

# Race and prevalence of percutaneous endoscopic gastrostomy tubes in patients with advanced dementia

## Original Article

**Cite this article:** Henao D, Gregory C, Walters G, Stinson C, Dixon Y (2023). Race and prevalence of percutaneous endoscopic gastrostomy tubes in patients with advanced dementia. *Palliative and Supportive Care* **21**, 224–229. <https://doi.org/10.1017/S1478951521002042>

Received: 4 June 2021

Revised: 20 September 2021


Accepted: 23 December 2021

### Key words:

Advanced dementia; Disparities; Gastrostomy tubes; Race

### Author for correspondence:

David Henao,  
Office of Diversity, Inclusion, and Equity,  
Novant Health, 2000 Frontis Plaza, Suite 101,  
Winston-Salem, NC 27103, USA.  
E-mail: [dhenao@novanthealth.org](mailto:dhenao@novanthealth.org)

David Henao, M.D., M.B.A.<sup>1</sup> , Chere Gregory, M.D., M.H.S.<sup>1</sup>, Gloria Walters, Ph.D., R.N.<sup>2</sup>, Charles Stinson, M.D.<sup>3</sup> and Yvonne Dixon, M.S.N., M.H.A., B.S.N., R.N.<sup>1</sup>

<sup>1</sup>Office of Diversity, Inclusion, and Equity, Novant Health, Winston-Salem, NC 27103; <sup>2</sup>Center for Professional Practice & Development, Novant Health, Winston-Salem, NC 27103 and <sup>3</sup>Palliative Care, Novant Health, Winston-Salem, NC 27103

### Abstract

**Objective.** Millions of Americans may face hard decisions when it comes to providing nutrition for their loved ones with advanced dementia. This study aimed to ascertain whether there is a difference in feeding tube placement between White and Black patients with advanced dementia and whether this potential difference varied by patient's other demographic and clinical characteristics.

**Method.** This is a retrospective, observational study conducted at Novant Health, a 15-hospital system in the southeastern United States. Data were obtained from Epic systems and included all hospital admissions with a diagnosis of advanced dementia, a total of 21,939, between July 1, 2015, and December 31, 2018. Descriptive statistics and logistics analyses were conducted to assess the relationship between receiving percutaneous endoscopic gastrostomy (PEG) and race, controlling for demographic and clinical characteristics.

**Results.** Among patients admitted with advanced dementia, the multivariable logistic regression, controlled for age, gender, LOS, palliative care, and vascular etiology showed that Blacks had higher odds of having PEG tubes inserted than White patients (OR 1.97; CI 1.51–2.55;  $P < 0.001$ ). Patients with longer stays had higher odds of PEG tube insertion. Females had lower odds of PEG tube insertion than males. There was no statistical significance in PEG insertion based on age, etiology, and palliative care consult.

**Significance of results.** The reasons for the observed higher odds of receiving PEG tubes among Black patients than White patients are likely multifactorial and embedded in a different approach to end-of-life care conversations by providers and caregivers of Black and White patients. Providers may need to be more aware of potential unconscious biases when talking to caregivers, especially in race-discordant relationships, have courageous conversations with caregivers, and be more aware of the importance of keeping in mind families' and caregivers' culture, including spirituality, when making end-of-life decisions.

## Introduction

Millions of Americans may face hard decisions when it comes to providing nutrition for their loved ones with advanced dementia. Thousands of providers around the country, in hospitals, intensive care units, and nursing homes, face similar decisions when caring for these patients. Eating and swallowing problems typically develop during the terminal stages of dementia and are among the most common issues in this population (Mitchell et al., 2009). These include aspiration secondary to pharyngeal dysphagia, the inability to feed oneself, and the refusal to eat.

Two options to treat sustained eating problems are oral-assisted feeding and tube feeding. Whether to initiate tube feeding or to focus on comfort is one of the most challenging dilemmas facing families, clinicians, and institutions caring for these patients. On one side, oral-assisted feeding is time-consuming, but it allows the patient to taste the food and to interact with caregivers during meals (Mitchell, 2015). Conversely, tube feeding may increase the length of survival and improve nutritional status (Shintani, 2013).

