Disparities in End-of-Life Care: A Perspective and Review of Quality

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THE ELDERLY CONSTITUTE an ever-increasing proportion of the US population. There was a 15% increase in the number of people older than age 65 between 2000 and 2010,¹ more than initially predicted by the US Census.² The same model forecasts a more than 70% increase in the same cohort over the next 20 years, and a more than 60% increase in those older than age 85. Already health care cost per capita for those older than age 65 is estimated to be 3 to 5 times greater than for those younger than age 65.³ A shift from acute care to chronic disease management and long-term health care modalities is anticipated. Simultaneous to this increase in the elderly population is a marked expansion in medical technology. Testing and procedural intervention are becoming not only more numerous, but far more sophisticated and costly.

As the proportion of the elderly population expands and medical technology advances, a rapidly increasing percentage of health care resources is being allocated to care at the end of life (EOL). However, it is unclear whether such resources provide value. In this context, there is a need to understand how such resources are utilized and how utilization decisions are made.

Variation in the use of EOL resources and decisions is attributed to patient variables, hospital factors, and the sociocultural platform in which both patient and provider exist.⁴⁻⁶ This article focuses on patient variables and employs a systematic approach to advance our understanding of factors that influence EOL care. In particular, we explore recent findings that minority patients are more likely to receive overtreatment and discuss possible explanations.

Although regional variation in EOL care has been studied,^{5,6} little is known about the patient-level variables, which include values and perceptions of what medicine can provide, and the individual's definition of an acceptable outcome. A better understanding of these factors can be used to design interventions aimed at improving EOL care.

In the current literature, we encountered 2 main study designs that examined the relationship between EOL care and patient and family preferences: (1) analysis of retrospective administrative and/or clinical data, and (2) qualitative surveys of individual patients or focus groups using

questionnaires or theoretical scenarios. Race and socioeconomic factors appeared to be a common patient and family characteristic that influence EOL care preferences throughout many of these studies.

One study examined patients who died in the intensive care unit (ICU) in 15 US hospitals.⁷ It found numerous racial differences in EOL care: nonwhite patients were less likely to have living wills, more likely to die with full support, and more likely to have discord documented among family members and physicians about EOL planning. The authors postulated that differences could be the result of treatment preferences, disparities, or both, and challenged the medical community to explore these issues in greater depth. Several other studies have used administrative databases to explore such patient-level trends. Using the Medicare database, Hanchate et al found that black and Hispanic decedents received substantially more life-sustaining interventions such as mechanical ventilation, gastrostomy, and hemodialysis.⁸ These findings were consistent with previous analyses of medical records and administrative databases, which have found that black nursing home residents receive more treatments,^{9,10} are more likely to die in the hospital,¹¹ and have higher expenditures at the EOL.^{12,13}

The use of more aggressive EOL interventions by minorities may be explained, at least in part, by patient preference. A literature review by Kwak et al emphasized the importance of recognizing the variety of values and preferences among racially diverse groups in EOL decisions.¹⁴ Garrett et al found that those who identified themselves as blacks were more likely than whites to prefer hospitalization and use of a feeding tube in the treatment of a terminal illness.¹⁵ Caralis et al reported that, when presented with hypothetical scenarios, blacks were more likely than whites to want aggressive interventions such as ICU care, cardiopulmonary resuscitation, mechanical ventilation, dialysis, or surgery if in a permanently unconscious state.¹⁶ Hopp's study provided further support for such preferences, showing that whites were more likely to discuss limiting treatments and ceilings of care.¹⁷

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Another study identified that blacks were more likely to want life-sustaining treatment in near-death situations.¹⁸ In multivariate analysis, Barnato and colleagues found that an overly optimistic belief about the likelihood of return to normal activities after mechanical ventilation for life-support explained some of the greater preferences for life-sustaining drugs and mechanical ventilation among nonwhites.¹⁹ In reality, in a study looking at Medicare beneficiaries, up to two thirds who survived an ICU admission that required mechanical ventilation were discharged to a skilled nursing facility.²⁰ In this landmark paper by Wunsch et al, requirement for mechanical ventilation doubled the mortality at 6 months and at 1 year among ICU survivors.

Several studies indicate that distrust and misunderstanding also might drive preferences for more intensive EOL care. In one study, Hauser and colleagues reported on themes related to trust.²¹ They found that blacks were suspicious of the motives behind advance directives and do-not-resuscitate (DNR) orders, and that they believed that physicians were interested in protecting themselves legally and in removing organs for transplantation. The authors theorized that a deep sense of mistrust arose from prior personal or family experiences that, consequently, resulted in a reluctance to rely on a piece of paper to represent one's preferences. In another study, Perkins et al observed that those who identified themselves as blacks were more likely to believe that the health care system controls which treatments people receive.²² It may be that this view of the health care system, whatever its origin, creates a perception that limiting any intensive treatment is a form of injustice.

