

Advance Care Planning Outcomes in African Americans: An Empirical Look at the Trust Variable

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Abstract

Context: Racial disparities in rates of hospice use, a marker of quality of end-of-life (EOL) care, have been a long-standing problem. Although distrust has been cited as a main reason for the preference of intensive EOL care among African Americans, the role of trust has not been closely analyzed in predicting EOL care in the context of advance care planning (ACP) outcomes.

Objectives: The goal of this review was to empirically examine the role of trust in ACP outcomes.

Methods: For this systematic review, we utilized methods adapted from the GRADE process developed by the Cochrane Collaboration. The research question guiding this review was “What is the quantitative influence of trust in the health care system or health care providers on the ACP process for African Americans?” We searched Medline, Embase, and Web of Science for articles published between 1975 and 2016.

Results: We identified nine quantitative studies that measured and evaluated trust as a predictor or correlate of ACP preferences. Of the studies, eight were observational and one was a pre–post-test study. Three studies were designated as low quality, and six studies were of moderate quality.

Conclusion: Distrust has been cited as a central reason for African Americans’ tendency to choose life-sustaining treatments over comfort-focused care; however, our findings do not support this hypothesis. The majority of studies found no significant differences in trust between African Americans and their White counterparts. Further, we found that trust was not associated with ACP outcomes in the majority of studies.

Keywords: advance care planning; African American; trust

Introduction

IN 2015, 50.5% of White Medicare decedents utilized the hospice benefit before death.¹ In contrast, only 38.3% of African American Medicare decedents did so.¹ Racial disparities in rates of hospice usage, often seen as a marker of quality of end-of-life (EOL) care, have been a long-standing problem.² Although hospice use has increased among both Whites and African Americans over the past decade, the disparity in rates has persisted.¹ Conversely, death in the intensive care unit, ventilator and cardio-pulmonary resuscitation use in the days and hours before death are higher among African Americans than their White counterparts.² Reducing the racial disparity in EOL care has proven to be a challenge for the health care system.

Trust, or rather mistrust, of the health care system and of health care providers has frequently been cited as a contrib-

utor to EOL care disparities. Distrust of the health care system by African Americans is a reasonable response to a history of medical experimentation and discrimination in the larger U.S. society.^{3–15} African American attitudes toward EOL care interventions, particularly their propensity for life-sustaining treatments, have often been attributed to their distrust.^{16–18} Distrust has been cited as a main reason for the preference of intensive EOL care among African Americans, whereas the role of trust has not been closely analyzed in predicting EOL outcomes, particularly within the context of advance care planning (ACP).

To date, much of the literature on African American trust in the context of ACP and EOL care preferences has been qualitative. These studies have reported various reasons for African Americans’ distrust, including incomplete information and a lack of substantive communication about ACP,¹⁹ problematic relationships with health care providers,²⁰ lack

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of health insurance,²¹ lack of trust regarding whether physicians will honor their wishes at the EOL,^{20,22–25} as well as historical mistreatment and discrimination.^{21,22} Although qualitative findings are important, they do not explain the empirical role of trust in actually predicting ACP outcomes. To our knowledge, no systematic reviews have assessed the role of trust and its association with ACP outcomes. The aim of this review is to evaluate quantitative evidence for the association of trust with African Americans’ ACP outcomes.

Methods

For this systematic review, we utilized methods adapted from the GRADE process developed by the Cochrane Collaboration. The research question, which guided the review, was “What is the quantitative influence of trust in the health care system or health care providers on ACP outcomes for African Americans?”

Criteria for inclusion of studies

Published, peer-reviewed, quantitative studies of ACP that examined trust among African Americans were included in this review. Articles were included if they were published in the English language and included African Americans exclusively or as a subgroup alongside other racial/ethnic groups. Also, to be eligible, studies needed to have included trust as a variable and examined the influence of trust on ACP. In addition, if African Americans were included as a subgroup alongside other racial/ethnic groups, an examination of the influence of race needed to be present.

Search methods

We searched Medline, Embase and Web of Science for articles published between 1975 and 2016. The detailed search terms used are delineated in Table 1. A broad definition of ACP terms was used (Table 1). For comprehensiveness, electronic theses, reference lists of relevant studies, and review articles were also searched to identify eligible studies.

Results

Study characteristics

We identified nine quantitative studies that measured and evaluated trust as a predictor or correlate of ACP. Of the studies, eight were observational and one was a pre–post-test study.²⁶ Based on the GRADE system,²⁷ three studies were designated as low quality and six studies were of moderate quality.

