.56	1.04	0.22
Insurance								
Insured	1.00				1.00			
Uninsured or receiving Medicaid	1.41	0.70-2.85	0.51	0.34	1.44	0.69-3.03	0.55	0.33
Missing	0.35	0.05-2.59	0.35	0.30	0.38	0.06-2.23	0.34	0.28
Age								
<65 years	1.00				1.00			
≥65 years	1.45	0.99-2.12	0.28	0.06	1.47	1.00-2.15	0.29	0.05
Gender								
Male	1.06	0.73-1.53	0.20	0.77	1.06	0.72-1.55	0.21	0.79
Female	1.00				1.00			
Race								
White	1.00				1.00			
Black	2.88	1.49-5.59	0.97	0.002	2.49	1.26-4.90	0.86	0.01
Asian/Pacific Islander	7.71	1.89-31.54	5.54	0.004	7.11	1.59-31.87	5.44	0.01
Other	2.78	1.10-7.02	1.31	0.03	2.54	1.00-6.41	1.20	0.05
Hispanic	1.55	0.64-3.73	0.69	0.33	1.39	0.57-3.37	0.63	0.46
Marital status								
Married or cohabiting	1.15	0.57-2.32	0.41	0.70	1.22	0.59-2.56	0.46	0.59
Divorced/separated/widowed	1.09	0.53-2.25	0.40	0.81	1.19	0.55-2.55	0.46	0.66
Single/never married	1.00				1.00			
Cancer type								
Colorectal	1.00				1,00			
Lung	0.26	0.17-0.40	0.06	<0.001	0.30	0.19-0.46	0.07	<0.0
Comorbidity								
None	1.00				1.00			
Mild	0.78	0.48-1.25	0.19	0.30	0.81	0.49-1.32	0.20	0.40
Moderate	0.47	0.28-0.81	0.13	0.01	0.49	0.28-0.87	0.14	0.01
Severe	0.86	0.46-1.61	0.28	0.63	0.90	0.47-1.74	0.30	0.76
Missing	1.23	0.66-2.28	0.39	0.52	1.12	0.60-2.09	0.36	0.72
Depressive symptoms	0.96	0.88-1.03	0.04	0.24	1.00	0.92-1.09	0.04	0.98
Days between diagnosis and baseline survey	1.00	1.00-1.00	0.57	< 0.01	1.00	1.00-1.00	0.52	<0.0
Self-reported fatalism Open-ended fatalism	N/A N/A				1.09	1.01-1.17	0.04	0.03
No, perceived surviva < 5 years	IN/A				1.00			
No, perceived survival ≥ 5 years					3.92	2.32-6.60	1.04	<0.0
Yes, survival is in God's hands					2.28	1.17-4.46	0.78	0.02
DK/Refuse/NA/Missing					2.20	1.45–3.40	0.48	<0.02

Note: CI = Confidence Interval; DK = Don't Know; GED = did not complete high school, but passed a series of General Educational Development tests certifying the attainment of high school levels skills; NA = Not Applicable; OR = Odds Ratio; SE = Standard Error.

Whites were less likely to believe they could be cured than Blacks and Asians/Pacific Islanders. Patients with lung cancer were less likely than those with colorectal cancer to believe they could be cured. Financial indicators of socioeconomic status were not significantly associated with the outcome variable.

Model 2 reports the findings after including fatalism. Those who scored higher in self-reported fatalism and those who spontaneously reported that their fate is in God's hands when asked how long they had to live were more likely to believe they could be cured. Although many of the odds ratios for the other variables are virtually unchanged by the addition of fatalism to the model (e.g., age, income, insurance, lung cancer, comorbidity), the association between education and the outcome variable was attenuated by about 39% and rendered nonsignificant (OR = 1.95; 95% CI: 0.79–4.85).

Adding these variables also attenuated the effects of race by 9% (Asian/Pacific Islander) to 21% (Black/African American) but had no effect on overall statistical significance. Again, nonwhites were more likely to believe they could be cured, and the same was true of those with colorectal cancer.

Sensitivity analyses using different operational definitions of beliefs about cure yielded substantively similar findings, as did analyses using indicators of household poverty, reading frequency, and financial worry.

