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Financial hardship and the intensity of medical care received near death

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Abstract

Background—While end-of-Life (EOL) care can present a substantial financial burden for the household, the influence of this burden on the intensity of care received at the EOL remains unknown. The goal of this study was to determine the association between financial hardship and intensive care in the last week of life.

Methods—The Coping with Cancer (CwC) Study is a longitudinal, multisite cohort study of terminally ill cancer patients and their informal caregivers, September 2002-February 2008. Patients (N=281) were followed from baseline to death, a median of 4.4 months after baseline assessment. Intensive care was defined as use of resuscitation and/or ventilation in the patient's last week of life. Financial hardship was measured at study baseline as a positive response to whether the household had to use all or most of their savings due to the family member's illness.

Results—Twenty-nine percent reported financial hardship and 9% received intensive EOL care. Patients reporting financial hardship had a 3.22 (95% CI: 1.38, 7.53) higher likelihood of receiving intensive EOL care compared to patients not reporting financial hardship. After adjusting for socio-demographic characteristics and patient preferences, patients reporting financial hardship had a 3.05 (95% CI: 1.22, 7.62) higher likelihood of receiving intensive EOL care.

Conclusion—The depletion of a family's financial resources is a significant predictor of intensive EOL care, over and above the influence of socio-demographic characteristics and patient preferences.

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Keywords

Cancer; Oncology; Financial hardship; Intensive care; End-of-life care; Caregiver

INTRODUCTION

Several factors are known to influence the intensity of care received at the end of life (EOL) including patient's race¹ and a preference for life-sustaining treatments.^{2;3} Black patients have been shown to receive, and often to prefer,⁴ intensive treatment at the EOL relative to White patients.⁵ However, few studies have investigated the role of socioeconomic circumstances on the intensity of care received at the EOL over and above the influence of race/ethnicity.⁶ Additionally, studies including socioeconomic variables generally focus on measures of socioeconomic status (SES) such as income, education, and health insurance status. Although these traditional measures are good proxies of SES, they may not adequately capture the financial impact of managing a terminal illness on patients and families.

Medical care can impose a substantial financial burden on the family, even for the insured.^{7;8} For instance, 31% of subjects in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) reported a loss of most or all of the family savings or a major source of income due to the cost of the serious illness.⁹ Similar results were also found in a study by Zafar et al (2013), where 42% reported a "significant or catastrophic" financial burden in managing their cancer, and 46% reported using their savings to defray the out-of-pocket expenses for care.¹⁰ Such a loss of savings and/or income to manage an illness may create financial hardship for the family.^{11;12}

The financial resources the household has available to manage a serious illness can determine the type of care accessed at the EOL.¹³ Out-of-pocket costs at the EOL may be substantial.¹⁴ In particular, the high out-of-pocket health care expenditures prior to death of a spouse have been shown to be associated with widow(er) poverty status.¹⁵ It has been suggested that families confronting extensive care-giving and financial burdens of a terminal illness may consume more health care resources.¹³ Kelley et al (2010) assert that financial constraints might encourage patients to seek more intensive [and expensive] hospital-based life-sustaining treatments as these treatments are covered by insurance, compared to less intensive home-based treatments that are less likely covered.¹³ There is a need to test this hypothesis using data that can examine associations between financial hardship and intensity of EOL care patients receive.

Studies have shown that patients at the EOL actually prefer care that maximizes comfort over intensive life-sustaining treatments.¹⁶ Data from the SUPPORT study suggest that financial hardship due to serious illness is associated with a patient's preference for comfort care over life-sustaining care.⁹ However, across studies African Americans have proven the exception, with a preference for life sustaining care.^{4;17;18} Studies that also investigated SES in addition to patient's race on the intensity of EOL care have shown an association between low SES (as measured by underinsured status⁶) and life sustaining therapies, independent of race/ethnicity.

In the SUPPORT study, patients who preferred life-prolonging care were more likely to receive aggressive care¹⁹ however patients' preferences were not shown to predict place of death.²⁰ Jenq and Tinetti (2013) suggest that place of death has been used as a proxy for the quality of EOL care as most people report a preference for wanting to die at home.²¹ It remains unknown if patients that exhaust all of their financial resources at the EOL receive more intensive EOL care, regardless of their EOL treatment preferences. Thus, there is a need for research on the influence of the financial burden of care on the type of care patients receive at the EOL.