All of the studies were completed in the United States: three in the northeast region, three in the southern region, one in the northwest, and two were multisite studies with sites in both the northeast and the south. Six studies were conducted in easily identified urban areas, whereas one study specified that it was conducted in more rural settings²⁸ (the population setting was not clearly identifiable for two studies).

Three studies focused on older adults, defined as either a minimum of 60 years of age²⁹ or 65 years of age.^{6,30} One study focused on middle-age to older adults (minimum of 40 years of age),¹² whereas the other five included all adults, defined variously as a minimum of 18 years,³¹ 19 years,²⁸ 20 years,³² 21 years²⁶ or no minimum age specified.³³ Four studies focused on those with a life-limiting illness and/or poor prognosis,^{12,31–33} whereas the other five recruited from a more general population without regard to diagnosis.

One study included African Americans only,²⁶ whereas the other eight included African Americans as a subgroup along with other racial/ethnic groups. Of note, only one study utilized patient–provider racial concordance (whether or not the patient and provider are from the same racial/ethnic group) as a variable³⁷; the other studies did not include this information or examine it as a variable.

Measurement of trust

The measurement of trust was highly heterogeneous across studies, with different aspects of trust being measured and different tools utilized. Among the nine studies, only four utilized validated tools.³¹ Three studies utilized dichotomous items (yes/no), whereas the other six utilized Likert scales.

TABLE 1. SEARCH TERMS (LIMITS ENGLISH LANGUAGE; YEARS 1975–2016)

Search topic	Database	Search terms
Advance Care Planning	Medline	“Advance Directives” [Mesh] OR “Health Care Planning” [tiab] OR “Medical Planning” [tiab] OR “Advance Care Planning” [Mesh] OR “Advance Care Planning” [tiab] OR “Advance Directive” [tiab] OR “Advance Directives” [tiab] OR “Power of Attorney” [tiab] OR “Ulysses Contracts” [tiab] OR “Ulysses Contract” [tiab]
	Embase	‘advance care planning’:ab,ti OR ‘advance directives’:ab,ti OR ‘living’/exp OR ‘health care proxy’:ab,ti OR ‘power of attorney’:ab,ti OR ‘power of attorney’/exp OR ‘ulysses contracts’:ab,ti OR ‘ulysses contracts’:ab,ti
	Web of Science	“advance care planning” OR “patient care” OR “advance directives” OR “living will” OR “health care planning” OR “health care planning” OR “medical planning” OR “power of attorney” OR “ulysses contracts”
African Americans	Medline	“African Americans” [Mesh] OR “African Americans” [tiab] OR “African American” [tiab] OR “Black Americans” [tiab] OR “Afro American” [tiab] OR “Minority Groups” [tiab] OR “Minority Group” [tiab] OR “Minority populations” [tiab] OR “Minority population” [tiab] OR “Race” [tiab] OR “Racial” [tiab]
	Embase	‘minority group’/exp OR ‘african american’/exp OR ‘minority group’:ab,ti OR ‘african american’:ab,ti OR ‘minority groups’:ab,ti OR ‘african americans’:ab,ti
	Web of Science	“minority group” OR “African American” OR “blacks” OR “minority groups” OR “African Americans” OR “Race” OR “Racial”

Three studies utilized one item, five utilized two to three items, and only one utilized a 10-item scale to measure trust. Five studies measured trust in physicians specifically, two studies measured trust in health care providers, and two studies measured trust in the health care system. Five studies measured trust generally (trust in physician overall, trust in physician or system competence), whereas four measured it in relationship to ACP and/or decision making. Two studies measured trust in relationship to discrimination (“I worry that I won’t be treated as well as other people”).^{29,30}

Outcomes

Multiple ACP outcomes, related to trust, were examined across the different studies. Outcomes included possession of an advance directive ($n=5$), patient desire for intensive EOL care ($n=3$), intent to complete advance directives ($n=2$), and perceptions of physician trustworthiness ($n=2$). Other outcomes included concordance between expressed wishes and care received at EOL ($n=1$), receipt of hospice and/or symptom management ($n=1$), attitudes toward advance directives ($n=1$), and attitudes toward hospice ($n=1$).

