



End-of-Life Planning and the Influence of Socioeconomic Status among Black Americans: A Systematic Review

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Purpose: The purpose of this systematic review is to explore end-of-life (EOL) care planning and the impact of socioeconomic status (SES) among people who identify as Black or African American. **Methods:** The Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) were used to guide and inform this systematic review process. The following academic electronic databases with publications that reflected the interdisciplinary fields related to the research objective were searched: APA PsycINFO, CINAHL, PubMed, Scopus, and Social Work Abstracts. **Results:** After the authors conducted the search, 14 articles (from 13 studies) ultimately met the criteria for inclusion. The results substantiated significant concerns highlighted in previous literature regarding SES and its relation to EOL planning, but also revealed an absence of original work and interventions to increase engagement in EOL planning among Black and African American populations. **Conclusion:** Black individuals deserve an equitable EOL experience. Researchers, practitioners, and policymakers need to move towards advocacy and action to meet this important need.

Key Words: Black or African American, Social class, Advanced care planning

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INTRODUCTION

1. Background

People who are Black are at a substantial disadvantage when it comes to healthcare, and current initiatives are insufficient [1]. Rooted in systems of racism and inequality, healthcare disparities in the United States (US) continue to be alarming [2]. Among all racial or ethnic groups in the US, Blacks have the highest rates of mortality [3], yet they are less likely to complete advanced directives and engage in end-of-life (EOL) planning [4]. Similar to other populations in the US; however, Blacks are living longer [4] and need to be able to age with a

quality EOL experience. It is expensive to age; it is expensive to die; and minority individuals are disproportionately ill-equipped to begin tackling this disparity. Additionally, Blacks have been strategically displaced in less desirable communities that have limited access to education around EOL resources [5]. Therefore, increased attention must be given to understanding socioeconomic status (SES) and EOL planning among Black communities in order to address the aforementioned issues and propose change at organizational, community, and policy levels.

As necessary and overdue attention continues to be drawn toward the effects of systemic racism in the US and related racial health inequities [6], this systematic review aims to

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address a critical topic for practitioners, policymakers, and researchers. The results of this review constitute an important step toward further understanding the current literature related to EOL planning among Black individuals, with a particular focus on SES. As this issue is understood more clearly, more intentionality may be given to informing interventions and systemic changes necessary to engage Black communities in critically needed, quality EOL planning and care.

EOL care planning can include any of the following: completion of advance directives, completion of a living will, securing final arrangements for funeral and burial, and/or allocating assets to other family members [7]. This planning process can also encompass a combination of medical care and support provided to individuals near death [8]. Although the EOL planning process is often a daunting task, it can be even more challenging for Black communities. Compared to Whites, people who are Black in the US are much less likely to complete advance directives and engage in EOL planning [9]. The reasons for this disparity are largely due to systemic racism and are elaborated upon in the next section.

Blacks are also more likely to engage in informal planning with family members and rely on their faith and spiritual guidance to direct their EOL planning and discussions [10]. Further, there is the belief that God has ultimate control of their life, and Blacks are less comfortable discussing death and dying [9]. To engage people who are Black in EOL planning, researchers have recently highlighted that service providers and healthcare systems need to give attention to underlying cultural beliefs and the inclusion of family members in EOL care conversations [11].

Several factors contribute to barriers to healthcare resources among people who are Black in the US. One factor is the lack of access to quality healthcare providers. Nouri and colleagues [5] found that the prevalence of poverty and lack of engagement in EOL planning is largely due to “redlining,” a system put in place to deny local and private resources to people of color. Another factor that stems from systemic racism is mistrust in the healthcare system. People of color often feel discriminated against and “disrespected” because of their race, and are, therefore, less likely to utilize health services or go to their physician for preventative care [12]. Relatedly, researchers have also found that lack of communication

between Blacks and their medical providers also serves as a significant barrier to EOL planning [13]. This lack of communication between providers and patients continues to promote uninformed decision-making and contributes to an ongoing system of the aforementioned distrust among Blacks within the healthcare system. These sociocultural discriminatory beliefs and experiences have led to fears around engaging in EOL planning [14]. For example, people who are Black have reported a belief that completing an advance directive would mean that healthcare providers would no longer care for them, or it would hasten death [15].