In 2009, a Cochrane review concluded that there was not enough evidence to support the benefits of tube feeding in patients with advanced dementia in terms of survival, quality of life, nutrition, functional status, the prevention of aspiration, or the prevention and healing of pressure ulcers (Sampson et al., 2009). Similarly, a study of skilled nursing facility residents with advanced dementia showed no difference in survival rates between those who had feeding tubes versus those who did not have feeding tubes (Teno et al., 2012).

In addition, the risks of feeding tube placement have been well documented. They include procedural complications such as chemical and physical restraints in agitated patients,

re-interventions, and increased risk of infection. Oral-assisted feeding has proved as beneficial as tube feeding for the outcomes of reduced mortality, aspiration pneumonia, functional status, and comfort (American Geriatrics Society, 2014). Due to a lack of data to support placing feeding tubes in patients with advanced dementia, several organizations recommend against placing feeding tubes in these patients. The American Geriatrics Society and the American Academy of Hospice and Palliative Medicine recommend offering oral-assisted feeding (Fischberg et al., 2013; American Geriatrics Society, 2014).

Overutilization of care is often found among White patients. On average, Whites tend to be more optimistic about the healthcare system, have more positive attitudes, are more receptive to new procedures, and have more financial resources (Kressin and Groeneveld, 2015). If this finding were extrapolated to feeding tubes, theoretically, White patients would be at higher risk for receiving unnecessary feeding tubes in advanced dementia. Of interest, the number of feeding tubes continues to decline in the United States based on the emergence of new research, expert opinion, and recommendations by national organizations that discourage the placement of feeding tubes.

However, a recent study found that among 71,251 advanced dementia residents, the proportion of White residents receiving feeding tubes declined from 8.6% to 3.1%, while for Black residents insertion rates went from 37.6% to 17.5% (Mitchell et al., 2016). Also, a recent study found that Black and Hispanic patients with dementia faced significantly greater odds of receiving feeding tubes compared to White patients (Schpero et al., 2017). Fewer than 5% of White Medicare patients with dementia received a feeding tube, compared to over 17% of Black and nearly 13% of Hispanic patients with dementia.

Several hypotheses have been formulated to explain these disparities. The phenomenon is likely multifactorial. Explanations included, but are not limited to:

- Different cultural attitudes toward death and dying (MacDonald, 1998)
- Apprehension and distrust of the medical system experienced by some historically underrepresented populations, particularly, in a race-discordant or socioeconomic status (SES)-discordant physician-patient relationship (Boulware et al., 2003; Armstrong et al., 2007)
- Quality of the shared decision-making process and communication of advance directives (Mitchell et al., 2003)
- Providers' perceptions regarding family support structure and home environment of the patient (Van Ryn and Burke, 2000; Faigle et al., 2016)
- Provider default to highlighting benefits of a percutaneous endoscopic gastrostomy (PEG) when counseling Black patients to avoid the perception of suggesting limits on treatment (Braun et al., 2008)
- Explaining and implementing alternatives to feeding via PEG can be time-consuming (Stathopoulos et al., 2011; Teno et al., 2011). This leads to a health equity concern as providers may spend more time with White patients than historically underrepresented patients when counseling about PEG tube placement, thus differentially affecting its perceived necessity (Cooper et al., 2003; Johnson et al., 2004).
- Prevalence of a paternalistic physician-patient relationship in certain cultures, which may increase willingness to accept a PEG when suggested by providers (Levinson et al., 2005; Murray et al., 2007)

No conclusive evidence explains these disparities and the potential role that culture may play. Some suggest that they are rooted in providers' biases. In the setting of racial/ethnic bias, the lack of providers from historically underrepresented groups may increase the possibility for bias. In the United States, only 5% of providers self-identify as Black or African American (Association of American Medical Colleges, 2020). Conversely, they may be rooted in non-White caregivers' lack of trust in the system, causing providers to aggressively promote feeding tubes in these patients. The answer may also be somewhere in between.

This study was performed to ascertain whether there is a disparity between Whites and Blacks in feeding tube placement in a large United States healthcare system. Further, variables that may impact the feeding tube decision in advanced dementia patients were considered. Demographic and clinical data from thousands of admissions of patients with advanced dementia were used.