Evidence synthesis

For seven studies, the authors found no statistically significant difference in trust of health care providers or the health care system between African Americans and White Americans.^{12,29–34} Johnson and colleagues authored the only study that compared African American and White American patients and found that African American patients were more distrustful of the health care system than White American patients were. They also found that this distrust accounted for some of the difference in outcomes by race. However, in multivariate analyses for the outcomes of possession of an advance directive and attitudes toward hospice, race was not a significant predictor of either outcome.

Other variables, including sociodemographic characteristics (age, gender, marital status, education, income), preferences for EOL care, spirituality, and beliefs about dying and ACP, also played a significant role in determining the examined outcomes.

Waters authored the only study to examine an intervention and the only study that included African Americans with no comparison racial group. Waters used the investigator-developed Advance Directives Knowledge, Attitude, and Utilization Questionnaire (AD-KAUQ), which was designed to obtain information about advance directives regarding knowledge, attitudes, and utilization. Items in the tool consisted of questions regarding advance directives, completion of a living will, as well as attitudes about living wills and family and health care provider involvement in end-of-life decision making.

Investigators used a pre–post-test method, wherein they administered the AD-KAUQ at a community educational forum, before and after group discussion. The investigator found that participants ($n=27$) held varying opinions on whether health care providers would treat them negatively if they had a living will.²⁶

Discussion

The goal of this review was to empirically examine the role of trust in African Americans’ ACP outcomes. Distrust has

been cited as a central reason for African Americans’ tendency to choose life-sustaining treatments over comfort-focused care; however, our findings, based on published quantitative studies, do not support this hypothesis. The majority of studies found no significant differences in trust between African Americans and their White counterparts. Further, we found that trust was not associated with ACP outcomes in the majority of studies.

Given that mistrust of the health care system and health care providers is so frequently cited as an issue for African American patients, we were surprised to find that seven of the nine articles found no differences between the trust levels of African Americans and White Americans. Indeed, the trust levels were surprisingly high, with more than 90% of respondents across the seven articles reporting trust in their health care provider or in the health care system. These levels of trust were more surprising given findings that indicated that African Americans would have good reason to mistrust the health care system, including the finding that White patients are three times more likely to have their EOL care preferences honored than African American patients.³²

However, trust is a multifaceted phenomenon and there are different levels and dimensions to trust. Zapka and DeSharnais found that racial concordance of patient and physician improves trust for African Americans, although this finding was likely influenced by the fact that African American physicians are more likely to be primary care physicians, with longer-standing relationships and higher trust levels than specialists.³³ African American physicians were seen as more trustworthy by both African American and White American patients.³³

Although African Americans may trust their health care providers as much as White Americans, this may not mean that they want to discuss EOL care or ACP with them. Morrison found that although African Americans were equally willing to discuss EOL with their health care proxies as White Americans, they were less likely to want to discuss it with their physician. This may be influenced by a perception that discussing EOL preferences with a physician may negatively affect their care, a belief that Waters found somewhat prevalent among a sample of African Americans.²⁶

The second major finding of this review is that trust is not a significant factor in African Americans’ preference for EOL treatments or ACP. However, other variables that are associated with racial status were found to be associated with EOL treatment preference and ACP. These variables included income, educational level, possession of health insurance, knowledge of health care proxies, knowledge about advance directives, and communication and relationships with health care providers.

Of note, the majority of the variables identified as important in explaining ACP outcomes in African Americans were socioeconomic status (SES) variables. This is not surprising as race significantly overlaps with SES in the United States. Minority populations, particularly African Americans,³⁵ experience high levels of socioeconomic disadvantages, including limited economic resources, limited education, and high rates of unemployment, and often hold jobs that do not offer access to health benefits (e.g., health insurance).^{35,36} Consistently, nearly half the studies in the current review reported that African American patients were less educated and had lower incomes than their white counterparts.^{6,12,29,37}