This population often lacks the knowledge and education to engage in critical EOL healthcare decision-making conversations [14]. Noh et al. [16] found that compared to White older adults, Black older adults were less likely to know about or complete EOL plans, and they had more inaccurate knowledge about hospice care. According to Rhodes et al. [15], although some attention has been given to developing interventions that increase access to quality healthcare providers and education for minority groups, little attention has been given to specifically intervening among Black, low-income communities.

SES among Black and African Americans has been operationally defined by researchers to include income level, education level, zip code, homeownership, possession of insurance, as well as other factors. Inequities related to SES among people who are Black have been documented substantially in the literature [5,17]. For centuries, these inequities have been reflected in healthcare systems across the US, where people who are Black have been intentionally displaced into impoverished neighborhoods [5]. The associated racially-driven poverty prevents access to the knowledge, means, and financial resources to plan for a quality EOL experience. As an example, Nouri et al. [5] found that neighborhoods with higher proportions of Black older adults had higher levels of poverty, lower income levels, and less engagement in EOL compared with those in higher SES neighborhoods. Others have found similar results [17].

2. Research objective

The primary purpose of this systematic review is to explore EOL care planning and the impact of SES among people who identify as Black or African American. An ancillary objective

associated with this review is to explore how studies have defined EOL and/or advance care planning, and what that entails among Black populations.

METHODS

The Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) were used to guide and inform this systematic review process [18]. Outlined below are the eligibility criteria for review inclusion, sources from which information was searched and ascertained, the search strategy employed, and the process by which data was extracted from the included studies.

1. Eligibility criteria

To be included in this review, studies: (a) quantitatively and/or qualitatively assessed EOL care planning among participants who identified as Black; (b) explicitly included an SES variable in data collection (e.g., income, education, zip code, home ownership, and/or health insurance status); (c) included participants who were adults aged 18 and older; (d) were reported in journal articles published through October 2022; (e) and were conducted in the United States.

2. Information sources and search strategy

Academic electronic databases with publications that reflected the interdisciplinary fields related to the research objective were searched: APA PsycINFO, CINAHL, PubMed, Scopus, and Social Work Abstracts. The following three search strings were utilized with Boolean operators to identify studies related to the research objective:

- 1) Black OR “African American” AND
- 2) “Socioeconomic Status” OR “SES” AND
- 3) “Advance care plan*” OR “end-of-life care plan*”

3. Selection and data collection process

Two reviewers independently searched and screened all studies. At each phase of the search process (including abstract and full-text review), reviewers compared results and reconciled all discrepancies to achieve 100% agreement. It is likely that inter-rater reliability would be lower for reviews of articles with poor methodology; thus, the Cochrane Collaboration states

that the double coding process and resolution of discrepancies are necessary, while the calculation of the kappa statistic is not [19].

The selected studies offered data on outcomes specifically related to EOL care planning among participants who identified as Black or African American. EOL care was operationally defined and included if data were collected for any following outcomes: completion of living wills, financial power of attorney, having a do-not-resuscitate order (or similar dependent on state), healthcare power of attorney, securing final arrangements, or open communication with providers or family regarding EOL care. Additionally, results from studies had to specifically include data on EOL care planning among participants who identified as Black or African American (studies that grouped all races together to report on EOL care planning were excluded). Finally, selected studies must have included at least one SES variable. Socioeconomic indicators were operationally defined as health insurance access, education level, income, homeownership, and/or zip code.