## Methods

### Data source

This study was conducted at Novant Health, a 15-hospital system in the southeastern United States. Data were obtained from Epic systems and included all encounters of hospitalized patients with a diagnosis of advanced dementia, a total of 21,939 admissions, between July 1, 2015, and December 31, 2018. The study was approved by the institutional review board of Novant Health Forsyth Medical Center and a patient waiver of consent was granted. The study used de-identified data, and no medical records were reviewed.

### Case selection

We identified patients admitted to all Novant Health hospitals with a primary diagnosis of advanced dementia, using the same list of ICD-9 and ICD-10 codes used by Schpero et al. (2017). Inclusion criteria included Black or White race, English language preferred, age 60 years of age or above, and acute care inpatient admission.

### Variables

The primary outcome of interest was the placement of a PEG as identified by ICD-9 and ICD-10 codes. The primary explanatory variable was self-reported race, classified as Black/African American or White/Caucasian. Other patient characteristics included age, gender, primary insurance, length of stay (LOS), vascular vs. nonvascular dementia identifier, palliative care identifier (yes/no), healthcare power of attorney (HPOA) identifier (yes/no), and code status (full code/do not resuscitate [DNR]).

### Statistical analysis

Descriptive statistics were used to characterize patient populations with and without a PEG tube using Pearson's chi square and regression for categorical and continuous variables, respectively. Univariate logistic regressions were performed to determine the unadjusted associations of PEG placement and race, gender, payer, LOS, vascular versus nonvascular dementia, palliative care, HPOA, and code status. The multivariable logistic regression analysis assessed the association of race and PEG placement while controlling for other risk factors that were identified through

univariate logistic regressions as statistically significant predictors of PEG placement. They included age, gender (female = 1), LOS (five days or lower = 0), vascular vs. nonvascular dementia identifier (vascular = 1), and palliative care identifier (palliative care = 1). We then stratified the patient population by race. A *P*-value of <0.05 was considered statistically significant, and 95% confidence intervals are reported. All analyses were conducted using R version 4.1.0.

## Results

There were 21,939 admissions that met all inclusion criteria. PEG tubes were performed in 266 patients (1.3%) (Table 1). Of the 4,138 Black patients admitted, 94 received a PEG tube (2.27%). Of the 17,801 White patients, 172 received PEG tubes (0.97%). Admissions for Black patients were 18.9% of the total, and they received 35.3% of total PEG tubes. White patients represented 81.3% of admissions and 64.7% of PEG tubes. Age at admission for patients who received a PEG tube was younger than patients who did not receive a PEG (average 78 years versus 82, *P* < 0.001). Women were older than men (average of 82.4 years old for women versus 80.2 for men) at admission. In the univariate logistic regressions, we found the patients with the following characteristics to have higher odds of PEG tubes: Blacks compared to Whites (*P* < 0.001), males compared to females (*P* < 0.001), patients who stayed 6 to 10 days, 11 to 14 days, and 15 days compared to patients who stayed 5 days or fewer (*P* < 0.001), patients with vascular dementia (*P* = 0.04), and patients who had palliative care consultation (*P* = 0.001). There was no association between PEG and insurance in univariate logistic regression analyses (commercial versus Medicaid: *P* = 0.10; Medicare: *P* = 0.62; and self-pay: *P* = 0.99), code status (*P* = 0.11), and HPOA document (*P* = 0.38).

Descriptive statistics of the utilization of services by race follows. Average LOS for Black and White patients was 8.5 days and 7.5 days, respectively. Univariate regression analyses show that Blacks received more palliative care consultations than White patients (OR 1.43, 95% CI 1.33–1.53). Black patients had full code orders at higher rates than White patients (OR = 2.07, CI 1.74–2.47), and Black patients with DNR orders in the medical record had a higher rate of PEG tube insertion than those with full code orders (OR 1.14, 95% CI 0.74–1.76).

In the multivariable logistic regression, in which we controlled for age, gender, LOS, palliative care, and vascular etiology, Blacks had higher odds of having PEG tubes inserted than White patients (OR 1.97; CI 1.51–2.55; *P* < 0.001) (Table 2). Patients with longer stays also had higher odds of PEG tube insertion. Females have lower odds of PEG tube insertion than males (OR 0.72, 95% CI 0.56–0.92.) There was no statistical significance in PEG tube insertion based on age, etiology, and palliative care consult in the medical record.