4. Discussion and conclusion

4.1. Discussion

Higher levels of futile treatments at the EoL are associated with worse quality of death and worse bereavement outcomes in family caregivers [31]. Growing recognition of the relationship between socioeconomic status and the quality of care received at the EoL [1-4] compelled this examination of socioeconomic correlates of beliefs about the curability of advanced cancer. Beliefs about curability were not associated with income or insurance status, but there was a significant association with education. People who do not complete high school are more likely to believe that advanced cancer is curable, but we hasten to add that this misguided belief is not unique to that group: fewer than 20% of respondents in the entire sample knew that cure was not a realistic expectation. Although our cross-sectional secondary analyses cannot definitively explain why there is a relationship between education and perceived curability, our findings hint at a plausible explanation. People who do not complete high school are more likely to hold fatalistic worldviews, which could lead them to be ever hopeful.

Whites were less likely to believe they could be cured than Blacks and Asians/Pacific Islanders. Adding fatalism to the regression model attenuated but did not eliminate these differences. It is plausible that race difference in beliefs about curability can be partially explained by race differences in fatalism [15,21], but our findings suggest that other explanations ought to be pursued. Prior research has documented communication challenges when doctors and patients have different racial or ethnic backgrounds [32]. Given the importance of oncologist communication about prognosis [12], addressing these challenges could help patients attain a better understanding of whether their cancer is curable.

Several qualifiers should be noted prior to discussing practice implications. First, findings may not generalize to other cancers or to patients who declined to receive cancer treatment. Second, data on religious practice and spirituality are unavailable. Third, findings may have differed if a cancer-specific fatalism inventory [21] had been used instead of the generic FS. Psychometric research on cancer-specific fatalism inventories has been conducted [24,33]. Similar research is needed on the psychometric properties of the FS in samples of cancer patients, including research on discriminant validity. Fourth, this study was not designed to comprehensively identify predictors of patient beliefs about curability. Creative research is needed to explain why so few patients, less than 20% in this sample, know that "there is essentially no chance" [14,pg.1621] that the treatments they are receiving will cure them. In addition to further exploring fatalism and other patient characteristics (e.g., trait hope), future studies could explore oncologist attributes that may influence how they talk with patients about prognosis, such as their comfort with EoL care, training in palliative care, and attitudes toward their own death [34,35]. Fifth, the cross-sectional design precluded causal inferences. Sixth, these are secondary analyses conducted on data gathered in an observational study that was not designed a priori to examine pre-specified relationships between educational level, fatalism, and beliefs about cure. Finally, our data should not be interpreted to mean that patients who do not complete high school are invariably fatalistic, or that all highly educated people are not fatalistic.

4.2. Conclusion

To the best of our knowledge, this is the first study in patients with advanced cancer to explore the effects of education on beliefs about the curability of cancer independent of objective and subjective economic indicators of socioeconomic status. People who do not complete high school are more likely to believe that their incurable cancer is curable. This is partially due to their higher levels of fatalism, a worldview that prioritizes the idea that bad things happen for reasons that are often mysterious and just have to be accepted. The observed relationship between education and fatalism is consistent with a large body of research on the role of higher education in cultivating beliefs about agency and control [22]. Although our study was not designed to explain why fatalistic patients might be more likely to believe they could be cured, prior research [15] and theory [36] suggests that fatalism allows patients to maintain hope in the face of adversity.

4.3. Practice implications

Given the well-established associations between education and perceived control [7,22], and emerging research on education and fatalism [15,23], the average patient and average physician probably have discrepant views about fatalism. This lengthens the social distance [37] between doctor and patient while potentially exacerbating communication difficulties in oncology care. It is not uncommon for cancer clinicians to think patients are in denial [38] and the prevalence of misunderstanding among patients in this study and others [39] would seem to reinforce this view. Although the concept of denial is often clinically useful, it can undermine care if what appears to be "denial" is actually a particular form of hope. Specifically, hope fueled by fatalism, borne of how people make sense of the world, must be recognized by clinicians to improve clinical care. This is challenging because a clinician's scientific worldview cloaks hope in data and future biomedical research, but a patient's fatalism shrouds hope in mystery, underscoring the unknowability of the physical world and, perhaps, even the limits of science. Not surprisingly, a biomedical, scientific worldview is feared by many patients [40], perhaps because it can rob them of hope.

A patient-clinician relationship that is characterized by a collision of worldviews – the fatalistic vs. the scientific – will not be patient-centered, and is unlikely to foster high quality prognostic communication. Although communication interventions have proven effective in oncology care, there is room for improvement [41,42]. Prior interventions have largely focused on information provision and the social and emotional components of communicational attainment and its relationship to fatalism. Interventions to help oncologists care for patients who hold fatalistic beliefs could mitigate socioeconomic disparities in end-of-life care.

Conflicts of interest

None.

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