4. Study selection and analysis

As demonstrated in Figure 1, the search initially yielded 312 records. Once duplicate records were removed (n=137), 175 abstracts were screened for inclusion. Ninety-four full articles were assessed for eligibility, and 14 articles ultimately met the criteria for inclusion in the systematic review. Both authors in-

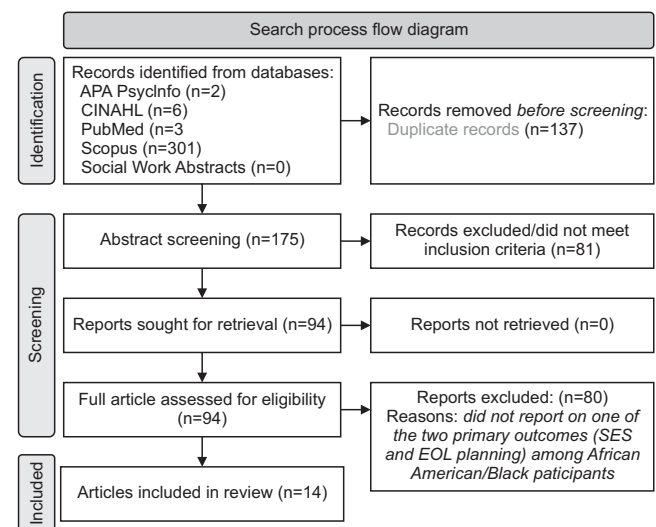


Figure 1. Study selection flow diagram. EOL: end of life, SES: socioeconomic status.

Table 1. Study Characteristics (N=146).

Reference no.*	First author citation	Study design	Location	Sample	Operational definition of SES	Main findings
A1	Bazargan et al. (2022)	Cross-sectional	California	N=773 (24.6% non-Hispanic Black)	Education; household income	Participants who expressed higher trust in their providers were two times more likely to have strong feelings about their EOL medical wishes. Blacks required a higher level of respect for their cultural beliefs from their providers and a closer relationship with providers than their White counterparts.
A2	Carr (2012)	Cross-sectional	United States	N=2,111 (5.1% Black)	Education; household income; homeownership	Blacks were less likely than Asians and Whites to have a living will and were less likely to have held EOL discussions compared to Whites. Blacks had lower levels of education, household income, and homeownership rates. A college education was associated with a greater likelihood of having a living will. Blacks were the least likely to have a living will relative to Whites with a high school diploma.
A3	Carr (2016)	Cross-sectional	Michigan (Detroit), Wisconsin, New Jersey	N=5,684 (percentage not specified)	Education; net worth; homeownership	Blacks were less likely than Whites to do formal health planning, have discussions around EOL, or have a written will. College graduates and homeowners were more likely to have completed a will. Wealth was a consistent predictor of end-of-life preparations.
A4	Choi et al. (2019)	Cross-sectional	United States	N=10,273 (13.5% non-Hispanic Black)	Education; income; wealth	Being older, female, White, and having more income and wealth, as well as more education, had a higher association with having an ACP or will.
A5	Garrido et al. (2014)	Cross-sectional	Connecticut, Massachusetts, New Hampshire, New York, Texas	N=606 (15.3% Black)	Education; health insurance	Blacks in this sample were significantly less likely to have health insurance (81% vs 36%) and less likely to have graduated high school (85% vs 59%) compared to Whites. Forty-five percent of Whites had a DNR in place, while 25% of Blacks at the start of the study. Blacks preferred life-prolonging treatment.
A6	Kahana et al. (2020)	Cross-sectional	Cleveland, Ohio	N=409 (25.2% Black)	Education	Blacks had lower odds of engaging in future care planning (FCP) than Whites. Older adults with an HS diploma were over 4 times more likely to complete FCP. Blacks were significantly less likely to have graduated high school. Blacks were also more likely to have a disability compared to Whites.
A7	Ko and Lee (2014a)	Cross-sectional	An urban area in California	N=256 (32.8% Black)	Education; Income	People with higher incomes were 2.4 times more likely to complete advanced directives. Whites were more likely to know about and complete AD. Blacks were more distrustful of the healthcare system and showed a greater preference for life-sustaining treatment.
A8	Ko and Lee (2014b)					Those with higher levels of knowledge, positive attitudes, or higher incomes were more likely to complete ADs than their counterparts.
A9	Lou and Liu (2021)	Cross-sectional	United States	N=9,902 (9.14% Black)	Education; household wealth	Racial minorities and respondents with low SES were less likely to have completed ADs. Black adults had the lowest SES. Compared to their White counterparts, Black older adults were significantly less likely to have an AD, living will, or power of attorney. Black older adults were less likely than Hispanics, Asians, or Native Americans to designate a health proxy.