The aim of this study was to investigate the association between financial hardship and intensive care in the last week of life. This aim is motivated by an interest in determining whether patients who exhaust their household financial resources at the EOL are also more likely to experience intensive life-sustaining care, once the confounds of race and treatment preferences are taken into account. We hypothesized that financial hardship would be positively associated with intensive EOL care even after adjusting for race and several indicators of SES, and that this association would be substantially attenuated (but remain significant) after adjusting for preferences for comfort care.

METHODS

Study Sample

The Coping with Cancer (CwC) Study was an NCI and NIMH funded prospective, longitudinal, multi-site cohort study of advanced cancer patients and their informal caregivers recruited from September 2002-February 2008. Patients were recruited from seven outpatient sites; and details of the study have been described elsewhere.²² The human subjects committee at each site provided approval and all enrolled patients and caregivers provided written informed consent.

Eligibility criteria included the following: 1) diagnosis of advanced cancer with metastases; 2) disease progression following first-line chemotherapy; 3) at least 20 years of age or older; 4) presence of an informal caregiver (e.g. spouse); and 5) adequate stamina to complete the 45 minute interview. Patient-caregiver dyads were excluded if either the patient or caregiver refused to participate, if either the patient or caregiver was significantly cognitively impaired, or did not speak English or Spanish.

For the present study only the responses from the caregivers of the deceased CwC cohort (N=380) were included. Respondents were dropped from analysis if they were missing responses on the outcome (intensive EOL care), primary predictor (financial hardship), or covariates used in analysis (N=99). The final sample used for analysis was N=281. Respondents with missing values were not statistically significantly different from the rest of sample on any of the variables used in analysis, except education ($\chi^2=10.11$; $p=.002$) and health insurance status ($\chi^2=6.67$; $p=.01$), with those with less education and uninsured more likely to have a missing response.

Protocol and Measures

—Patients and their caregivers received a baseline interview and the patients were followed through to death. Postmortem interviews were conducted with the caregiver to assess care received in the final week of life. Medical charts were also reviewed to confirm patients' clinical information and disease characteristics. After an average of 2–4 weeks following the patient's death, the caregiver most involved in the patient's last week of life was contacted to provide information regarding the patient's care and quality of death.

Outcome (Intensive EOL care): The primary outcome variable for this study was intensive life-prolonging care, defined as receipt of ventilation or resuscitation in the last week of life.

Primary Predictor (Financial hardship): The primary predictor variable for this study was financial hardship, defined as whether the household had to use all or most of their savings due to the family member's illness. An affirmative response to this question in the interview indicates the presence of financial hardship. Financial hardship was measured at baseline when patients entered the study and was reported by the caregiver.

Covariates

Patient socio-demographics: Patient socio-demographic characteristics were self-reported. The following socio-demographic characteristics were reported: race, age, gender, educational attainment, and health insurance status. For the health insurance status item, patients were asked: "Do you have health insurance coverage now?" For analysis, age and educational attainment were continuous variables.^{23;24} Patient socio-demographics were also measured at baseline.

Patient preference for EOL care: Patients were asked "If you could choose, would you prefer: (a) a course of treatment that focused on extending life as much as possible, even if it meant more pain and discomfort, or (b) on a plan of care that focused on relieving pain and discomfort as much as possible, even if that meant not living as long?" We categorized response (a) as a preference for life-extending treatment response (b) as a preference for comfort care. Patient preference for EOL care was measured at baseline.

Statistical Analysis—Bivariate analyses (χ^2 -tests) were conducted to test the association between the outcome and primary predictor variables as well as the association between these variables and the dichotomized covariates (race, gender, health insurance status, and patient preference). T-tests were conducted to determine differences in age and educational attainment across categories of financial hardship and intensive EOL care. Multivariable logistic regression models were estimated in SAS 9.2© to obtain the odds of receiving intensive EOL care. We estimated four models to evaluate the incremental influence of socio-demographic characteristics on the association between financial hardship and intensive EOL care: 1) a simple model including only the primary predictor variable, financial hardship; 2) model adjusting for potentially confounding demographic characteristics (age, gender); 3) model adjusting for potentially confounding socioeconomic characteristics (educational attainment, health insurance status); 4) model adjusting for

patient preference for EOL care. The fourth model was also used to evaluate if patient preference attenuated the association between financial hardship and intensive EOL care.

