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Racial and Ethnic Disparities in Palliative Care: A Systematic Scoping Review

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Abstract

Despite the advances and spread of palliative care programs, communities of color remain significantly underserved. Although these disparities are widely known, there is a marked lack of empirical evidence. The authors conducted a systematic scoping review that synthesized the literature since 2000 about racial and ethnic disparities in palliative and end-of-life care. We searched PubMed, Medline, SocIndex, CINAHL, Social Work Abstracts, and PsycINFO, using search terms including *palliative care or end-of-life care, disparities or barriers or utilization, and race or ethnicity or African American or Hispanic*. Findings lend support to extant literature that social-environmental barriers and disparities distinctly affect access to care for these populations. The review expands upon understanding of how social determinants drive disparities in palliative and end-of-life care and suggests implications for practice, policy, and research in promoting health equity in serious illness.

Keywords

palliative care, disparities, race/ethnicity, health equity, Social Work Grand Challenges, social determinants of health

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Beginning with the modern hospice movement over a half century ago, palliative care has provided patient-centered, evidence-informed care that reduces symptom burden, limits unnecessary hospitalizations, and increases well-being for individuals and families living with serious illness. Despite well-documented advances in specialist palliative care and the proliferation of programs around the nation (Dumanovsky et al., 2016), significant gaps in access and utilization persist (Goldsmith, Dietrich, Du, & Morrison, 2008; Smith & Brawley, 2014). Reflecting systemic inequities in health and health care, disparities in palliative and end-of-life care are experienced by communities of color; people who are economically disadvantaged; lesbian,

gay, bisexual, and transgender individuals; and members of other marginalized groups. African

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American and Latin Americans are, for example, significantly less likely to access and use hospice services than their white non-Hispanic peers (Johnson, 2013; Payne, 2016). These disparities deny a growing population of adults living with chronic and advanced illnesses access to an evidence-informed model of care and represent a significant public health concern.

Although disparities in palliative and end-of-life care are widely observed (Goldsmith et al., 2008; Smith & Brawley, 2014), they represent an emerging area of research, and there are numerous gaps in the empirical literature. Palliative care programs are heterogeneous in structure, composition, services, and setting (Smith et al., 2013), research in this area lacks theoretical or methodological consistency, and there are few systematic or large-scale studies documenting disparities or barriers to care. Gaps in the literature on barriers to access and use of palliative care among marginalized populations have limited the ability of the field to move beyond descriptive depictions and toward strategies and interventions targeted to reducing disparities and eradicating inequities (Bierman, Lurie, Collins, & Eisenberg, 2002).

Systematic scoping reviews are well-suited to mapping key findings, concepts, and a range of empirical literature in emerging fields (Arksey & O'Malley, 2005). A scoping review of the literature on racial and ethnic disparities in palliative care can document inequities, identify key barriers in access to and utilization of care, and suggest next steps in terms of research and practice to reduce disparities and promote health equity among seriously ill adults. The authors conducted a scoping review of the empirical literature on racial and ethnic disparities to palliative and end-of-life care from the last two decades. The aim of the review was to identify and synthesize the literature on barriers to palliative care in the United States and to generate implications for social work practice, policy, and research to address these barriers.

Background

Social work has played an integral role in the delivery of comprehensive palliative care

since the establishment of modern hospice programs in the late 1960s (Harper, 2011; Reith & Payne, 2009). Core members of the interdisciplinary palliative care team, social workers provide multidimensional assessment of pain and biopsychosocial-spiritual suffering, counsel and coordinate care for patients and family caregivers, assist in identifying and communicating care preferences and goals, and advocate within teams and larger systems for the delivery of culturally competent person- and family-centered care (Cagle & Altilio, 2011; Gwyther et al., 2005). In 2016, the American Academy of Social Work and Social Welfare (AASWSW, 2016) developed a roadmap of 12 "Grand Challenges" facing the nation in the 21st century. The Academy recognized "closing the health gap" as a critical challenge for the profession and called for social work leadership in addressing significant health care disparities (Walters et al., 2016). Documenting and addressing gaps in access to and use of palliative care among marginalized communities represents an important step toward advancing health equity for the communities that social workers serve.

A large and growing literature suggests that health care inequalities such as racial and ethnic barriers to palliative care are driven by social determinants of health, including access to educational and employment opportunities; economic security; safe and affordable housing; healthy food and nutrition; high-quality health care; and supportive social relationships and social networks throughout the life course (Braveman, Egerter, & Williams, 2011; Newman, Baum, Javanparast, O'Rourke, & Carlon, 2015; Walters et al., 2016). These upstream socioeconomic and environmental factors are thought to influence individual and population health more than individual-level health behaviors (e.g., smoking, overeating, or lack of exercise), by means of complex physiological, systemic, social, and cultural causal pathways (Braveman et al., 2011; Gehlert et al., 2008). Healthy People 2020 (Koh, Piotrowski, Kumanyika, & Fielding, 2011), for example, promotes research into the social and environmental determinants of health and their causal mechanisms as critical

to addressing disparities in care and promoting the health equity of all Americans.