We then stratified the patient population by gender, palliative care, and etiology. Black females had higher odds of receiving a PEG tube than white females (OR 2.62, 95% CI 1.82–3.76) (Table 3). Black males had also higher odds of receiving a PEG tube than white males (OR 1.45, 95% CI 0.97–2.12). The magnitude of the OR was significantly higher for females than males. Furthermore, disparities by race were most pronounced in black patients who had a palliative care consult (OR 2.68, 95% CI 1.85–3.87) as compared to those who had no palliative care consult (OR 1.42, 95% CI 0.95–2.07). Black patients had higher odds of PEG than white patients if they were diagnosed with

**Table 1.** Baseline characteristics of the study population stratified by PEG status

	PEG	No PEG	<i>P</i> -value
Total	266	21,673	
Age	78 years old	82 years old	<0.001
Race			<0.001
Black	94 (35.3)	4,044 (18.7)	
White	172 (64.7)	17,629 (81.3)	
Gender			<0.001
Female	127 (47.7)	12,997 (60.0)	
Male	139 (52.3)	8,676 (40.0)	
Insurance			0.088
Commercial	10 (3.8)	926 (4.3)	
Institutional	0 (0.0)	1 (0.0)	
Medicaid	4 (1.5)	140 (0.6)	
Medicare	249 (93.6)	19,639 (90.6)	
Other Govt	3 (1.1)	932 (4.3)	
Self-pay	0 (0.0)	35 (0.2)	
Type of dementia			0.004
Nonvascular dementia	229 (86.1)	19,595 (90.4)	
Vascular dementia	37 (13.9)	2,078 (9.6)	
Length of stay			<0.001
1–5 days	20 (7.5)	11,498 (53.0)	
6–10 days	60 (22.6)	6,316 (29.1)	
11–14 days	44 (16.5)	1,742 (8.0)	
15 or more days	142 (53.4)	2,117 (9.8)	
Palliative care			0.001
No	143 (53.8)	13,875 (64.0)	
Yes	123 (46.2)	7,798 (36.0)	
Code status			0.105
DNR/No CPR	113 (42.5)	10,152 (46.9)	
Full Code	137 (51.5)	10,008 (46.2)	
HPOA			0.379
No	215 (80.8)	17,961 (82.9)	
Yes	51 (19.2)	3,712 (17.1)	

vascular dementia (OR 3.56, 95% CI 1.73–7.46) and nonvascular dementia (OR 1.79, 95% CI 1.34–2.37), but the differences by race were more pronounced among patients with vascular dementia.

## Discussion

Decisions on PEG tube placement largely depend on perceptions of necessity among clinical care team members, patients, family members, caregivers, and healthcare decision-makers. The decision may be influenced by the providers' unconscious biases, especially when it comes to perceived patients' support structure

**Table 2.** Association between PEG placement and race and other determinants (multivariate logistic regression)

Variable	OR	95% CI
Race: AA/Black	1.97	[1.508, 2.547]
Gender: female	0.72	[0.561, 0.921]
Age	1	[0.982, 1.010]
LOS 6–10	5.24	[3.214, 8.924]
LOS 11–14	13.44	[7.990, 23.396]
LOS >14	33.96	[21.580, 56.371]
Etiology: vascular	1.34	[0.898, 1.924]
Palliative care: yes	1.25	[0.971, 1.603]

**Table 3.** Association between PEG placement and race (multivariate logistic regression, models stratified by gender, palliative care, etiology)

Patient population	OR [CI] for Black vs. White
Total population	1.97 [1.508, 2.547]
Stratified by gender	
Female	2.62 [1.818–3.759]
Male	1.45 [0.971–2.124]
Stratified by palliative care	
No	1.42 [0.953, 2.074]
Yes	2.68 [1.847, 3.874]
Etiology	
Nonvascular	1.79 [1.341, 2.374]
Vascular	3.56 [1.734, 7.456]

and home environment (Van Ryn and Burke, 2000; Faigle et al., 2016). Family member and caregiver experiences with healthcare systems and social injustices may make them less likely to believe that providers will provide appropriate care for their loved ones (Tucker et al., 2014). Distrust often occurs when care teams do not reflect the racial/ethnic diversity of the communities served (Boulware et al., 2003; Armstrong et al., 2007). Some providers, perhaps conscious of this situation, may try to offer more aggressive care to mitigate caregivers' feelings that they are withholding care. Also, time constraints and the potential duration of difficult end-of-life conversations may influence both providers and families to choose feeding tubes.

