

ORIGINAL RESEARCH

Advance directives completion and hospital out-of-pocket expenditures

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Abstract

Introduction: Health care costs remain high at the end of life. It is not known if there is a relationship between advance directive (AD) completion and hospital out-of-pocket costs. This analysis investigated whether AD completion was associated with lower hospital out-of-pocket costs at end of life.

Methods: We used Health and Retirement Study participants who died between 2000 and 2014 ($N = 9228$) to examine the association between AD completion status and hospital out-of-pocket spending in the last 2 years of life through the use of a two-part model controlling for socioeconomic status, death-related characteristics and health insurance coverage.

Results: About 44% of decedents had completed ADs. Having an AD was significantly associated with \$673 lower hospital out-of-pocket costs, with a higher magnitude of savings among younger decedents. Decedents who completed ADs 3 months or less before death had higher out-of-pocket costs (\$1854 on average) than those who completed ADs more than 3 months before death (\$1176 on average).

Conclusions: AD completion was significantly associated with lower hospital out-of-pocket costs, with greater out-of-pocket savings among younger decedents. Early AD completers experienced lower costs than decedents who completed ADs closer to death.

INTRODUCTION

Health care costs incurred at end of life are high. Studies have found that about 25% of Medicare expenditures incurred were for care for patients in their last year of life.¹ The average healthcare cost per capita in the last year of life was estimated at \$80,000, and about 44% of these costs were related to hospitalizations.² Moreover, these costs include out-of-pocket costs insured patients may incur in the form of cost-sharing, such as deductibles, copayments, coinsurance, and expenses for services that are not covered by health insurance plans. Studies have found that high out-of-pocket costs in hospital

settings can lead to financial catastrophes.³ In the United States, average out-of-pocket costs were estimated at \$38,688 in the 5 years prior to death.⁴ In the last year prior to death, total out-of-pocket costs for health-related care were \$11,618,⁵ and inpatient out-of-pocket costs were \$2176.⁶ Furthermore, research has found a strong association between aggressive care and end-of-life costs, leading to increased risk of financial hardship.⁷

Concerns about incurring high out-of-pocket copayments may influence patients' health care decision-making.^{8,9} In a study of cancer patients, researchers found that patients may be less willing to pay high out-of-pocket charges when treatment results in modest

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clinical benefits.¹⁰ Other studies have found that those with lower socioeconomic status may forego expensive treatment regardless of its effectiveness.^{11–13} Moreover, terminally ill patients may prefer to spend less on personal medical costs with limited benefits, and instead use the money for other meaningful pursuits at end of life.¹⁴

Advance directives (ADs) have been associated with improved care concordance with care preferences, lower health care utilization, lower healthcare expenditures, and lower odds of dying in a hospital.^{15–21} In addition, researchers also found that overall, most patients completing ADs elect limited or comfort care, but that individuals completing ADs in the last 3 months of life had higher odds of preferring aggressive, life-sustaining care.²²

However, absolute healthcare costs may not correlate to patient out-of-pocket costs, as some insurances (e.g., Medicare or Medicaid) may bear the brunt of healthcare expenditures.²³ Although it is important to know the total costs of end-of-life health care, we believe hospital costs are more directly related to costs that can be influenced by care choices made within an AD. Thus, given this lack of correlation in expenditures coupled with patient concern related to incurring high out-of-pocket costs associated with hospital care at end of life, research is needed to understand the relationship between AD completion and hospital out-of-pocket cost. Therefore, this study aims to fill that gap. We hypothesized that (1) compared to decedents without ADs, those who completed ADs would have lower hospital out-of-pocket costs at the end of life. (2) Completing an AD would have more hospital out-of-pocket reduction among younger decedents. (3) Among those with ADs, the timing of completion and documented care preferences would be associated with hospital out-of-pocket costs.