TABLE 2. STUDIES MEASURING TRUST QUANTITATIVELY

Study	Sample size	GRADE and level of analysis	Type of measure	Validity of measure	How trust was measured	Outcome variables	Trust-relevant results	Other significant variables
Mahaney-Price et al. ³⁴	African American (n=82) White (n=118) Used for trust analysis (n=30). Unsure what proportion of these are African American	Low quality Multiple logistic regression	Investigator developed dichotomous question, response options "Yes, I do not trust" and "No."	Not validated	Dichotomous question: "Do not trust health care providers"	Possession of living will (yes/no) Desiring help in writing living will (yes/no)	Trust was not significantly associated with having a living will Race of health care provider not mentioned.	Older age, race, possession of health insurance (Medicare), type of disease, and inference with work life
McKinley et al. ¹²	African American (n=92) White (n=114)	Low quality Multiple logistic regression	Four-point Likert Scale (strongly agree to strongly disagree)	Not validated	Likert Scale questions explored patient beliefs about: (1) Trustworthiness of medical system. (2) The possibility of receiving inadequate or excessive medical care. (3) Whether having a living will would increase sense of being in control of their medical care when terminally ill.	Desire for more or less life-sustaining treatments Intent or lack of intent to complete a living will	African American and White patients answered questions regarding trusty identically. 96% of each group felt that the medical system was trustworthy 94% felt that doctors can be trusted 96% felt that doctors generally treat all patients equally well Less than 20% of both groups feared inadequate medical care Race of health care provider not mentioned	Bivariate analyses: African American race, stronger religious beliefs, and lower income associated w/LST. White race, more education, higher income, and younger age associated w/living will Logistic analyses After controlling for income, strength of religious beliefs, and age, African American patients were more likely to desire more LST than Whites.
Waters ²⁶	African American (n=27) No comparison group	Low quality Paired t and McNemar tests (p≤0.05)	AD-KAUQ, two trust items. One item assessed using a 4-point Likert Scale; the other assessed using a 5-point Likert Scale.	Inter-rater agreement 0.91, Cohen's kappa 0.89.	Likert Scale questions were designed to obtain information about advance directives regarding knowledge (1 item), utilization (1 item), and attitudes (includes trust) (11 items) In the attitudes section, trust items are rated on a scale of alternative responses ranging from (strong disagree) to (strongly agree). Items: Health care providers will treat you negatively if you have a living will (4-pt scale) Extent of caring by health care providers if you have a living will (5-pt scale)	Change in participants' initial and final responses on the AD-KAUQ questions regarding knowledge, utilization, and attitudes toward EOL care directives	Participants slightly disagreed that health care providers would treat them negatively if they had a living will. Participants believed that health care providers would provide adequate care if they had a written living will. Race of health care provider not mentioned.	Community-centered educational group discussion significantly changed participants' consideration for using a living will. Communication education significantly changed participants' perceptions of whether discussion about a living will should occur in a community setting.

(continued)

TABLE 2. (CONTINUED)

Study	GRADE and level of analysis	Sample size	Type of measure	Validity of measure	How trust was measured	Outcome variables	Trust-relevant results	Other significant variables
Smith et al. ³¹	Moderate quality Multivariable regression ($p \leq 0.05$)	African American ($n = 115$) White ($n = 688$)	1-item from the 135-item, NEST, 4-point Likert Scale (strongly agree to disagree)	Validated, $\alpha = 0.63$ – 0.85 . ⁵⁶	Likert Scale Questions assessed quality of patient–physician relationship: “Patient has complete trust in the physician.”	Presence of advance care planning (i.e., living will, health care proxy, having talked with family or physician about plans for EOL care) Preferences for intensive life-sustaining treatment	There was no statistically significant difference between trust in physicians between White and African American patients. 96.5% of African American patients agreed that they completely trusted the physician 95.2% of White patients agreed that they completely trusted the physician African American patients have lower ratings of the quality of the relationship with their physicians than White patients. All differences in aspects of the relationship were significant, except trust. Race of health care provider not mentioned.	African Americans reported lower quality of the relationship with physicians: Physician respects patient Physician tells bad news in a sensitive and caring manner Physician listens to what the patient has to say about illness Patient participates in decisions about care Physician helps patient with the medical system Has an advance care plan Adding measures of patient–physician relationship to the multivariable model had no impact on the differences in advance care planning and treatment preferences. Patient-reported quality of the patient–physician relationship does not fully explain differences in advance care planning and preferences for LST between African Americans and white Americans.
Morrison et al. ³⁰	Moderate quality Multiple logistic regression ($p \leq 0.05$)	African American ($n = 65$) White ($n = 67$) Latino ($n = 65$)	Part of 51-item measure, 4-point Likert Scale	Validated, $\alpha = 0.74$.	Likert Scale items on Trust Scale included: “I trust the doctors to make the right decisions about my medical care if I were to be very ill or in a coma” “I worry that I won’t be treated as well as other people in the hospital if I were to be very sick or dying.”	Completion of health care proxy	White (84%) and African American (81.5%) patients agreed that they trusted the physician to make the right decision about their health care if they were to get very sick. Race of health care provider not mentioned.	White participants had significantly more knowledge of health care proxies. African Americans and white Americans were significantly more comfortable talking about EOL care than Hispanic participants For all participants (white, African, and Hispanic), regression analysis showed positive predictors of health care proxy completion included: Knowledge of health care proxies Availability of a friend or family member to serve as a proxy Previous exposure to ventilator support Older age Health status perceived as fair or poor