Table 1. Continued.

Reference no.*	First author citation	Study design	Location	Sample	Operational definition of SES	Main findings
A10	McAfee et al. (2017)	Cross-sectional	United States	N=386 (16.6% Black)	Education	Whites were significantly more likely to have completed an ACP compared to Blacks. People who are Black reported more levels of mistrust toward the medical system when compared to White participants. Those with a bachelor's or post-bachelor's degree were more likely to complete an ACP than those with an associate's degree or less.
A11	Noh et al. (2018)	Cross-sectional	Alabama	N=1,044 (27.9% Black)	Education; Income	Whites were more likely to have the knowledge and to have completed living wills than Blacks. Whites were more likely to have concerns about EOL and have knowledge about hospice care. Nearly half of the Blacks in this study reported a total household income of less than \$30,000 compared to their White counterparts (nearly 90% of Whites reported a higher income than this).
A12	Nouri et al. (2020)	Cross-sectional	San Francisco, California	N=13,104 (6.8% Black)	Neighborhood-level income	Compared to patients living in the highest SES neighborhoods, those in lower SES neighborhoods had lower odds of ACP. Over half of the Blacks in this study (56%) resided in the two lowest SES neighborhoods, while (42%) of Whites resided in the highest SES neighborhood.
A13	Shapiro (2015)	Mixed-method	Urban area in Illinois	N=2,216 (percentage not specified)	Health insurance	African Americans had fewer ADs than Whites. Those with insurance (SES) were more likely to have ADs in place.
A14	Shrank et al. (2005)	Qualitative	Denver, Colorado	N=70 (48.6% Black)	Education; Income	African Americans were more inclusive of who was involved in EOL discussions. Whites placed more value on the quality of life, while Blacks are more likely to value keeping the person alive for as long as possible irrespective of quality. White participants desired more content on medical options and cost implications, while Black participants preferred spiritually-focused content.

*References in Appendix 1.

EOL: end of life, ACP: advance care planning, AD: advance directive, SES: socioeconomic status.

dividually analyzed all 14 articles and extracted content related to study design, study location, sample size, operational definition of SES, and main findings related to EOL care planning and the impact of SES among people who identified as Black or African American. Once the individual analysis was complete, the authors compared the extracted data and resolved any discrepancies.

RESULTS

1. Study characteristics

The majority (n=11) of the studies [A1–A11] employed a cross-sectional research design, while one [A13] reported the results from a qualitative study and one [A12] from a mixed-methods design (see Table 1). Almost all reports were secondary data analyses, where researchers used content previously collected. The studies were published between 2005 and 2022, and over half of them were published in the past 5 years. This reflects the growing focus and emphasis related

to EOL care among Black communities. The majority [A4–A11] of the participants were over 55 years of age (n=8) and all samples included both male and female individuals. Four studies [A2,A4,A8,A9] reported data from participants across the United States, while others were from mostly urban areas in Alabama (n=1) [A10], California (n=3) [A2,A7,A11], Colorado (n=1) [A13], Illinois (n=1) [A12], Ohio (n=1) [A6], as well as combined results from a few states (n=2) [A3,A5]. Most studies [5,11,16,17,20–25] reported on participants from a general population; however, some focused on a specific population: participants with a diagnosis of cancer (n=1) [A5], participants using Medicare (n=1) [A6], participants who were previously homeless (n=1) [A7], and participants from outpatient settings (n=1) [A5]. Among the samples, participants who were Black ranged from 5% to 48%.