METHODS

Data and sample

We used the Health and Retirement Study (HRS is sponsored by the National Institute on Aging and is conducted by the University of Michigan), a longitudinal panel study of United States adults age 50 years or older and their partners. Participants are interviewed every 2 years following enrollment, and among those who die, HRS Exit Interviews are conducted with a proxy approximately 2 years following the participant's death. For this study, we used Harmonized HRS End-of-Life (1992–2014) data for 12,952 decedents' death-related details, health conditions, health care utilization including hospital out-of-pocket costs, and AD completion status.²⁴ We only included participants from wave 6 through wave 12 Exit Interviews ($N = 9228$) as earlier waves reported combined hospital and nursing home out-of-pocket costs, making it impossible to separate these costs. We then merged the RAND HRS Longitudinal File (1992–2016) for participant sociodemographic characteristics and health insurance coverage.²⁵

Hospital out-of-pocket costs

During HRS Exit Interviews, proxies were asked to report the amount of hospital out-of-pocket costs incurred since the previous interview or in the last 2 years prior to death. The value was assigned to zero if the decedents did not use any hospital services. Depending on the year of death, the cost of hospital out-of-pocket expenses was adjusted to 2014 dollars in the Harmonized HRS End of Life data set.²⁶

AD completion

Proxies were asked if decedents had written instructions about their preferences for medical treatment during their final days of life, also known as living wills. Participants indicating decedents had documented their preferences were further asked about the year and month of AD completion. The time from AD completion to death was also provided in the data set. In addition, proxies reporting ADs were in place at the time of death were asked whether ADs included instructions to limit care in certain conditions, withhold treatment (not initiating an intervention), be kept comfortable (pain-free but forgo extensive intervention to prolong life), or prolong life (receive all care possible under any circumstances).²⁵

Among those with an AD, we dichotomized the time period between AD completion and death to 3 months or less before death or more than 3 months before death. This allowed us to explore the effect of differences in AD completion timing on hospital out-of-pocket costs. Three months was selected as the cut-off period in line with previous studies that found different patterns of healthcare use and care preferences among those completing ADs in the last 3 months of life.^{22,27}

Covariates

Participants' sociodemographic status included gender and years of education. Race/ethnicity was grouped as non-Hispanic White, non-Hispanic Black, and Hispanic. Although the Harmonized End of Life data set includes decedents' total estate value, it may not fully capture respondents' entire financial situation, therefore, we chose to use household income and total wealth from the last wave of the core interview prior to death.

Characteristics associated with the end of life included age at death, whether death was expected, the location of death (private home, hospital, nursing home, hospice, and other), the main cause of death (cancer, cardiovascular diseases, and other), duration of final illness (e.g., less than 1 year: over 1 month but less than 12 months), and the number of days between the last core interview and death.

Finally, we controlled for health care insurance coverage due to its potential impact on out-of-pocket costs. In this analysis, whether or not the decedents had one of the main types of insurance were

included: Medicare fee-for-service, Medicare Advantage, Medicaid, veteran benefits, and private and/or employer-based health insurance.

Analysis

To compare health insurance coverage, sociodemographic and death-related characteristics between decedents with and without an AD, we conducted a two-sample *t*-test for continuous variables, and Wilcoxon rank-sum tests for the skewed distribution of out-of-pocket costs data, and χ^2 test for categorical variables.

We found 219 observations with missing data on AD completion as well as 2359 missing information on covariates in the model. Thus, we conducted a multiple imputation by chained equations approach to impute the missing data. Multiple imputation creates multiple values using both categorical and count data during the imputation process.²⁸

Due to the skewedness and large quantity of zeros in our out-of-pocket costs data, we elected to conduct a two-part model to analyze the data. In this model, hospital out-of-pocket costs served as the dependent variable and AD completion as the main independent variable of interest. All covariates including sociodemographic status, end-of-life characteristics, and insurance coverage were included in the model. In the first stage of this analysis, we used logit regression to predict the probability of whether the decedent had any hospital out-of-pocket costs. In the second part of the model, we conducted a generalized linear model (GLM) on those who had at least some out-of-pocket costs (nonzero expenditures). Natural logarithm as link function and Gamma type distribution was applied in the GLM analysis. Next, the post estimation marginal effects were predicted by using both parts of the model including those with zero expenditures. This same two-part model approach was then applied to examine hospital out-of-pocket costs by care preference among those who completed ADs. This two-part model has been widely used in health economics, particularly for health care expenditure data.^{29–35} Among those with an AD, we investigated hospital out-of-pocket costs in relation to the timing of when the ADs were completed. We used Wilcoxon rank-sum test to examine whether the hospital out-of-pocket costs for decedents who developed ADs in the 3 months prior to death were statistically different from those completing ADs earlier in the disease trajectory. Additionally, we compared the cost results yielded from our model with 2014 (aligning with the adjusted 2014 out-of-pocket costs for our sample) federal poverty level to explore the potential impact among low-income populations.