Methods

The authors conducted a systematic scoping review of peer-reviewed, empirical studies published in health and social science journals from 2000 to the present. We followed Arksey and O'Malley's (2005) guidelines for conducting scoping reviews in order to answer the following questions:

- 1) What barriers do adult African Americans/Blacks, Latinos, and other communities of color experience in access and use of palliative care?
- 2) What does the empirical literature tell us about these disparities and their causes?
- 3) What are the implications for social work practice, policy, and research toward ending disparities and reducing health inequities?

Search Strategy

Six databases were searched to identify appropriate literature for this review—PubMed, Medline Complete, SocIndex, CINAHL, Social Work Abstracts, and PsycINFO—using the following terms: (1) palliative care or end-of-life care, (2) access or utilization, (3) barriers or disparit* or inequit*, and (4) Rac* or ethnic*. After consulting with a social work research librarian, we expanded the search to target empirical literature on Black or African Americans, American Indians and Alaska Natives, Asian Americans, Native Hawaiians and Pacific Islanders, and Hispanic or Latin adults. In addition, we searched two databases of systematic reviews, the Cochrane Library (www.cochranelibrary.com/) and PROSPERO (<https://www.crd.york.ac.uk/prospéro/>), to uncover any empirical reviews on palliative care disparities.

Inclusion and Exclusion Criteria

We searched peer-reviewed studies presenting empirical findings from data collection, analysis, or systematic reviews published

since 2000. For inclusion, articles had to meet the following criteria: (1) presenting data on barriers to or disparities in access or use of palliative care or end-of-life care among African American, Latino, and other racial/ethnic populations; (2) concerning adult (≥ 18 years old) populations; and (3) settings in the United States. We excluded studies done outside of the United States, given unique historical, sociostructural dynamics that shape the environmental dynamics for Americans of color, and studies that evaluated interventions to reduce disparities (which assume the presence of disparities but do not empirically examine them).

Much of the extant research on disparities in palliative and end-of-life care uses hospice—a subspecialty of palliative care for terminally ill patients—as a proxy for all palliative care. Although both are person- and family-centered models that share a philosophy of care, they differ in several structural ways. In both hospice and palliative care, interdisciplinary teams provide care to ameliorate suffering, honor the patient's care preferences, and enhance the biopsychosocial and spiritual well-being of seriously ill patients and their families. Palliative care, however, provides supportive care throughout the continuum of illness and can be provided concurrently with curative treatment (National Consensus Project [NCP], 2013). Similarly, whereas attention to pain and symptom management and advance care planning (ACP) or advance directives are integral to the provision of high-quality palliative and end-of-life care, we excluded studies that solely examined access to or use of hospice services, pain and symptom management, ACP discussions, and end-of-life care preferences; we included, however, studies that looked at a combination of these services as part of comprehensive palliative care services.

Data Extraction and Synthesis of Findings

Covidence systematic review software (<https://www.covidence.org/>) helped organize the iterative review of articles conducted by