2. Operational definitions of EOL and SES

Among most studies included (n=10) [A2–A5,A8–A10,A12–A14] EOL planning was operationally defined as obtaining a living will or other essential documents, such as a do-not-resuscitate (DNR) order or healthcare power-of-attorney. Some (n=6) [A1–A3,A6,A7,A10,] studies included in this review gathered data on “informal” EOL planning, which included discussions around and knowledge of EOL planning. Socio-economic status was operationally defined through variables such as income, education level, homeownership, and health insurance, and one study used an SES composite index score for neighborhoods.

3. EOL planning among black participants

Among the studies included in this review, almost all (n=11) [A2–A10,A12,A13] reported on the differences between Black participants and other racial groups’ engagement in EOL planning. All 11 studies found that Blacks were less likely to engage in EOL planning. Most (n=9) [A2,A3,A5,A6,A9–A13] of the differences reported were comparing Blacks specifically to Whites; but some studies reported on a few EOL planning differences between Blacks and other races. For example, Lou & Liu [A9] found that Black older adults were less likely than Hispanic, Asian, or Native American older adults to designate a health proxy.

4. Influence of SES

A number of studies [A2,A4,A6–A9,A11,A12] specifically reported results on SES and engaging in EOL planning (n=8). Having higher levels of SES (most commonly defined by education and income), was found to be associated with engagement in EOL planning in all eight studies. For example, Ko & Lee [A7] found that people with higher incomes were 2.4 times more likely to complete an advanced directive. Kahana et al. [A6] found that older adults with a high school diploma were over four times more likely to engage in future care planning, and Black participants were significantly less likely to have graduated high school than other races.

About half of the studies (n=6) [A2,A5,A6,A8,A10,A11] reported results related to SES among Black participants, and all consistently found Black participants to have lower SES than other racial groups. For example, Nouri et al. [A12] examined SES and zip codes, and they found that over half of the Black participants resided in the two lowest SES neighborhoods, while 42% of Whites resided in the highest SES neighborhoods. Others found that Black participants were less likely to own homes, less likely to have health insurance, and had lower levels of household income and education compared to other racial groups.

5. Ancillary results

Some notable themes from this review additionally emerged. First, two studies [A1,A7] found that people who are Black reported having greater levels of mistrust toward the medical system and healthcare professionals when compared to other races. Black individuals in two studies [A1,A13] were also more likely to value cultural and spiritual beliefs related to EOL planning. Lastly, three studies [A5,A7,A13] found that participants who were White placed more value on the quality of life, while Black individuals were more likely to choose life-sustaining treatments irrespective of quality.

DISCUSSION

As the first systematic review on this topic, the purpose of this review was to examine EOL care planning among people who identify as Black in the United States, with particular

attention given to the impact of SES on EOL planning. The results of the review substantiate previous research; however, they also highlight important needs for future studies related to EOL planning and SES among Black populations.

Several results from this review confirmed previous research [4,6,10,11]. The following are themes that were consistent with previous literature: Black individuals are much less likely than other races to engage in EOL planning, with the largest differences existing between Black and White populations [21]; low SES (low income and less education) is correlated with low EOL planning [17]; people who are Black are more likely to reside in low SES communities than any other race [5]; Blacks had lower levels of education and lower levels of knowledge related to EOL planning (e.g., [20]); and Black participants reported mistrust in the healthcare system and healthcare providers [21], but instead placed high value on spiritual beliefs and cultural norms related to EOL planning (e.g., [22]). These results are important because lower SES can hinder proactive EOL planning for Black and non-Black older adults [23]. Understanding the cultural beliefs and circumstances of minority older adults in EOL planning is relevant for individuals with lower SES because of the high value placed on religiosity and other cultural norms [24].