Lastly, to improve the robustness of this study, we performed sensitivity analysis by using propensity score weighting combined with regression analysis to address potential confounders such as health insurance coverage. In this process, we included the same covariates in the two-part model described previously to predict the propensity score of having completed an AD. Propensity score weighting can improve comparability between control and intervention groups and has been used to address potential selection bias

when estimating the average effect.³⁶ However, we ultimately chose to report the main results generated from the two-part model because nonlinear health care expenditures can yield bias and inefficiency under the propensity-based approach.³⁷ Additionally, results from the propensity score weighting were consistent with those achieved via the two-part model.

All analysis was conducted in 2020 using STATA 14 (StataCorp).

RESULTS

Demographics

Sample characteristics before imputation are shown in Table 1. More than half the decedents were female. Overall, 3950 (44%) of decedents had completed ADs. Non-Hispanic White decedents had higher AD completion rates (3512 out of 6710, 52%) compared to non-Hispanic Blacks (259 out of 1456, 18%) and Hispanics (124 out of 675, 18%). The average number of days from decedents' last interview to death was 420 days (range: 0–730, SD = 230) and there was no statistical difference between decedents who completed ADs and those who did not complete ADs ($p = .54$). The average hospital out-of-pocket cost was \$2114 (SD = \$20,507). On average, the top 1% of out-of-pocket costs among AD completers was \$67,093 (SD = \$79,916), while the top 1% of out-of-pocket costs for those who did not complete an AD was \$169,636 (SD = \$175,803). Bivariate analysis revealed that decedents with completed ADs had significantly lower hospital out-of-pocket costs (mean difference = –\$1137), lived longer (mean difference = 3.79 years), and had a higher education level (mean difference = 1.55 years) than those without ADs. In addition, participants with ADs were less likely to die in a hospital than those without ADs (33% [1285 out of 3950] vs. 39% [1980 out of 5059]) and more likely to receive hospice services (11% [423 out of 3950] vs. 7% [360 out of 5059]) than those without ADs. Differences in hospital out-of-pocket costs with and without ADs varied by health condition; patients with ADs and diagnosed with cancer had the greatest magnitude of out-of-pocket spending reduction, dropping from an average of \$4872 (SD = \$36,041) without an AD to \$1835 (SD = \$6707) with a completed AD.

Analytic results

The logit model in the first part of the two-part model indicated that decedents with ADs were more likely to have some hospital out-of-pocket spending compared with those without an AD (odds ratio [OR] = 1.20, 95% confidence interval [CI], 1.08–1.34, $p = .001$) after controlling for sociodemographic status, health insurance coverage, and death-related characteristics. However, the second part of the GLM model showed that for those who had at least some expenditures, participants with ADs had significantly lower out-of-pocket costs than those without ADs (OR = 0.62, 95% CI, 0.49–0.80, $p < .001$).