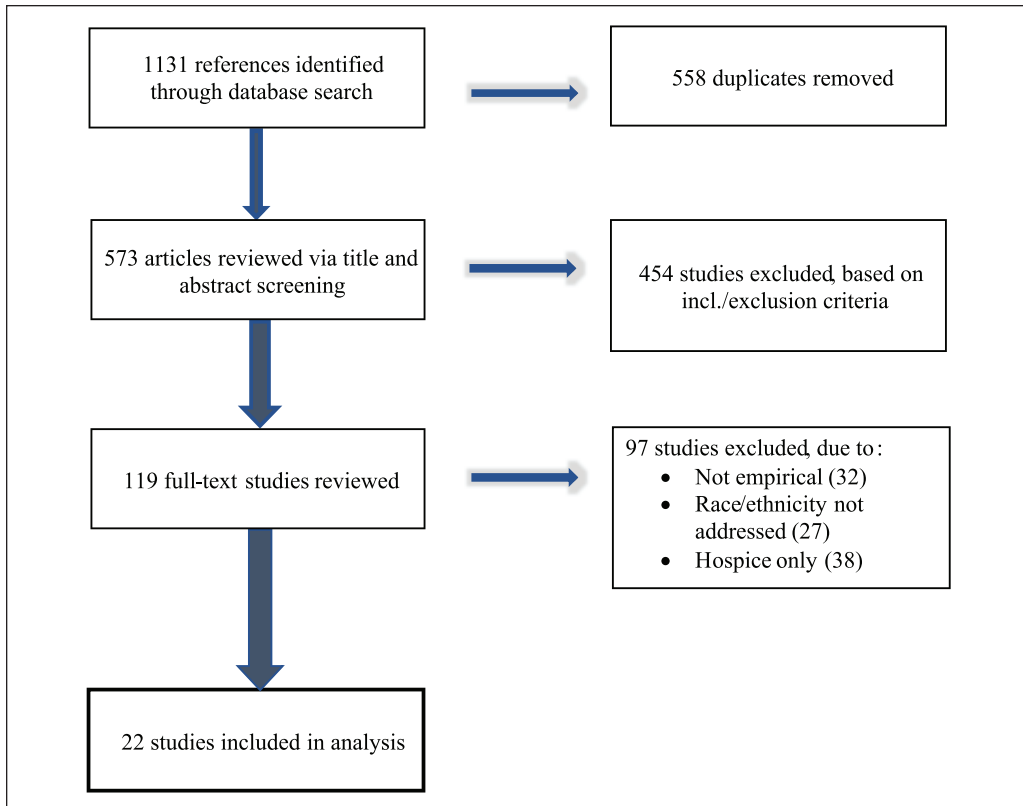


Figure 1. Study selection process.

all of the authors. After removing duplicates, the first and second authors simultaneously screened titles and abstracts in a blinded process. Conflicts were resolved with the other authors before moving into a full-text review of the remaining studies. Using the same blinded process to review the full-text articles, we selected articles for inclusion based on their relevance to the review questions. Once the final set of articles were agreed upon, we extracted pertinent data onto a spreadsheet, from which we synthesized findings. Figure 1 presents a summary of our abstraction process and eligibility decisions.

Findings

There were 22 articles that met our search criteria (see Table 1). The articles reflect a range of designs, methods, and topics related to racial/ethnic disparities. Of the 22, 6 were retrospective medical chart reviews, 4 were sec-

ondary analyses (namely of the U.S. National Inpatient Sample [NIS], a longitudinal, national hospital discharge database), 3 were systematic literature reviews, 3 were cross-sectional surveys, and 6 were qualitative or mixed-methods studies that analyzed semistructured interview and focus group data. Given the exploratory nature of this scoping review and the substantive and methodological diversity of the studies, we did not evaluate the methodological rigor of articles.

Fourteen of the articles investigated racial and ethnic differences in access to and utilization of palliative and end-of-life care. Included in these were studies that tracked the rates of palliative care referrals and consults and studies that examined racial and ethnic differences in the experience of high-quality palliative and end-of-life care. Reflecting a diverse array of study aims and methods, the sample sizes in the extracted studies ranged from 7 to 378,256. Details about the articles, including

Table 1. Studies Investigating Racial/Ethnic Disparities in Palliative Care (N = 22).

Authors	N	Aims	Methods	Key Findings	Barriers/Disparities
Bhatraju et al. (2014)	N = 378 Patients in a racially/ethnically diverse urban hospital	Explore factors associated with inpatient palliative care consultation (IPCC) in urban public hospital	<ul style="list-style-type: none"> Medical record review Quantitative 	<ul style="list-style-type: none"> Younger patients, higher education, cancer predicted use of IPCC Born outside the United States and preferring to speak a language other than English predicted IPCC 	<ul style="list-style-type: none"> No significant differences in IPCC found by race/ethnicity
Burgio et al. (2016)	N = 1,690 African American (AA) and white patients in a VA hospital	Examine end-of-life (EOL) care differences between AA and white VA in-patients in last 7 days of life	<ul style="list-style-type: none"> Medical record review Quantitative 	<ul style="list-style-type: none"> AAs less likely to have do not resuscitate (DNR) order, advance directive (AD), opioid ordered/administered or antipsychotic administered No race differences in IPCC 	<ul style="list-style-type: none"> Racial differences found in ADs and medication for pain and agitation during last 7 days of life No significant differences in palliative care (PC) referral or consultation
Cervantes et al. (2017)	N = 20 Latino end-stage renal disease (ESRD) patients on dialysis	Explore symptom management and advance care planning (ACP) preferences of Latino patients on dialysis	Qualitative interviews	<ul style="list-style-type: none"> Themes: Avoiding harms of medication; Barriers and facilitators to ACP; Enhancing well-being day-to-day; Distressing aspects of living with illness 	<ul style="list-style-type: none"> Preference for nonpharmacologic symptom management and family group decision making Communication and language barriers in accessing health care Financial hardship
Connolly, Sampson & Purandare (2012)	N = 20 Dementia patients and physicians	Explore state of science regarding EOL care for racial/ethnic minority patients with dementia	Systematic review	<ul style="list-style-type: none"> Racial minorities (AA, Hispanic, Asian) more likely than white patients to have artificial nutrition, ICU, and mechanical ventilation AA and Hispanic patients less likely to have ACP discussion or withdraw life-saving treatment (LST) 	<ul style="list-style-type: none"> AA, Hispanic, and Asian patients with dementia more likely to have aggressive EOL care

(continued)

Table 1. (continued)