RESULTS

The frequency distributions of patient characteristics across the financial hardship and intensive EOL care categories are shown in Table 1. The average age of the sample was 59 years old and the average patient reported a slightly over 12 years of educational attainment (see Table 1). Twenty-nine percent of the sample reported financial hardship and 9% received intensive EOL care. Bivariate analyses showed a statistically significant association between financial hardship and intensive EOL care ($\chi^2=7.93$; $p=.005$). Black patients were more likely to receive intensive EOL care compared to White patients ($\chi^2=4.66$; $p=.03$) and patients who preferred life extending care over comfort care were more likely to receive intensive EOL care ($\chi^2 =5.62$; $p=.02$). Black patients were also more likely to report financial hardship compared to White patients ($\chi^2 =7.63$; $p=.01$) and patients without health insurance were more likely to report financial hardship compared to patients with health insurance ($\chi^2 = 23.01$; $p<.0001$). See Table 1.

The results from multivariable tests of the association between financial hardship and intensive EOL care are shown in Table 2. The simple model showed that patients reporting financial hardship had a 3.22 (95% CI: 1.38, 7.53) higher odds of receiving intensive EOL care. After adjusting for demographic and socioeconomic characteristics, patients reporting financial hardship had 3.27 (95% CI: 1.30, 8.20) higher odds of receiving intensive EOL care. After adding patient preferences to the model, the association between financial hardship and intensive EOL care was slightly attenuated (6.7% reduction), with those reporting financial hardship having a 3.05 (95% CI: 1.22, 7.62) higher odds of receiving intensive EOL care compared to those not reporting financial hardship. Black patients had a statistically significant 3.17 (95% CI: 1.11, 9.04) higher odds of receiving intensive EOL care compared to White patients, even after controlling for financial hardship and other socio-demographic variables (See Table 2); this association became non-significant when patient preferences were added to the model. It should be noted that prior to including socioeconomic indicators (educational attainment and health insurance status) there was no statistically significant difference in receiving intensive EOL between white and black patients. Because the sample size of this study was relatively small, we conducted a sensitivity analysis with 10% smaller sub-samples randomly selected from this study sample; and confirmed that the fitted models were stable.

DISCUSSION

This study investigated the association between financial hardship and intensive EOL care in a sample of patients with terminal cancer and their caregivers. Consistent with the SUPPORT study results over 15 years ago that found financial hardship in 31% of families in their study,^{9;25} the results in this study showed that 29% of the sample reported financial hardship. In multivariable analysis, race and other socio-demographic characteristics attenuated the association between financial hardship and receipt of intensive EOL care, but the association remained statistically significant even after adjusting for these confounds.

The association between race and intensive EOL care was also statistically significant when financial hardship and the other socio-demographic variables were included in the model indicating that Black patients were more likely to receive intensive care than White patients in these models (see Model 3, Table 2). However, the effect of race on intensity of EOL care was no longer significant in models including financial hardship and treatment preferences. Also, the statistically significant racial difference in the intensity of EOL care was only present when socioeconomic indicators were included (Model 3, Table 2) and not in models with financial hardship and demographic characteristics (gender, race, and age; Model 2, Table 2). Yet, when treatment preferences were included in the fully adjusted model the association between financial hardship and intensive EOL was slightly attenuated but remained statistically significant. As such, these results suggest that the family's depletion of life savings is an important indicator of receipt of aggressive EOL care, over and above the influence of the other socio-demographic and preference variables included in our models.

The results found in our study may appear counter-intuitive; that is, those who have exhausted their financial resources appear to get more aggressive (and costly) care. These results highlight the importance of the "out of pocket" factor as a potential explanation. As Kelley et al. note, EOL care that is more costly in absolute terms (e.g., that would be more costly to Medicare as payor) may be less costly out-of-pocket for the patient/family; and it is the latter that may determine the intensity of care received.¹³ Menzel (2011) agrees with this notion, suggesting an "insurance effect" that may distort the perception of financial cost of care, where care with even a relatively small chance of benefit is sought regardless of financial cost.²⁶ Although some research among Medicare beneficiaries suggests a strong influence of region on the intensity of EOL care over socio-demographic characteristics²⁷, others have proffered a more nuanced explanation that incorporates multi-level influences (e.g. patient/family factors, provider factors, hospital system factors, and regional factors) on the intensity of EOL care with emphasis on more "demand side" characteristics.^{28,29} More specifically, these "demand side" characteristics that have been shown to predict aggressive EOL care have included patient demographic characteristics such as race/ethnicity and age; as well as, health status, functional decline, prognostic understanding, treatment preferences, religious views, and participation in EOL discussions.^{28;30} Our results are consistent with a demand side argument, whereby patients pursue care that will not increase their out of pocket expenses.²⁸ These results point to a need for greater attention to be paid to the financial burdens on the family managing terminal illness and EOL care decisions⁹, rather than absolute levels of income and even race/ethnicity, in accounting for medical care disparities. In particular, measures of financial hardship experienced by the family may provide greater insight to the socioeconomic resources the family has to bring to bear on managing illness and care-related expenses than annual income.³¹