TABLE 1 Sample descriptions

Variables	Total ^a (N = 9228)	AD completed (N = 3950)	No AD (N = 5059)	Missing on AD (N = 219)	p Value ^c
Hospital out-of-pocket cost, mean (SD)	2091.3 (18,667.1)	1475.7 (10,915.4)	2612.6 (25,599.7)	1152.8 (78,540.3)	<.001
Age at death, mean (SD)	79.7 (10.9)	81.8 (9.8)	78.0 (11.3)	80.6 (11.4)	<.001
Education in years, ^b mean (SD)	11.3 (3.5)	12.1 (3.0)	10.6 (3.8)	11.7 (3.2)	<.001
Total income, ^b mean (SD)	40,203.8 (90,334.3)	45,896.7 (116,142.9)	35,955.9 (82,634.1)	31,844.6 (34,149.6)	<.001
Total wealth, ^b mean (SD)	34,0020.1 (1,102,521)	456,855.5 (1,496,045)	247,761.4 (902,525)	297,629.1 (552,839)	<.001
Female, n (%)	4929 (53.4)	2210 (56.0)	2592 (51.2)	127 (58.0)	<.001
Insurance coverage, ^b n (%)					
Medicare fee-for-service	7363 (81.8)	3272 (84.0)	3934 (79.8)	157 (90.8)	<.001
Medicare advantage	810 (9.8)	375 (10.6)	432 (9.5)	3 (1.5)	.093
Medicaid	2399 (27.6)	794 (20.8)	1561 (32.9)	44 (30.8)	<.001
Veteran benefits	543 (6.0)	258(6.6)	271(5.5)	14 (8.1)	.026
Private or employment	4841 (52.5)	2402 (60.8)	2285 (45.2)	154 (70.3)	<.001
Race, ^b n (%)					<.001
Non-Hispanic White	6876 (74.6)	3512 (88.9)	3198 (63.3)	166 (75.8)	
Non-Hispanic Black	1495 (16.2)	259 (6.6)	1197 (23.7)	39 (17.8)	
Hispanic	684 (7.4)	124 (3.1)	551 (10.9)	9 (4.1)	
Other	166 (1.8)	54 (1.4)	107 (2.1)	5 (2.3)	
Death expected, ^b n (%)	5383 (58.7)	2523 (64.2)	2738 (54.5)	122 (57.3)	<.001
Death location, ^b n (%)					<.001
Private home	2640 (28.7)	1083 (27.5)	1503 (29.8)	54 (25.5)	
Hospital	3343 (36.3)	1285 (32.6)	1980 (39.2)	78 (36.8)	
Nursing home	2211 (24.0)	1091 (27.7)	1065 (21.1)	55 (25.9)	
Hospice	802 (8.7)	423 (10.7)	360 (7.1)	19 (9.0)	
Other	208 (2.3)	64 (1.6)	138 (2.7)	6 (2.8)	
Cause of death, n (%)					<.001
Cancer	2098 (23.7)	976 (25.3)	1085 (22.6)	37 (18.9)	
Cardiovascular diseases	3080 (34.7)	1245 (32.2)	1753 (36.4)	82 (41.8)	
Other	3694 (41.6)	1644 (42.5)	1973 (41.0)	77 (39.3)	
Duration of final illness, n (%)					<.001
No warnings	809 (9.0)	247 (6.4)	538 (10.9)	24 (11.9)	
Less than 1 day	615 (6.8)	215 (5.5)	385 (7.8)	15 (7.4)	
Less than 1 week	1521 (16.9)	689 (17.8)	806 (16.4)	26 (12.9)	
Less than 1 month	1780 (19.8)	813 (21.0)	939 (19.1)	28 (13.9)	
Less than 1 year	2305 (25.6)	1002 (25.8)	1246 (25.3)	57 (28.2)	
More than 1 year	1971 (21.9)	913 (23.5)	1006 (20.5)	52 (25.7)	
Number of days from death to last core interview, mean (SD)	419.9 (229.5)	420.8 (227.4)	417.8 (230.9)	456.1 (235.1)	.537

Note: Insurance coverage is not mutually exclusive.

Abbreviations: AD, advance directive; SD, standard deviation.

^aMissing data on AD completion (N = 219) were excluded in this table.

^bp Value indicates significant difference between decedents who had AD completed versus no AD at .05 level.

^cVariables with additional missing data.

The marginal effects predict the hospital out-of-pocket costs based on the combination of both probability of spending (logit model) and the amount of spending (GLM) from the two-part model. Having an AD was associated with lower hospital out-of-pocket costs at \$1639 (95% CI, \$1306–\$1972) for those with ADs, compared with \$2312 (95% CI, \$1806–\$2817) for those that did not have ADs, a statistically significant difference of -\$673 (95% CI, -\$1203 to -\$142, $p = .01$) after controlling for death-related information, insurance coverage and other sociodemographic characteristics (Table 2). Hospital out-of-pocket costs also declined with older age at death (-\$65, 95% CI, -\$94 to -\$36, $p < .001$). In addition, the average difference in hospital out-of-pocket spending between patients with an AD and without an AD dropped from -\$1646 (95% CI, -\$3028 to -\$264, $p = .02$) at age 50 to -\$442 (95% CI, -\$811 to -\$73, $p = .02$) at age 90 (Figure 1).