Authors	N	Aims	Methods	Key Findings	Barriers/Disparities
Duffy, Jackson, Schim, Ronis, & Fowler (2006)	N = 73 Healthy adults over 50 years old	Explore how EOL care preferences vary by race/ethnicity and gender	<ul style="list-style-type: none"> Focus groups Mixed-method 	<ul style="list-style-type: none"> Arab patients prefer family provide EOL care, not to break bad news, less LST Hispanics prefer to avoid nursing home, avoid loss of dignity; Hispanic women want more LST AA men concerned about being a burden, want less intervention, distrust for doctors; AA women opposed to "pulling the plug" Non-Hispanic white patients preferred to die at home, ADs, less LST PC use lower in hospitals that serve primarily minority patients Minority patients less likely to receive PC in any hospital type (white, mixed race, or minority) White and non-white stroke patients equally unlikely to receive PC in mixed and minority hospitals AA patients more likely to have ADs discussion and DNR on record than white patients Race/ethnicity not a predictor of differences in presence of pain and symptom-focused plan of care in record 	<ul style="list-style-type: none"> Barriers to patients inferred from preferences: <ul style="list-style-type: none"> Arabs: withholding prognosis information; Hispanics: preference for more LST; AA women: opposed to ending LST Delivery of PC may be designed to meet preferences of white patients whose preferences align with PC/hospice providers Racial/ethnic minority patients less likely to receive PC after stroke than non-Hispanic white patients Hospital type plays role in PC disparities No significant ethnic disparities reported
Faigle, Ziai, Urrutia, Cooper, & Gottesman (2017)	N = 378,256 Intracerebral hemorrhage and ischemic stroke minority patients	Examine PC after intracerebral hemorrhage and ischemic stroke	<ul style="list-style-type: none"> Population-based cohort analysis Quantitative 		
Fischer, Kurner, Saaia & Kramer (2007)	N = 217 VA patients with cancer, chronic illness, or multiorgan failure	Determine if PC use varies by race/ethnicity in one VA hospital	<ul style="list-style-type: none"> Medical record review 		

(continued)

Table 1. (continued)

Authors	N	Aims	Methods	Key Findings	Barriers/Disparities
LoPresti, Dement, & Gold (2016)	N = 25 AA, Hispanic, Asian American cancer patients	Explore state of science on ethnic/ racial disparities in EOL care for cancer patients	<ul style="list-style-type: none"> Systematic review 	<ul style="list-style-type: none"> AA and Hispanic patients prefer more LST, fewer DNRs/ADs; more likely to have misconceptions about AD; importance of faith; fatalistic beliefs about pain and suffering Preference for consistent care higher for white than AA patients 	<ul style="list-style-type: none"> Preference for life-sustaining care, which some believe is at odds with PC Misconceptions about advance care planning Fatalistic beliefs about pain and suffering Knowledge/understanding of PC
Matsuyama et al. (2011)	N = 133 AA and non- Hispanic white cancer patients	Explore awareness of hospice and PC among AA and non-Hispanic white patients at a cancer center	<ul style="list-style-type: none"> Cross-sectional survey 	<ul style="list-style-type: none"> Only 23% of the sample (N = 31) reported having heard of PC Those who had heard of PC more likely to have a high school education, higher income, and be white 	<ul style="list-style-type: none"> Individual, familial, cultural/religious, systems-level, and structural (economic) barriers
Periyakoil, Neri, & Kraemer (2016)	N = 315 AA, Hispanic, or Asian patients	Identify barriers to high-quality EOL care reported by multiethnic patients and families	<ul style="list-style-type: none"> Cross-sectional Mixed-methods 	<ul style="list-style-type: none"> Six barriers identified: Finance/health insurance, physician behaviors, communication chasm between doctors and patients, family behaviors and beliefs, healthcare system barriers, and cultural or religious barriers 	<ul style="list-style-type: none"> Mistrust of health system and providers Financial and insurance barriers Underresourced, rural geographical regions Lack on AI/AN input in program development Lack of AN/AI cultural training programs for providers Insufficient funding for PC programs, lack of program infrastructure in AN/AI areas Misconceptions about PC
Isaacson & Lynch (2018)	N = 17 American Indians and Alaska natives (AI/ANs)	Explore the state of science on accessibly, culturally sound PC practices for AI/ANs	<ul style="list-style-type: none"> Systematic review 	<ul style="list-style-type: none"> Four themes identified: Communication; Cultural awareness and sensitivity; Community guidance for PC and EOL care programs and Barriers Two subthemes: trust and respect; and mistrust 	<ul style="list-style-type: none"> Mistrust of health system and providers Financial and insurance barriers Underresourced, rural geographical regions Lack on AI/AN input in program development Lack of AN/AI cultural training programs for providers Insufficient funding for PC programs, lack of program infrastructure in AN/AI areas Misconceptions about PC
Isaacson et al. (2015)	N = 7 Patients and physicians	Explore the perspectives of native and nonnative health care professionals on the use of PC	<ul style="list-style-type: none"> Qualitative interviews 	<ul style="list-style-type: none"> Barriers to PC program success: poor funding, lack of infrastructure, and misconceptions about both PC and AN/AI preferences 	<ul style="list-style-type: none"> Mistrust of health system and providers Financial and insurance barriers Underresourced, rural geographical regions Lack on AI/AN input in program development Lack of AN/AI cultural training programs for providers Insufficient funding for PC programs, lack of program infrastructure in AN/AI areas Misconceptions about PC