The out-of-pocket costs, income loss, and many other financial burdens on the household that accompany a terminal illness are gaining more attention in the research literature.^{8;32;33} Some have suggested that clinicians should include a discussion early in the treatment process on whether patients would like costs to be included in treatment discussions.³² However, discussions that include not only the direct costs of treatment, but the costs of managing the indirect costs of care (e.g. time from work, transportation costs, non-

prescription medications)^{34;35} may require a multidisciplinary approach that includes not only the physician but also psycho-social staff (e.g. social work, patient financial services). An area for further research would be to determine if an intervention to ameliorate familial financial hardship due to the direct and indirect costs of care for those near the EOL would result in a decrease in the intensity of aggressive EOL care. Such an intervention might even be financial (e.g., the provision of a modest familial financial benefit for the terminally ill to address family financial hardship and to financially incentivize home care). Thus, the association noted in our study may lead to such interventions that have important policy implications with respect to the role of the government, insurers, and health care institutions in potentially addressing hardships present prior to cancer care as well as those that present as the result of care.

Research on the well-being of families that experience terminal cancer^{36;37} and the death of a loved one in an intensive care unit suggests a high prevalence of psychological symptoms (e.g. symptoms of depression, anxiety) among family members.³⁸⁻⁴³ Thus, the association between financial hardship and intensive care at the EOL found in our study highlights a troubling phenomenon. First, families have to endure the terminally ill patient receiving aggressive and perhaps painful care right before death; and subsequent to death the family must then confront the fact that their financial resources have been exhausted. This situation is made even more troubling if the death of the family member meant the loss of the family's primary wage earner.¹⁵ This confluence of events may exacerbate psychological consequences such as post-traumatic stress or prolonged grief,⁴³⁻⁴⁶ and economic consequences such as sustained poverty or bankruptcy among family members.

There are several strengths and limitations to the present study. The strengths include the inclusion of potential psychosocial (e.g. patient preference in EOL care) and socioeconomic (e.g. health insurance and educational attainment) confounders in our analysis; and our use of prospective data to examine the influence of financial hardship on care received in the last week of life. In particular, our measure of financial hardship was assessed at baseline and the study followed the patients forward to the receipt of aggressive EOL care and death; in so doing, minimizing the risk of the potential of reverse causality in the association between financial hardship and intensive EOL care. The limitations include the lack of repeated measures of financial hardship to show how changes in hardship over time affect EOL care, only a single item to measure hardship, and no measure of actual out-of-pocket direct and indirect health care-related costs. In addition, those with less education and the uninsured were more likely to have missing responses on the variables in this analysis; but, neither educational attainment nor health insurance status was associated with the outcome. However, health insurance status was associated with financial hardship, and we contend that the effect of missingness here might be an underestimation of the effect of financial hardship on the outcome. Lastly, although the study was large enough to give us robust qualitative findings about the association between financial hardship and intensive EOL care, it was not large enough for us to obtain a more precise estimate of the odds ratio with more narrow confidence intervals; thus, additional studies are needed to further investigate the strength of this association.