(continued)

TABLE 2. (CONTINUED)

Study	Sample size	GRADE and level of analysis	Type of measure	Validity of measure	How trust was measured	Outcome variables	Trust-relevant results	Other significant variables
Morrison and Meter ²⁹	African American (n = 237) White (n = 239) Hispanic (n = 224)	Moderate quality Multiple logistic regression (p ≤ 0.05)	Part of 51-item measure, 4-Point Likert Scale	Validated, α = 0.74.	Likert Scale items on Trust Scale included "I trust the doctors to make the right decisions about my medical care if I were to be very ill or in a coma," "I worry that I won't be treated as well as other people in the hospital if I were to be very sick or dying."	Completion of health care proxy Differences in attitudes and beliefs about the trustworthiness of physicians Difference in fatalism Differences in beliefs about surrogate decision making	African American reported more trust in physicians than white Americans did. White (72%) and African American (92%) patients agreed that they trusted the physician to make the right decision about their health care if they were to get very sick. Race of health care provider not mentioned.	White participants were significantly older, more educated, and less likely to have Medicaid White Americans and African American participants rated their health significantly better than Hispanic participants Designation of health care proxy associated with: Having a primary care physician Knowledge about advance directives Having seen a friend or family member use a mechanical ventilator
Johnson et al. ⁶	African American (n = 110) White (n = 95)	Moderate quality Multivariate logistic and linear regression (p ≤ 0.05)	Health Care System Distrust Scale, 5-Point Likert Scale ³⁷	Validated, α = 0.75.	Likert Scale items measure perceptions of health care system competence (2 items), confidentiality (2 items), honesty (4 items), and fidelity (2 items).	Possession of advance directive (living will or DPOA) Attitudes and beliefs about hospice	In a multivariate model that included demographic variables and the Health Care System Distrust Scale, trust was a significant predictor of possession of an advance directive or beliefs about hospice among African Americans. However, when spirituality, preferences for EOL care, and beliefs about dying and ACP were added to the multivariate model, there was no longer a significant association between race and possession of an advance directive or beliefs about hospice.	African American Americans were: Less educated, had lower income, were less likely to complete a living will or durable power of attorney, had greater preference for life-sustaining treatment, were less comfortable discussing death, spiritual beliefs more likely to conflict with goals of palliative care, and less favorable attitudes toward hospice care

Scales used in the study included: Preferences for End-of-Life Care Scale, Spirituality Scale, Beliefs About Dying and Advance Care Planning Scale, and the Health Care System Distrust Scale.
Race of health care provider not mentioned.

(continued)

TABLE 2. (CONTINUED)

Study	Sample size	GRADE and level of analysis	Type of measure	Validity of measure	How trust was measured	Outcome variables	Trust-relevant results	Other significant variables
Loggers et al. ³²	African American (n = 68) White (n = 234)	Moderate quality Multiple logistic regression Separate regression models due to small African American sample size	Investigator developed dichotomous question, response options "yes" or "no."	Not validated	Dichotomous question: "Do you trust your doctors here?"	Receipt of intensive EOL care (i.e., CPR and/or ventilation within last week of life followed by death)	African American patients (98.5%) and White patients (98.7%) trust physician. Race of health care provider not mentioned.	African Americans were younger, less likely to be married, less educated, less likely to be insured than White participants, and reported higher scores on the existential and social support subscales than their White counterparts
Zapka et al. ³⁷	African American (n = 51) White (n = 39)	Moderate quality Multiple logistic regression (p ≤ 0.05)	Investigator developed dichotomous question, response options "yes" or "sometimes, but not always."	Not validated	Dichotomous question: Physician rating items were: consideration of needs, trust in physician's judgments, and belief that physician was an expert "in taking care of medical problems like yours."	Care experience (e.g., receipt of pain and symptom treatment at home; participation in hospice) Patient's perception of physician Patients' awareness of prognosis	80 of 90 participants (88.9%) trusted physician's judgment. African American patients cared for by White physicians reported significantly lower trust compared with patients' trust levels in the following patient-physician match categories: African American patients cared for by African American physicians; White patients cared for by African American physicians; and White patients cared for by White physicians. African American patients cared for by African American physicians reported higher ratings of viewing the physician as an expert. Significantly more patients of African American physicians reported yes to the rating of trusting the physician's judgment.	Factors influencing use of hospice: disease (HF vs. CA), awareness of diagnosis, better communication, location of treatment (rural vs. urban) African Americans are less educated

AD-KAUQ, Advance Directives Knowledge, Attitude, and Utilization Questionnaire; DPOA, durable power of attorney; CA, advanced cancer; HF, heart failure; NEST, Needs at the End-of-Life Screening Tool.