(continued)

Table 1. (continued)

Authors	N	Aims	Methods	Key Findings	Barriers/Disparities
Kumar et al. (2012)	N = 313 Cancer patients at a comprehensive cancer center	Measure rates of utilization of Outpatient Supportive and palliative care Services (SPCS); identify factors related to the use of SPCS and barriers to access to SPCS	<ul style="list-style-type: none"> Cross-sectional survey 	<ul style="list-style-type: none"> Women, highly educated more likely to use SPCS Age, ethnicity, employment, marital status, and cancer stage not associated with SPCS use Non-whites patients less physician referral for SPCS 	<ul style="list-style-type: none"> No racial/ethnic disparities found Non-white patients cited lack of physician referral as barrier to accessing SPCS
Reynolds, Hanson, Henderson, & Steinhauer (2008)	N = 1,133 Nursing home residents	Examine racial and/or age-based differences in EOL care in an institutional setting	<ul style="list-style-type: none"> Medical chart review 	<ul style="list-style-type: none"> White patients two times more likely than minority patients to have DNR orders, eight times more likely to have living wills, three times more likely to have health care proxy (HCP) Nurses rated minority residents as having a greater intensity of pain No differences by race in either medication-based or nonpharmacological treatments for pain 	<ul style="list-style-type: none"> Minority patients less likely to have ACP discussions and ADs documented
Rhodes, Batchelor, Lee, & Halm (2015)	N = 12 PC providers	Examine provider-identified barriers to using EOL services among AAs	<ul style="list-style-type: none"> Qualitative interviews 	<ul style="list-style-type: none"> Barriers to PC and hospice use: Prognosis understanding; Desire for LST Family resistance, and Finances/lack of insurance Lack of programs to increase awareness of EOL care options for underrepresented minorities 	<ul style="list-style-type: none"> Mistrust of medical system Religious and spiritual beliefs Financial hardship/insurance problems Preference for LST
Rosenfeld et al. (2018)	N = 67,947 AA, Hispanic, white, and Asian gynecologic cancer patients	Explore the factors associated with inpatient PC use among patients with metastatic gynecologic cancer	<ul style="list-style-type: none"> Population-based cohort analysis 	<ul style="list-style-type: none"> 5% used PC Older, AA patients had higher rate of PC Uterine and cervical cancer used PC more; patients with Medicare used PC less 	<ul style="list-style-type: none"> AA patients in this study were more likely to use PC than white patients

(continued)

Table 1. (continued)

Authors	N	Aims	Methods	Key Findings	Barriers/Disparities
Rosenzweig, Wiehagen, Brufsky, & Arnold (2009)	N = 48 AA patients with breast cancer	Explore how race and income status influence women's experiences with metastatic breast cancer	<ul style="list-style-type: none"> Surveys and interviews Mixed-methods 	<ul style="list-style-type: none"> Low-income AA women reported greater physical and social distress and less understanding of illness and treatment goals 	<ul style="list-style-type: none"> Greater pain, distress and psychosocial problems Unclear understanding of illness and treatment plan
Rush, Walley, Celi, Rajoriya, & Brahma (2017)	N = 39,349 AA, Hispanic, white, and other liver disease patients	Examine the referrals to and use of PC in patients with end stage liver disease hospitalized in the United States	<ul style="list-style-type: none"> Population-based cohort analysis 	<ul style="list-style-type: none"> Factors associated with lower referral to PC: Hispanic ethnicity and insurance coverage Factors associated with increased referral to PC: age and DNR status 	<ul style="list-style-type: none"> Hispanic ethnicity, younger age, lack of DNR Large teaching hospitals in West facilitated referral
Sharma et al. (2015)	N = 6,288 AA, Hispanic, and white, metastatic cancer inpatients	Examine rates of inpatient palliative care consult (IPCC) by race	<ul style="list-style-type: none"> Medical chart review 	<ul style="list-style-type: none"> AA greater likelihood of IPCC consult than whites, even after adjusting for insurance, hospitalizations, marital status, and illness severity. Among patients who received IPCC consult, AA patients had higher number of days from IPCC to death than white patients 	<ul style="list-style-type: none"> African American patients more likely to have inpatient palliative care consults
Singh, Peters, Tirschwell, & Creutzfeldt (2017)	N = 395,411 AA, white, Hispanic, Asian/Pacific Islander, Native American, other stroke patients	Explore patterns of PC utilization and death in hospitalized patients with stroke in the United States	<ul style="list-style-type: none"> Population-based cohort analysis 	<ul style="list-style-type: none"> Patient characteristics independently associated with the use of PC include older age and female sex PC use was significantly lower in Blacks, Hispanics, and Asians 	<ul style="list-style-type: none"> AA, Hispanic, and Asian stroke patients less likely to have inpatient PC
Welch, Teno, & Mor (2005)	N = 1,447 AA and white members of deceased patients' families	Compare the EOL experiences of AA and white patients and their families	<ul style="list-style-type: none"> Cross-sectional retrospective survey 	<ul style="list-style-type: none"> AA families less likely to rate EOL care as excellent/very good; more likely to report absent or problematic communication, support, information; more likely to report financial hardship, savings depletion, difficulty paying for care Race not a significant predictor of time to IPCC, hospice, or LOS AA more likely to be young, female, poor health status 	<ul style="list-style-type: none"> For AA families: <ul style="list-style-type: none"> Financial hardship Communication problems with health care provider Less documented advance care planning No racial barrier or disparity noted in time to IPCC AA patients may be younger and sicker
Worster et al. (2018)	N = 3,207 AA, Hispanic, Asian/Pacific Islander, Native American, white inpatients	Determine if race is a significant predictor of time to IPCC, hospice, and length of service (LOS)	<ul style="list-style-type: none"> Retrospective record review Quantitative 	<ul style="list-style-type: none"> AA more likely to be young, female, poor health status 	<ul style="list-style-type: none"> AA patients may be younger and sicker