Over 15% of Black parents receive informal care from children and/or children-in-law compared with less than 3% of White parents, a difference that is statistically significant (Byrne et al., 2009). Children of Black patients may tend to be more involved in end-of-life care and decisions, and the noted disparity in PEG insertions could potentially be a result (Sterritt and Pokorny, 1998). There are no studies we are aware of that show that providers make different decisions when end-of-life care conversations involve children as opposed to spouses or an unrelated caregiver.

Many socioeconomic factors are likely to play a role in the PEG decisions. The education and income of patients and family members may play a role. For instance, Byrne et al. (2009) found

that, all else being equal, family members have less incentive to spend time caring for more highly educated parents.

### Role of gender

In the multivariate analysis, gender was independently associated with PEG tube placement, along with LOS and race. Similarly, in the literature, gender has been independently associated with PEG placement in patients with advanced dementia (Faigle et al., 2016). There are several potential explanations for these disparities.

Byrne et al. (2009) provided a structural model to explain gender influence in the provision of informal senior care. In this model, children have greater incentives to provide care for mothers than for fathers. Moreover, this model suggests that informal care provided to mothers (wives) is significantly less burdensome than care provided to fathers (husbands), providing children with greater incentive to spend time caring for elderly mothers than fathers. According to Checkovich and Stern (2002), adult children are more likely to provide care for elderly mothers than for elderly fathers, all else being equal. It has been suggested that families value informal care provided by children more highly for mothers than for fathers (Hiedemann and Stern, 1999). Therefore, children may have a greater incentive to choose oral-assisted feeding for their mothers than they would for their fathers. Similarly, in terms of the quantity of care received, it has been reported that lone fathers receive fewer hours of care than do lone mothers, which may also point to the fact that males receive more PEGs (Katz et al., 2000; Pezzin et al., 2006).

### Race and DNR orders

In this study, Black patients had full code orders at higher rates than White patients, which is consistent with previous findings that Blacks may tend to distrust the system and be more in favor of more aggressive ways to prolong life. A controlled trial by Johnson et al. (2008) found that Blacks were almost twice as likely (OR 1.91) as Whites and others to choose full code status, even after controlling for other variables that may have influenced the relationship, such as LOS in the ICU, age, and diagnosis on admission (Johnson et al., 2010). Similar findings regarding racial differences in preferences for end-of-life care have been reported in nursing homes (Messinger-Rapport and Kamel, 2005) and hospice (Johnson et al., 2008). A patient with a full code order in the medical record, in theory, should have a higher likelihood of receiving a PEG than one with a DNR order. However, we did not find a statistically significant association between code status and PEG tube insertion. In skilled nursing facilities, Mitchell et al. (2016) found that those with a relatively smaller proportion of the resident population with DNR orders had a greater likelihood of patients having a feeding tube. Although we are aware of potential differences between acute care facilities and skilled nursing facilities, we are using data from the latter as a proxy given the scarcity of data on acute care facilities. Interestingly, in our study, Black patients with DNR orders had a higher rate of PEGs than those with full code.

### Race and palliative care

Some studies have shown that Blacks are more likely to receive palliative care consultation. Sharma et al. (2015) found that, in patients with cancer, after adjusting for insurance, hospitalizations, marital status, and illness severity, Black patients had a



greater likelihood of receiving palliative care (odds ratio, 1.21; 95% CI, 1.01–1.44) (Sharma *et al.*, 2015). This may be due to discussion discord. A study of critically ill patients found that physicians were more likely to document discord in discussions with families of non-White patients than with families of Whites (Muni *et al.*, 2011). One reason was that physicians may perceive greater discord between Black patients/families and physicians and were thus more likely to seek help in discussing goals of care. Some physicians may also expect that Black patients are reluctant to discuss hospice and more likely to prefer aggressive care at the end-of-life than Whites (Wicher and Meeker, 2012). In our study, the multivariate regression, when adjusted for race and LOS, showed no impact of palliative care consult on PEG insertion.