Comparison among those completing an AD

Further investigation of hospital out-of-pocket costs by AD completion timing revealed that decedents who had their AD documented within 3 months ($N = 473$) experienced higher costs than those who completed their AD more than 3 months prior to death ($N = 3025$). For individuals who completed ADs more than 3 months prior to death, the mean hospital out-of-pocket cost was \$1176 (SD = \$5437), while the top 5% of out-of-pocket expenditures for these early AD completers was \$10,116 (SD = \$3712). In comparison, those who completed ADs within 3 months of death had an average of \$1854 (SD = \$10,232) in out-of-pocket spending, with the top 5% of this group spending \$12,858 (SD = \$3794). The results from the Wilcoxon rank-sum test revealed that hospital out-of-pocket spending was significantly different between those who completed ADs closer to death and those that completed ADs earlier in the trajectory ($p = .001$).

In this sample, over 90% of decedents with an AD expressed a desire to limit care (3506 out of 3867) or to be kept comfortable (3560 out of 3859), 79% (3000 out of 3805) indicated that they wanted to withhold treatment, and just 6% (217 out of 3887) wanted to prolong life. In addition, choosing to limit care was significantly associated with lower hospital out-of-pocket costs (-\$1443; 95% CI, -\$2702 to -\$185, $p = .025$).

Sensitivity analyses

We conducted sensitivity analyses to assess the analytic and modeling assumptions. We used propensity score weighting with imputation among our sample to reach a good balance between decedents with and without ADs. Results of subsequent analysis of these propensity weighted subsamples produced similar results as found in the two-part model (see Supporting Information content) in that having an AD was significantly associated with lower hospital out-of-pocket costs (-\$1354; 95% CI, -\$2382 to -\$326, $p = .010$).

TABLE 2 Predicted hospital out-of-pocket costs combining both parts of the two-part model (in 2014 US dollars)

	Predicted costs	95% confidence interval	p Value ^a
AD completed	-672.8	-1203.4 to -142.2	.013
Age at death	-64.6	-93.7 to -35.6	<.001
Female	866.4	304.7–1428.0	.003
Medicare advantage	-1354.7	-1985.0 to -724.4	<.001
Medicaid	-1537.2	-2091.4 to -983.0	<.001
Veteran benefits	-1102.0	-1645.2 to -558.9	<.001
Private or employer insurance	-767.1	-1339.0 to -195.2	.009
Death expected	1019.6	483.9 to 1555.3	<.001
Death location (private home as reference)			
Hospital	1569.6	879.2 to 2260.0	<.001
Nursing home	774.5	158.2 to 1390.8	.014
Cause of death (cancer as reference)			
Other	-1148.3	-2016.4 to -280.2	.010

Abbreviation: AD, advance directive.

^aSignificant results were provided, other covariates were omitted in this table.

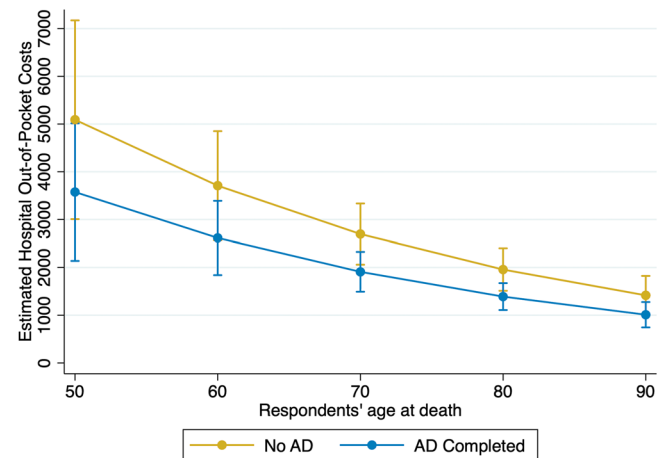


FIGURE 1 Marginal effects of advance directive (AD) completion by age.

DISCUSSION

We found AD completion was significantly associated with lower hospital out-of-pocket spending after controlling for socioeconomic status, health conditions, and health care insurance. One factor that most likely contributed to this finding was that patients with ADs were more likely to elect to limit care and focus on comfort care, rather than elect aggressive, life-prolonging care that can involve

expensive procedures and hospitalizations. Previous studies have found that the majority of decedents with ADs receive the care they desired,³⁸ and our finding suggested preferences for limiting care were associated with lower hospital out-of-pocket spending. Thus, these lower out-of-pocket costs may be influenced, in part, by the desire for less aggressive care expressed in ADs.