specific aims, sample, key findings, and barriers to palliative care, are presented in Table 1.

Analysis of the final 22 articles yielded two major themes: (1) disparities in access and use of palliative and end-of-life care, which tracked patient consultations, referrals, and use of specialized palliative care services by race and ethnicity, and (2) social determinants of high-quality palliative and end-of-life care, which explored drivers of—and barriers to—palliative care among communities of color.

Disparities in Palliative and End-of-Life Care

Findings from the 14 studies that investigated disparities fell into two distinct categories: (a) racial/ethnic differences in palliative care referrals, consults, and services, and (b) racial/ethnic differences in end-of-life care. Nine studies examined the rates of palliative care utilization by racial and ethnic minorities in an effort to measure racial disparities in access to care. Findings across these studies are decidedly mixed. Four studies, using medical chart reviews, found that there were no racial differences in rate of inpatient palliative care consult (Bhatraju, Friedenberg, Uppal, & Evans, 2014; Burgio et al., 2016), time to inpatient palliative care consult (Worster et al., 2018), or use of outpatient palliative care services (Kumar et al., 2012). However, three studies using the NIS, a nationwide, population-based database of inpatient care in the United States, found that minority patients received fewer palliative care services (Faigle et al., 2017; Rush et al., 2017; Singh et al., 2017). Two studies, examining the rates of palliative care use in cancer patients, found that African American patients actually received more palliative care services than white and other minority patients (Rosenfeld et al., 2018; Sharma et al., 2015).

Six studies did not directly examine disparities in palliative care services but instead explored racial differences in end-of-life and serious illness care. Variables examined included documentation of advance directives, life-sustaining “aggressive” versus symptom-focused “comfort” treatments, and the experi-

ence of pain, distress, and unmet care needs. Again, the findings across studies were inconsistent. A systematic review of 20 studies on end-of-life care for ethnic minority patients with dementia found that African American, Hispanic, and Asian patients with dementia had more aggressive end-of-life care in the form of artificial nutrition and hydration and mechanical ventilation and CPR and were less likely to have documented ACP (Connolly et al., 2012). Two studies confirmed these disparities in ACP—namely, the documentation of advance directives such as health care proxy, DNR, or living will (Reynolds et al., 2008; Welch et al., 2005). Another study found that minority patients in a VA hospital received less pharmacologic treatment for pain and agitation in the last 7 days of life (Burgio et al., 2016). Similarly, a mixed-method exploration of racial and economic differences in the experience of metastatic breast cancer found that African American women were more likely to have unmanaged pain, psychosocial distress, and unmet informational needs regarding their care (Rosenzweig et al., 2009). Only one study, conducted in a VA hospital, found no racial differences in end-of-life care and found that African American patients in this sample were more likely than white patients to have ACP discussions and DNR orders documented in the medical chart (Fischer et al., 2007).

Social Determinants of High-Quality and End-of-Life Care

The remaining studies explored barriers to high-quality palliative and end-of-life care. In our analyses, five subthemes emerged that represent possible drivers of existing racial and ethnic differences in the use of and experiences with palliative and end-of-life care: (a) financial/insurance barriers, (b) cultural preferences for end-of-life care, (c) care setting/geographic region, (d) misconceptions/lack of information about palliative care, and (e) provider communication problems/perceived discrimination.