To understand EOL care, it may be important to look at patterns in primary care provider (PCP) visits. Kronman et al explored the association between primary care visits and key outcomes during the last 6 months of life.²³ They examined PCP visits of Medicare beneficiaries aged 65 or older during the preceding 12 months ("pre period") as a predictor of hospital use and costs in the last 6 months of life. Using a multivariate regression analysis, they found that more PCP visits in the pre period were associated with reduced hospital days, in-hospital deaths, and cost. By using fixed effect regression analysis with geographic clustering, they adjusted for both measurable and immeasurable geographic factors. They found that within a geographic area, more primary care visits were associated with less resource utilization at the EOL.

Several studies have reported that black and Hispanic patients have fewer and less comprehensive primary care visits, possibly contributing to differences in management of EOL care issues.^{24–26} When Fiscella et al analyzed claims for Medicare beneficiaries age 65 and older over a 12-month period they found that minorities were more likely to have had no primary care visits as compared to white patients.²⁴ They found that this contributed to racial disparities in the provision of 5 preventive services: colorectal cancer screening, influenza vaccination, lipid screening, mammography, and Pap smear screening. Racial disparities in the receipt of the procedures were not fully explained by the number of visits, suggesting that minorities differ not only in the quantity, but also in the quality of primary care visits. The association between race and the quality of preventive care was greatly attenuated after adjusting for income, education level, and health status. This suggests that racial disparities

are explained in part by the socially controllable factors associated with poverty. Some authors theorize that, most particularly, disparities in education and the closely related construct of poor health literacy (a component of poverty) contribute the most to racial disparities in health care.^{27–29}

We feel that an appropriate research agenda requires analyzing the data from several perspectives. Studying trends in utilization of health care within racial cohorts may help identify factors associated with increased use, and thus provide insight into areas that may be targeted for intervention. Are minority groups at increased risk of overtreatment at the EOL because of lower socioeconomic status, lower educational attainment, poorer health status, or other factors? Understanding possible factors behind racial differences is vital to improving EOL care.

Prospective studies can best capture one's interaction with the medical system over a lifetime. This might be done by collecting specific educational and socioeconomic information at the time of Medicare enrollment and then studying how these variables correlate with the intensity of EOL care. Although this type of prospective study would be extremely informative, it also would be very costly and time consuming.

In addition to prospective studies, effort also should be made to perform retrospective database analyses covering longer time periods. Rather than the standard 6-month to 2-year analyses before death, 5–10 year analyses of administrative data before death may provide the lead time needed to fully understand the problem in order to build a more comprehensive model of intervention.

In summary, some patients are more likely to receive overtreatment at the EOL because of both the quantity and quality of care they receive over the course of their lives. As a result, they may be poorly prepared to understand EOL issues such as expectations and limitation of care at a time of critical illness. The only way to improve EOL care may be to improve care during life. Minorities have been associated with increased EOL treatment intensity but more research must be done to determine the actionable factors underlying patient race that lead to these preferences. Investing more time and resources to address these life course factors may prove to be the best strategy to reduce cost at the EOL.

Acknowledgment

The authors thank Professor Stephen Gilman for his comments and suggestions.

Disclosure Statement

Drs. Perry, Kwok, Kozycki, and Celi disclosed no conflicts of interest and received no funding with respect to the research, authorship, and/or publication of this article.

References

1. US Census Bureau. International database. Table 094. Mid-year population, by age and sex. Available at: <http://www.census.gov/population/www/projections/natdet-D1A.html>. Accessed October 1, 2011
2. Centers for Disease Control and Prevention. Public health and aging: Trends in aging—United States and worldwide. Available at: <http://www.cdc.gov/mmwr/preview/mmwr.html/mm5206a2.htm>. Accessed July 11, 2012.