### **Race and LOS**

As expected, LOS was also significantly associated with PEG insertion, even after controlling for other variables in the multivariate regression analysis. LOS for Black patients was on average 1 day longer than for White patients. Studies have shown that Black patients tend to have longer LOS (Giglia *et al.*, 2017). This finding may also reinforce the possibility that providers will choose PEGs, given the higher likelihood that caregivers would choose more aggressive care.

### **Race and age**

Age was also associated with receiving a PEG. As age increased, PEGs were less common, which is consistent with other studies (Faigle *et al.*, 2016). For patients who received PEGs, Black patients were about 6 months older than White patients, but almost 2 years younger if they did not receive a PEG. Multivariate analysis showed that age was not a statistically significant independent variable for explaining PEG insertion. This may be due to the inclusion of other factors, such as etiology and race, in the model, which are significant predictors.

### **Implications for practice**

This study was designed to help better understand the roots of the disparity between Blacks and Whites and PEG placement. There is no consensus in the literature explaining the reasons for the disparity between Blacks and Whites in PEG insertion rates. There is no evidence showing that Blacks benefit from having higher feeding tubes rates. Based on current knowledge and opinion, most authors agree the gap should be closed by reducing the number of Black patients receiving PEGs.

The data show that this disparity is likely multifactorial. It is unlikely the disparity is due only to system issues or provider biases. The reasons are probably embedded in how both providers and caregivers approach end-of-life conversations in patients with advanced dementia. This research shows that providers may need to be more aware of potential unconscious biases when talking to caregivers, especially in race-discordant relationships. It also suggests that providers need to take the time to have honest, courageous conversations with caregivers, especially with patients' children and be willing to push back and educate caregivers on the pros and cons of oral-assisted feeding and tube feedings. Also, it is vital to create more awareness on the importance of keeping in mind families' and caregivers' culture, including spirituality, when making end-of-life decisions. Providers need to redirect conversations with family members who want a feeding tube

by acknowledging the symbolic value of satisfying the need to feed (Gillick and Volandes, 2008). As Johnson *et al.* (2005) reported, spirituality is a fundamental tool for coping with the experience of death, particularly among Blacks. Understanding the impact of spirituality on the decision-making process for Blacks may allow providers to assist Black patients and families through the death and dying process in a manner that is harmonious with their culture and results in evidence-based best practice.

Distrust of the healthcare delivery system may also be an important factor in decision-making at the end-of-life among Blacks. The historical root of distrust stems from generations of perceptions of unequally rendered services, abuses in medical experimentation, and economic injustice (Teno *et al.*, 2011). Such perceptions have led to a general loss of credibility of healthcare providers and institutions.

A third factor that may influence decision-making by Blacks at the end-of-life is the collective community (Johnson *et al.*, 2005). Black culture places a strong value on the "collective": family, friends, and the faith community. Honoring members of this community, especially family, is a central focus of this collective culture; decisions made without the consensus of the community are considered disrespectful. Arranging for inclusion of family members, faith community, and clergy in discussions and decision-making is an important way to assist Black patients at the end-of-life.

Finally, it is possible that this disparity is simply another reflection of social determinants of health. Do more Black patients choose tube feedings because somehow it makes more sense from the economical point of view? Future research should consider whether caregivers include a cost-benefit analysis when deciding between oral-assisted feeding and tube feedings.

### **Limitations**

The first limitation is that data were mined from medical records analytics, and no medical records were reviewed. Not all patients with advanced dementia may have been captured based on coding. Second, since our goal is to inform all providers, we are not sure these results can be extrapolated to patients in academic centers. Some may consider this a limitation. However, Novant Health is a large health system and includes tertiary centers with a diverse patient population. Third, since the system is located in the south-eastern United States, findings may not be generalizable to other regions of the country. Fourth, data regarding patients' and caregivers' education and income were not available. In addition, caregiver employment status and availability to provide appropriate care were not available. Further research to illuminate these disparities should include providers' race and ethnicity for both the primary attending as well as the physician who performs the PEG procedure. That research will be able to determine the potential of race-discordant physician-patient relationships. Finally, we did not match patients by risk factors, or use a risk-adjusted score, which would have helped assess whether illness severity was higher in Black than in White patients. Despite these limitations, our study identifies race, LOS, and gender as independent variables for the disparities seen in PEG insertion. These differences were not accounted for by etiology (vascular versus nonvascular), age, and code status. Our findings emphasize that race appears to influence decision-making regarding PEG tube placement. Further studies are needed to clarify the reasons for the observed differences.