Financial/insurance barriers. Four studies suggested financial and insurance problems

facing minority patients constituted a barrier to accessing palliative and high-quality end-of-life care. In one study, Latino, community-dwelling, end-stage renal disease ESRD patients cited financial problems as a major source of distress and a barrier to high-quality care. They noted difficulties paying for food, transportation, and essential utilities like gas and electric (Cervantes et al., 2017). In a sample of largely Asian patients, financial problems were ranked as the number one barrier to high-quality end-of-life care (Periyakoil et al., 2016). In two studies focused on the barriers and end-of-life care experiences of African American patients, providers noted lack of health insurance (Rhodes et al., 2015), and family members cited financial hardship and savings depletion (Welch et al., 2005) as primary barriers.

Cultural preferences for end-of-life care. Five studies focused on how the cultural and religious preferences of racial and ethnic minorities might constitute a barrier to care. The qualitative study of Latino, community-dwelling ESRD patients revealed that Latino patients, due to a fear of harms caused by medication, may have a preference for nonpharmacologic treatments for pain and other sources of distress and discomfort. Further, they reported a strong preference for family, group decision-making regarding end-of-life care. Rather than assigning a single health care agent or laying out advance directives themselves, these patients felt it was culturally meaningful for those decisions to be made by their close family members. It also revealed a somewhat fatalistic belief about suffering, a sense that the pain and suffering of illness were a punishment from God that they were meant to endure (Cervantes et al., 2017). A systematic review drew similar conclusions about African American and Hispanic patients, who were more likely believe that they “deserved to be punished” and would opt for life-sustaining treatment because it would be immoral to voluntarily choose to shorten their life by any amount (LoPresti et al., 2016). This spiritually grounded preference for life-sustaining treatment was found most strongly

among African American and Hispanic women, who felt it immoral to “pull the plug” and felt they would opt for nearly all aggressive interventions when asked (Duffy et al., 2006). Palliative care providers viewed faith as a barrier for African American patients, who they felt preferred to “leave it in God’s hands” (Rhodes et al., 2015). However, when a largely Asian sample was asked to rank the barriers they experienced to high-quality end-of-life care, they ranked “cultural and religious barriers” last (Periyakoil et al., 2016).

Care setting/region. Three studies specifically identified racial/ethnic barriers to care constituted by the setting and/or geographic region of care. A large analysis of racial/ethnic disparities in palliative care in hospitals that served either majority white, mixed, or majority minority patients found that stroke patients of any race/ethnicity were less likely to receive palliative care in a mixed or majority minority hospital (Faigle et al., 2017). The only two studies that examined palliative care for American Indians/Alaskan Natives found that rural care settings were underresourced for culturally competent, accessible palliative care for this population (Isaacson et al., 2015; Isaacson & Lynch, 2018).

Misconceptions, mistrust, and lack of information about palliative care. Five studies found barriers related to misconceptions, mistrust, and lack of information on palliative care among minority patient populations. A systematic review found that African American and Hispanic patients held misconceptions about advance directives and ACP. Specifically, some believed that once an advance directive was documented that it could not be changed (LoPresti et al., 2016). One study asked white, African American, and Hispanic patients if they had ever heard of palliative care, and those who had were more likely to be white and have higher education and income levels (Matsuyama et al., 2011). Mistrust of the medical system was cited in studies of American Indians (Isaacson et al., 2015) and African Americans, particularly strong in African American males (Duffy et al., 2006). These

findings were echoed by palliative care providers who noted that mistrust of providers and lack of information on palliative care were strong deterrents to receiving high-quality end-of-life care in the African American community (Rhodes et al., 2015).

Provider barriers: Communication and discrimination. Six studies cited provider-level challenges including communication issues and language barriers, perceived discrimination, and lack of cultural competency training and research. Language and cultural barriers were cited as a problem for Latino ESRD patients who felt that they would be more comfortable discussing serious matters regarding their care and making end-of-life care decisions with someone who understood their language and culture (Cervantes et al., 2017). Similarly, communication problems (either absent or disrespectful communication with providers) were reported by African American family members of deceased loved ones (Welch et al., 2005). Similarly, provider behaviors and problems with communication were ranked by a largely Asian sample as problematic barriers to high-quality end-of-life care (Periyakoil et al., 2016). Only one study looked at discrimination directly and found African American patients readily cited historical medical mistreatment of the African American community as a barrier to trust (Duffy et al., 2006). In another study, African American cancer patients were more likely than white patients to feel that they were overlooked by providers in delivering information and referrals for available outpatient palliative and supportive care services (Kumar et al., 2012). Two studies that focused on provider perceptions found that providers felt their lack of preparation and training in cultural sensitivity constituted a barrier to palliative care for minority populations (Isaacson et al., 2015; Rhodes et al., 2015).