Previous studies have observed lower end-of-life health care costs among older age groups.^{39,40} For example, a Medicare expenditure study found that the youngest decedents (age 65–69) spent twice as much in the last year of life as those in the oldest strata (age 85 and over).³⁹ In our study, we found similar trends in that older age was associated with lower hospital out-of-pocket costs. In addition, compared with older decedents with ADs, younger patients with ADs had a greater magnitude of out-of-pocket cost reduction (Figure 1). This trend similarly aligned with earlier studies examining age-related differences in AD care preferences. Hamel et al.⁴¹ found that older patients were less likely to desire and receive aggressive care in the hospital. Thus, ADs were associated with a greater reduction in hospital out-of-pocket costs among younger patients who otherwise would most likely have received costly life-prolonging care.

Among those who had ADs, early completers had lower hospital out-of-pocket costs than those who completed an AD within 3 months prior to death. This finding also is consistent with a study examining AD completion timing that found a higher prevalence of electing aggressive care among decedents who completed ADs in the months prior to death.²² Some have suggested that late AD completion often involves decision-making “in the moment” of a health care crisis and may lack thorough consideration, education, and discussion.^{42–44} A qualitative study on health care providers suggest ADs should be initially developed when individuals are healthy, and then regularly modified as diseases develop and progress.⁴⁵

Lastly, our findings also have policy implications for physician–patient communication about costs of care. While some patients may not feel comfortable discussing out-of-pocket costs during advance care planning conversations, a recent study found that the majority of patients did take financial concerns into consideration in decision-making and want to have such conversations with their health care providers to understand expected cost associated with treatment and care decisions.⁴⁶ Thus, there is a growing call for transparency in treatment recommendations and in requirements for out-of-pocket costs to be discussed as side effects of treatment recommendations due to the negative impact financial burden has on patients and their family members.⁴⁷ Although research reports that both patients and physicians think it is important to discuss out-of-pocket costs, few physicians have the conversation with patients because of the complexity of health care and cost prediction.^{47–49} For patients with terminal illnesses, in particular, several advocates suggest that patients may make trade-offs in less costly treatment to avoid financial burden on their families.^{14,47} Our findings may encourage such conversation to help patients shape end-of-life decision-making in light of their financial circumstances. However, it is important for physicians to ask patients if healthcare out-of-pocket costs would impact decision-making prior to initiating these

discussions. Given that the federal poverty level was about \$973 per month for individuals in 2014, our predicted average \$689 reduction on out-of-pocket costs may relieve a substantial burden among financially disadvantaged individuals.

This study has several potential limitations. First, we focused on hospital out-of-pocket costs rather than all types of health care costs such as long-term-care and home-care costs, as these costs may not be as amenable to change by having an AD due to their different goals of care related to each care venue. Additionally, Exit Interviews are not weighted for national representation as the HRS does not apply sample weight variables for decedents.²⁶ Depending on the timing of death, participants may have had low out-of-pocket costs if they died close to the last core interview, while others surviving the entire 2 years between interview windows could have had relatively higher costs. However, we adjusted for this survival time in our analytic models and found that AD completion status remained significantly associated with lower hospital out-of-pocket costs. Finally, proxies may experience recall bias on AD-related questions and misreport out-of-pocket spending during surveys.⁵ However, French et al. found the out-of-pocket expenditure reported in the HRS Exit Interviews were relatively consistent with the data in the Medicare Current Beneficiary Survey (MCBS), indicating reliable quality and validity of the HRS exit medical expenditure data.⁵⁰

To date, this is the first paper to examine the relationship between AD completion and hospital out-of-pocket expenditures. Given that patients often consider out-of-pocket costs when engaging in health care decision-making, understanding the relationship between ADs and end-of-life treatment choices may motivate some consumers to complete ADs. Additionally, early (e.g., more than 3 months before death) AD completion resulted in even lower hospital out-of-pocket costs, thereby potentially adding greater patient incentive to engage in early advance care planning conversations and AD completion.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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