Conclusion

The results of this study highlight the importance of the influence of financial hardship over and above other socio-demographic/economic characteristics on the intensity of EOL care for patients. Future research should examine the consequences of the association noted in this study; as families that deplete all of their financial resources and receive intensive care at the end of a family member's life may have lasting psychological and economic effects for the family that endure well after the patient dies. Interventions that specifically target family financial hardship during EOL care, and financially incentivize families to choose home or hospice care instead of expensive hospital based care may very well help to ameliorate these psychological and economic effects.^{43;47}

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Frequency and percent of patient characteristics across financial hardship and intensive EOL care categories

Table 1

	N	% [†]	Financial Hardship [§]		Intensive EOL care [§]	
			yes (%)	no (%)	Yes (%)	No (%)
Financial hardship						
Gender						
Female	130	46%	38 (29%)	92 (71%)	9 (7%)	121 (93%)
Male	151	54%	44 (29%)	107 (71%)	15 (10%)	136 (90%)
Race						
White	185	66%	44 (24%)	141 (76%)	11 (6%)	174 (94%)
Blacks	96	34%	38 (40%)	58 (60%)	13 (14%)	83 (86%)
Health Insurance Status						
Insured	177	63%	34 (19%)	143 (81%)	14 (8%)	163 (92%)
Not Insured	104	37%	48 (46%)	56 (54%)	10 (10%)	94 (90%)
Patient Preference						
Life extending care	72	26%	25 (35%)	47 (65%)	11 (15%)	61 (85%)
Comfort care	209	74%	57 (27%)	152 (73%)	13 (6%)	196 (94%)
Age						
Average Age (SD)	59 (12.37)		55 (10.70)	61 (12.64)	56 (10.53)	60 (12.5)
Educational Attainment						
Average Education in years(SD)	12.59 (4.03)		11.84 (3.53)	12.90 (4.19)	12.71 (3.25)	12.58 (4.10)

[†]Totals may not add to 100% due to rounding

[§]Percentage frequency in parentheses unless otherwise indicated as SD

Table 2

Bivariate associations (p-value) between intensive EOL and financial hardship and socio-demographic and patient preference variables

	<i>N</i>	<i>%[†]</i>	<i>p-value Intensive EOL Care[*]</i>	<i>p-value Financial Hardship[/]</i>
Financial hardship			p = .005	
Gender			p =.37	p=.99
<i>Female</i>	130	46%		
<i>Male</i>	151	54%		
Race			p =.03	p =.01
<i>White</i>	185	66%		
<i>Blacks</i>	96	34%		
Health Insurance Status			p =.62	p<.0001
<i>Insured</i>	177	63%		
<i>Not Insured</i>	104	37%		
Patient Preference			p = .02	p=.23
<i>Life extending care</i>	72	26%		
<i>Comfort care</i>	209	74%		
Age			p <.001	p=.04
<i>Average Age (SD)</i>	59 (12.37)			
Educational Attainment			p=.15	p=.89
<i>Average Education in years(SD)</i>	12.59 (4.03)			

* bivariate (chi-square; t-tests) association with intensive EOL care

[/] bivariate association with financial hardship

Table 3

Odds Ratio (and 95% confidence intervals) for the multivariable associations between financial hardship and intensive EOL care

	Odds Ratios for Intensive EOL Care			
	Model 1 simple model including only financial hardship	Model 2 adjusting for demographic characteristics	Model 3 adjusting for demographic and socioeconomic characteristics	Model 4 adjusting for demographics, socioeconomic characteristics, and patient preference
Financial Hardship				
No financial hardship	Reference			
Financial hardship present	3.22* (1.38, 7.53)	2.70* (1.12, 6.45)	3.27* (1.30, 8.20)	3.05* (1.22, 7.62)
Demographics				
Gender				
Male		Reference	Reference	Reference
Female		.68 (.27, 1.64)	.68 (.27, 1.67)	.73 (.30, 1.81)
Race				
White		Reference	Reference	Reference
Black		1.97 (.82, 4.73)	3.17* (1.11, 9.04)	2.48 (.86, 7.13)
Age				
Age		.98 (.95, 1.02)	.98 (.95, 1.02)	.99 (.95, 1.03)
Socioeconomic Characteristics				
Educational Attainment				
			1.05 (.93, 1.19)	1.34 (.51, 1.03)
Health Insurance Status				
Not Insured			Reference	Reference
Insured			1.90 (.62, 5.88)	1.98 (.63, 6.18)
Patient Preference				
Comfort care				Reference
Life Sustaining care				2.01 (.80, 5.02)

* p <.05

Model 1: simple model including only financial hardship

Model 2: adjusting for demographic characteristics

Model 3: adjusting for demographic and socioeconomic characteristics

Model 4: adjusting for demographics, socioeconomic characteristics, and patient preference