Discussion

This systematic scoping review synthesizes empirical research from the past two decades on racial and ethnic disparities in palliative

care in the United States. The studies that met our criteria vary considerably in their research aims, methods, sample size, and operationalizations of palliative and end-of-life care. The findings of these articles are largely consistent, however, with extant empirical literature on disparities in hospice and the scholarly literature on palliative care, providing evidence of significant differences in goals of care and care preferences for racial/ethnic minority adults with serious illness (Goldsmith et al., 2008). While the majority found significant racial and ethnic disparities, three studies found no racial/ethnic differences in palliative care access, and two studies found that African American patients received more palliative care services than white and other non-white patients. The studies that showed no differences in palliative care use (Bhatraju et al., 2014; Kumar et al., 2012; Worster et al., 2018) analyzed data from a single, urban hospital and used small samples. The studies that indicated greater use of palliative care by minority patients (Rosenfeld et al., 2018; Sharma et al., 2015) sampled only cancer patients and one in particular only female patients with gynecological cancers. One potential explanation for these unanticipated findings is that racial and ethnic disparities in palliative care referral, consultation, and use may be moderated by diagnosis, gender, or setting.

Some limitations to our review must be considered. The palliative care landscape has changed dramatically over the last 20 years, rendering some of the findings from older studies hypothetically less relevant than current research findings. Examining racial and ethnic disparities rather than one or two specific groups entailed combining all non-white groups, which reduced some precision. In addition, we chose to exclude studies that examined solely hospice data and research solely focused on care preferences or ACP; these categories represent factors that may be associated with disparities among marginalized populations, but our aim was to identify evidence of barriers to comprehensive palliative care. In addition, only empirical studies published in refereed journals were included for review, and therefore books, book chapters,

commentaries, and nonsystematic literature reviews were also excluded. These decisions, and our exclusion of data collected outside of the United States, may have limited our search and reduced the output of empirical evidence of racial/ethnic disparities in palliative care and represent opportunities for further investigation in the future.

Despite these limitations, our systematic scoping review highlights several barriers to high-quality palliative and end-of-life care among racial/ethnic minority adults. Social and structural challenges including economic insecurity and lack of adequate insurance, cultural and spiritual values about health and medicine, and geographic location all had observable effects on access to and use of palliative care among marginalized populations. These findings are consistent with extant literature on barriers in access to and use of palliative care (Francoeur, Payne, Raveis, & Shim, 2007; Smith & Brawley, 2014). Provider-level barriers to palliative care, including communication barriers and perceptions of discrimination related to race or ethnicity, were also identified in the review, echoing the findings of other researchers (Francoeur et al., 2007; Kayser, DeMarco, Stokes, DeSanto-Madeya, & Higgins, 2014; Linton & Feudtner, 2008). Inconsistent findings across studies and ongoing gaps in the empirical literature, however, suggest the need for further empirical consideration, including the potential moderating effects of distinct diagnoses, care settings, and demographics such as gender and age. Additional research on provider and patient perceptions of disparities and of barriers facing other marginalized populations (e.g., individuals who are lesbian, gay, bisexual, or transgender; individuals living with disabilities; and immigrant communities) would further illuminate dynamics of the problem.

Conclusions/Implications for Practice

Findings from this review suggest several implications for social work practice, policy, and research. Social workers must be aware of distinct barriers that racial and ethnic minority

families face in accessing palliative and end-of-life care and work by means of culturally sensitive and culturally competent practice and advocacy to reduce health care disparities. Being curious about patients and families' unique and intersecting cultural, social, and linguistic backgrounds is essential for understanding and respecting diverse perspectives and preferences regarding health, illness, and care. Palliative social workers should be sensitive, for example, to diverse preferences for life-sustaining treatment or concerns about ACP among Latino or African American patients and families. Including social indicators, cultural and linguistic backgrounds, and care preferences and perceptions in all biopsychosocial assessments and treatment plans, for example, would help to highlight the distinct needs of patients and families to other providers associated with the case. As core members of interdisciplinary palliative care teams, social workers should also advocate across systems and settings for cultural sensitivity and open communication, understanding, and empathy among patients, family members, and providers.

Health care policy reform is critical to expanding care options for all seriously ill adults and making care accessible over the course of serious illness. In order to advocate for equitable access to high-quality palliative care for underserved populations, social workers must develop and advance policies that address treatment-related financial hardship and to extend optimal support for people who need temporary or long-term care and their families and caregivers. Finally, social workers can advocate for increased research funding to support increased collection and analysis of data on racial and ethnic disparities in care, identification of continuing gaps in the research, and evaluating interventions designed to reduce disparities (Bierman et al., 2002; Walters et al., 2016).

In summary, palliative care has demonstrated the potential to ameliorate suffering and enhance the quality-of-life of people living with serious illness, but still remains inaccessible to many individuals and communities. Despite some inconsistencies in

the emerging empirical literature, this scoping review provides evidence of significant racial and ethnic disparities in access to and use of high-quality palliative care. In order to eliminate health disparities and “close the health gap” for Americans with serious illness, social workers must actively promote equitable and just distribution of palliative care and bring awareness to the social and environmental factors that negatively affect the health and well-being of individuals, families, and communities.

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