**Acknowledgments.** This paper and the research behind it would not have been possible without the exceptional support of Tanya Blackmon, EVP and Chief

Diversity, Inclusion and Equity at Novant Health. We also want to thank Melody Myers, manager professional writing at Novant Health, and Alica Sparling, VP Senior Healthcare Economist, for reviewing and improving this paper.

**Funding.** This research received no specific grant from any funding agency, commercial, or not-for-profit sectors.

**Conflict of interest.** There are no conflicts of interest..

## References

- American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee (2014) American geriatrics society feeding tubes in advanced dementia position statement. *Journal of American Geriatrics Society* 62(8), 1590–1593.
- Armstrong K, Ravenell KL, McMurphy S, *et al.* (2007) Racial/ethnic differences in physician distrust in the United States. *American Journal of Public Health* 97(7), 1283–1290.
- Association of American Medical Colleges (2020) Diversity in Medicine: Facts and Figures 2019. <https://www.aamc.org/data-reports/workforce/interactive-data/figure-18-percentage-all-active-physicians-race/ethnicity-2018>
- Boulware LE, Cooper LA, Ratner LE, *et al.* (2003) Race and trust in the health care system. *Public Health Reports* 118, 358–365.
- Braun UK, McCullough LB, Beyth RJ, *et al.* (2008) Racial and ethnic differences in the treatment of seriously ill patients: A comparison of African-American, Caucasian and Hispanic veterans. *Journal of the National Medical Association* 100(9), 1041–1051.
- Byrne D, Goeree M, Hiedemann B, *et al.* (2009) Formal home health care, informal care, and family-decision making. *International Economic Review* 50(4), 1205–1242.
- Checkovich TJ and Stern S (2002) Shared caregiving responsibilities of adult siblings with elderly parents. *The Journal of Human Resources* 37(3), 441–478.
- Cooper LA, Roter DL, Johnson RL, *et al.* (2003) Patient-centered communication, ratings of care, and concordance of patient and physician race. *Annals of Internal Medicine* 139(11), 907–915.
- Faigle R, Bahouth MN, Urrutia VC, *et al.* (2016) Racial and socioeconomic disparities in gastrostomy tube placement after intracerebral hemorrhage in the United States. *Stroke* 47(4), 964–970.
- Fischberg D, Bull J, Casarett D, *et al.* (2013) Five things physicians and patients should question in hospice and palliative medicine. *Journal of Pain and Symptom Management* 45(3), 595–605.
- Giglia MD, DeRussy A, Morris MS, *et al.* (2017) Racial disparities in length-of-stay persist even with no postoperative complications. *Journal of Surgical Research* 214, 14–22.
- Gillick MR and Volandes AE (2008) The standard of caring: Why do we still use feeding tubes in patients with advanced dementia? *Journal of the American Medical Directors Association* 9(5), 364–367.
- Hiedemann B and Stern S (1999) Strategic play among family members when making long-term care decisions. *Journal of Economic Behavior & Organization* 40(1), 29–57.
- Johnson RL, Roter D, Powe NR, *et al.* (2004) Patient race/ethnicity and quality of patient-physician communication during medical visits. *American Journal of Public Health* 94(12), 2084–2090.
- Johnson KS, Elbert-Avila KI and Tulskey JA (2005) The influence of spiritual beliefs and practices on the treatment preferences of African Americans: A review of the literature. *Journal of the American Geriatrics Society* 53(4), 711–719.
- Johnson KS, Kuchibhatla M, Tanis D, *et al.* (2008) Racial differences in hospice revocation to pursue aggressive care. *Archives of Internal Medicine* 168(2), 218–224.
- Johnson RW, Newby LK, Granger CB, *et al.* (2010) Differences in level of care at the end of life according to race. *American Journal of Critical Care* 19(4), 335–344.
- Katz SJ, Mohammed K, Langa KM, *et al.* (2000) Gender disparities in the receipt of home care for elderly people with disability in the United States. *Journal of the American Medical Association* 284(23), 3022–3027.