3. The Dartmouth Institute for Health Policy and Clinical Practice. The Dartmouth Atlas of Health Care. Available at: <<http://www.dartmouthatlas.org/index.shtml>>. Accessed July 22, 2010.
4. Jacobzone S, Oxley H. Ageing and health care costs. Internationale Politik und Gesellschaft Online (International Politics and Society). Available at: http://www.fes.de/ipg/ipg1_2002/ARTJACOBZONE.htm. Accessed July 16, 2012.
5. Wunsch H, Linde-Zwirble WT, Harrison DA, Barnato AE, Rowan KM, Angus DC. Use of intensive care services during terminal hospitalizations in England and the United States. *Am J Resp Crit Care Med* 2009;180: 875–880.
6. Angus DC, Sirio CA, Clemont G, Bion J. International comparisons of critical care outcome and resource consumption. *Crit Care Clin* 1997;13:389–407.
7. Muni S, Engelberg RA, Treece PD, Dotolo D, Curtis JR. The influence of race/ethnicity and socioeconomic status on end-of-life care in the ICU. *Chest* 2011;139:1025–1033.
8. Hanchate A, Kronman AC, Young-Xu Y, Ash AS, Emanuel E. Racial and ethnic differences in end of life costs: Why do minorities cost more than whites? *Arch Intern Med* 2009; 169:493–501.
9. Gessert CE, Mosier MC, Brown EF, Frey B. Tube feeding in nursing home residents with severe and irreversible cognitive impairment. *J Am Geriatr Soc* 2000;48:1593–1600.
10. Gessert CE, Curry NM, Robinson A. Ethnicity and end-of-life care: The use of feeding tubes. *Ethn Dis* 2001;11:97–106.
11. Pritchard RS, Fisher ES, Teno JM, et al. Influence of patient preferences and local health system characteristics on the place of death. *J Am Geriatr Soc* 1998;46:1242–1250.
12. Levinsky NG, Yu W, Ash A, et al. Influence of age on Medicare expenditures and medical care in the last year of life. *JAMA* 2001;286:1349–1355.
13. Hogan C, Lunney J, Gabel J, Lynn J. Medicare beneficiaries' cost of care in the last year of life. *Health Aff (Millwood)* 2001;20:188–195.
14. Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *Gerontologist* 2005;45:624–641.
15. Garrett JM, Harris RP, Norburn JK, Patrick DL, Danis M. Life-sustaining treatments during terminal illness: Who wants what? *J Gen Intern Med* 1993;8:361–368.
16. Caralis PV, David B, Wright K, Marcial E. The influence of ethnicity and race on attitudes toward advance directives, life-prolonging treatments, and euthanasia. *J Clin Ethics* 1993;4:155–165.
17. Hopp FP, Duffy SA. Racial variations in end-of-life care. *J Am Geriatr Soc* 2000;48:658–663.
18. Phipps E, True G, Harris D, et al. Approaching the end of life: Attitudes, preferences, and behaviors of African-American and white patients and their family caregivers. *J Clin Oncol* 2003;21:549–554.
19. Barnato AE, Anthony DL, Skinner J, Gallagher PM, Fisher ES. Racial and ethnic differences in preferences for end-of-life treatment. *J Gen Intern Med* 2009;24:695–701.
20. Hauser JM, Kleeffeld SF, Brennan TA, Fischbach RL. Minority populations and advance directives: Insights from a focus group methodology. *Camb Q Healthc Ethics* 1997;6:58–71.
21. Wunsch H, Guerra C, Barnato A, Angus DC, Li G, Linde-Zwirble WT. Three-year outcomes for Medicare beneficiaries who survive intensive care. *JAMA* 2010;303:849–856.
22. Perkins HS, Geppert CM, Gonzales A, Cortez JD, Hazuda HP. Cross-cultural similarities and differences in attitudes about advance care planning. *J Gen Intern Med* 2002;17: 48–57.
23. Kronman AC, Ash AS, Freund KM, Hanchate A, Emanuel EJ. Can primary care visits reduce hospital utilization among Medicare beneficiaries at the end of life? *J Gen Intern Med* 2008;23:1330–1335.
24. Fiscella J, Holt K. Impact of primary care patient visits on racial and ethnic disparities in preventive care in the United States. *J Am Board Fam Med* 2007;20:587–597.
25. Forrest CB, Whelan EM. Primary care safety net delivery sites in the United States: A comparison of community health centers, hospital outpatient departments, and physicians' offices. *JAMA* 2000;284:2077–2083.
26. Schappert SM, Burt CW. Ambulatory care visits to physician offices, outpatient departments and emergency departments: United States, 2001–02. *Vital Health Stat* 13 2006;159: 1–66.
27. Scott TL, Gazmararian JA, Williams MV, Baker DW. Health literacy and preventive health care use among Medicare enrollees in a managed care organization. *Med Care* 2002;40: 395–404.
28. Howard DH, Sentell T, Gazmararian JA. Impact of health literacy on socioeconomic and racial differences in health in an elderly population. *J Gen Intern Med* 2006;21:857–861.
29. Agency for Healthcare Research and Quality. National healthcare disparities report, 2006. Available at: <http://www.ahrq.gov/qual/nhdr06/nhdr06.htm>. Accessed July 22, 2010.

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