Literature indicates that individuals with lower income and education levels are less likely to use advance directives and hospice, compared with those with higher income and education levels.^{38–41} This makes sense as individuals with higher levels of education are more apt to gather, process, and understand health information and services, and thus have higher health literacy.^{42,43} These variables are especially important to consider in the context of EOL care.

The decision to continue life-sustaining treatments is also associated with African American patients' limited knowledge of treatment outcomes.^{44–47} Patients' EOL care decisions, which are often based on an overestimation of long-term survival, reflect their limited knowledge about the disease diagnosis as well as the risks and benefits of treatment options.⁴⁴ African Americans often do not use hospice and advance directives due to limited knowledge of these services.^{30,48–51} Limited knowledge of the availability of hospice services, enrollment criteria, and contact information⁵² serve as barriers for African Americans to access EOL care.⁴⁸

Patients and family members require appropriate education and prognostic information to understand the course of illness and plan for the future.^{53,54} Morrison and Meier found that African Americans' knowledge about advance directives and health care proxies were significantly associated with African Americans' designation of a health care proxy.^{29,30} This evidence suggests that knowledge of a health care service increases positive attitudes regarding use of the service.

Review limitations

This review represents a progression toward gaining a better understanding of the empirical role of trust in African American EOL care outcomes. However, several methodological limitations in the studies prevent a more complete understanding of trust and its role in EOL care. These limitations include small sample sizes, inadequate measurements of trust, and emphasis on irrelevant outcome variables.

First, many studies in this review had small sample sizes particularly of the African American subgroup (Table 2). The failure to find a significant relationship between the trust variable and ACP outcomes may indicate the presence of a Type II error. However, this concern is dampened due to two reasons: the fact that the lack of a significant role for the trust variable remained in studies that employed adequate sample sizes,^{29,30} and that the direction of the effect is consistent in the majority of the studies.

Second, inadequate measurement of trust resulted in issues with validity across the studies. Only four of the nine studies assessed trust by using a validated measure. Both the measurement of trust and the aspect of trust (in health care provider, in the health care system) was assessed differently across the studies. Trust was measured dichotomously or via Likert scale, and the majority of studies utilized very few items to measure trust. Given this wide range of variability, it is difficult to compare results across studies in this review.

Beyond measuring a singular construct of trust, it is unlikely that the measures used in the studies included in this review adequately covered all aspects of trust. The findings of a qualitative study detailing African Americans' perceptions about trust and distrust in physicians underscore the vital importance of measuring trust by using robust and multidimensional tools. Jacobs et al. found that, among African

Americans, trust and distrust are multifaceted constructs.⁵⁵ In this study, African Americans perceived trust because of physicians' interpersonal and technical competence. Distrust, conversely, was more complex and a consequence of perceptions of physicians' racism, greed, financial discrimination, and expectations of experimentation in medical care.⁵⁵

Conclusion

The evidence in this review tells a starkly different story about the role of trust than the one painted across the majority of nonempirical literature regarding the factors that affect African American EOL care preferences. The disproportionate focus on trust as a contributing factor has distracted us from addressing other modifiable risk factors contributing to African American's poor outcomes at the EOL. Although it is important to recognize the historical events that may influence some African Americans' perspectives on the health care system, it is essential to our understanding of African American EOL care to explore alternative explanations for the care disparities that African Americans face during this critical time in the health care continuum.

Beyond trust, factors that affect African American EOL care include lack of access to care, lower income and education levels, as well as relationships and quality of communication with health care providers. The studies included in this review provide essential information, but they are not without limitations since we found only nine studies of mixed quality assessing trust in the context of ACP. Despite the imperfection of the science, this small amount of literature represents our best empirical evidence regarding African American trust at the EOL, and it highlights the desperate need for further research to broaden our understanding in this very important area.

Author Disclosure Statement

No competing financial interests exist.

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