- Kressin NR and Groeneveld PW (2015) Race/ethnicity and overuse of care: A systematic review. *Milbank Quarterly* 93(1), 112–138.
- Levinson W, Kao A, Kuby A, *et al.* (2005) Not all patients want to participate in decision making. A national study of public preferences. *Journal of General Internal Medicine* 20(6), 531–535.
- MacDonald W (1998) The difference between blacks' and whites' attitudes toward voluntary euthanasia. *Journal for the Scientific Study of Religion* 37(3), 411–426.
- Messinger-Rapport BJ and Kamel HK (2005) Predictors of do not resuscitate orders in the nursing home. *Journal of the American Medical Directors Association* 6(1), 18–21.
- Mitchell SL (2015) Advanced dementia. *New England Journal of Medicine* 372(26), 2533–2540.
- Mitchell SL, Teno JM, Roy J, *et al.* (2003) Clinical and organizational factors associated with feeding tube use among nursing home residents with advanced cognitive impairment. *Journal of the American Medical Association* 290(1), 73–80.
- Mitchell SL, Teno JM, Kiely DK, *et al.* (2009) The clinical course of advanced dementia. *New England Journal of Medicine* 361, 1529–1538.
- Mitchell SL, Mor V, Gozalo PL, *et al.* (2016) Tube feeding in US nursing home residents with advanced dementia, 2000–2014. *Journal of the American Medical Association* 316(7), 769–770.
- Muni S, Engelberg RA, Treece PD, *et al.* (2011) The influence of race/ethnicity and socioeconomic status on end-of-life care in the ICU. *Chest* 139(5), 1025–1033.
- Murray E, Pollack L, White M, *et al.* (2007) Clinical decision-making: Patients' preferences and experiences. *Patient Education and Counseling* 65(2), 189–196.
- Pezzin LE, Pollak RA and Barbara S (2006) Efficiency in family bargaining: Living arrangements and caregiving decisions of adult children and disabled elderly parents. *CESifo Economic Studies* 53(1), 69–96.
- Sampson EL, Candy B and Jones L (2009) Enteral tube feeding for older people with advanced dementia. *Cochrane Database of Systemic Reviews*. doi:10.1002/14651858.CD007209.pub2
- Schpero WL, Morden NE, Sequist TD, *et al.* (2017) For selected services, Blacks and Hispanics more likely to receive low-value care than Whites. *Health Affairs (Millwood)* 36(6), 1065–1069.
- Sharma RK, Cameron KA, Chmiel JS, *et al.* (2015) Racial/ethnic differences in inpatient palliative care consultation for patients with advanced cancer. *Journal of Clinical Oncology* 33(32), 3802–3808.
- Shintani S (2013) Efficacy and ethics of artificial nutrition in patients with neurologic impairments in home care. *Journal of Clinical Neuroscience* 20(2), 220–233.
- Stathopoulos P, Karamanolis G, Papanikolaou IS, *et al.* (2011) Percutaneous endoscopic gastrostomy: Patients' outcomes, adequacy and quality of information given to decision-makers and procedure acceptance. *Annals of Gastroenterology* 24(1), 29–34.
- Sterritt PF and Pokorny ME (1998) African-American caregiving for a relative with Alzheimer's disease. *Geriatric Nursing* 19(3), 127–134.
- Teno JM, Mitchell SL, Kuo SK, *et al.* (2011) Decision-making and outcomes of feeding tube insertion: A five-state study. *Journal of American Geriatrics Society* 59(5), 881–816.
- Teno JM, Gozalo PL, Mitchell SL, *et al.* (2012) Does feeding tube insertion and its timing improve survival? *Journal of American Geriatrics Society* 60(10), 1918–1921.
- Tucker CM, Moradi B, Wall W, *et al.* (2014) Roles of perceived provider cultural sensitivity and health care justice in African American/black patients' satisfaction with provider. *Journal of Clinical Psychology in Medical Settings* 21, 282–290.
- Van Ryn M and Burke J (2000) The effect of patient race and socio-economic status on physicians' perceptions of patients. *Social Science & Medicine* 50(6), 813–828.
- Wicher CP and Meeker MA (2012) What influences African American end-of-life preferences? *Journal of Health Care for the Poor and Underserved* 23(1), 28–58.