One of the themes that was surprisingly absent was the focus on families. Significant literature exists (e.g., [10]) related to the importance of including the family system in EOL planning among Black communities. Despite the robust literature on the importance of family involvement among Black families, it was not explicitly discussed in the articles included in this review. It is possible that this theme is missing because of research design and lack of original studies focusing on this important topic (see below). Future research is needed that is inclusive of family involvement in EOL planning among Black individuals in low SES communities. Also noteworthy was the absence of data collected in rural communities. Many of the research studies in this literature review were in urban and suburban settings. It is important for future research to include those living in rural communities, as there is less availability of healthcare resources in these settings.

Lastly, original research data was largely absent from this review. All quantitative results from the included studies (n=12) were derived from previously collected, cross-sectional

data for the purpose of secondary data analyses. Despite the expansive aforementioned research available that supports the critical concerns related to the impact of SES, education, culturally sensitive healthcare, and systemic racism on EOL planning among Black participants, the quantitative results offer no original research indicative of addressing these important needs. The evidence in this review substantiates many issues that have been raised in previous studies, and original research investigating solutions and change is overdue.

Practitioners, policymakers, and researchers must acknowledge that systems are rooted in racism, and oppress persons of color, and advocacy for change is needed. About 15 years ago, Griffith et al. [12] suggested that health disparities are ingrained in institutional racism, and until researchers understand both the “metrics” of institutional racism and the goals of the targeted organization, interventions applied in the community will fail. More recently, Sloan and colleagues acknowledged that system-level policies are still “colorblind” and reinforce racism [2]. Work toward strategies that are inclusive of known research related to Black individuals in low SES communities is paramount to eradicating this disparity.

According to Johnston et al. [23], cultural values and social determinants of health influence health-related behaviors and decision-making, which is relevant for decision-making among racial and ethnic minorities. Engaging Black participants requires building upon previous research and offering a culturally sensitive approach. As an example, Blacks are more likely to include multiple family members and clergy members when having formal or informal EOL discussions [22]. Thus, attention could be given to offering strategies and interventions in church settings where there is high Black family participation in low SES communities. Because this review and additional research have indicated the importance of spirituality and the involvement of family members in EOL decision-making among this population, offering educational resources in the church setting might improve EOL planning. Although some work has been done to increase EOL planning among some populations, strategies targeting increasing EOL planning among Blacks in low SES communities are needed [14].

We acknowledge that this systematic review has limitations. First, relevant research may have been excluded due to the SES inclusion criteria. It is possible that work is being done

related to EOL planning among Black individuals without a focus on SES. Nevertheless, the researchers believe the strong correlation between SES and EOL planning among Blacks is significant and must be explored together. Additionally, there might be missing research due to publication bias. It is possible that interventions have been developed to engage Black, low SES communities and results have just not been published. Despite limitations, this is the first systematic review to address EOL planning and SES among people who are Black, and we believe the results will provide an important and needed contribution.

This review highlights that low SES exerts a profound influence on EOL planning within Black communities, shaping access to resources, healthcare options, and the ability to make informed decisions about one's final wishes. Specifically, disparities in SES create challenges for comprehensive EOL planning because of differential access to quality healthcare, legal services, financial resources, and educational opportunities. Limited access to education and mistrust in healthcare systems may impact the perspective of the importance of advance care planning. Understanding ways in which trusted ideologies (related to culture, spirituality, and religion) and family systems may be considered and included in educational outreach related to advance care planning is an impor-

tant next step. It is crucial to address these disparities among Black communities and ensure that individuals can navigate these critical discussions with access to the necessary information and resources to make informed decisions that align with their values and preferences.

CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

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AUTHOR'S CONTRIBUTION

Conception or design of the work: all authors. Data collection: all authors. Data analysis and interpretation: all authors. Drafting the article: all authors. Critical revision of the article: all authors. Final approval of the version to be published: CW.

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