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Racial and Ethnic Inequities in End-of-Life Pain Management

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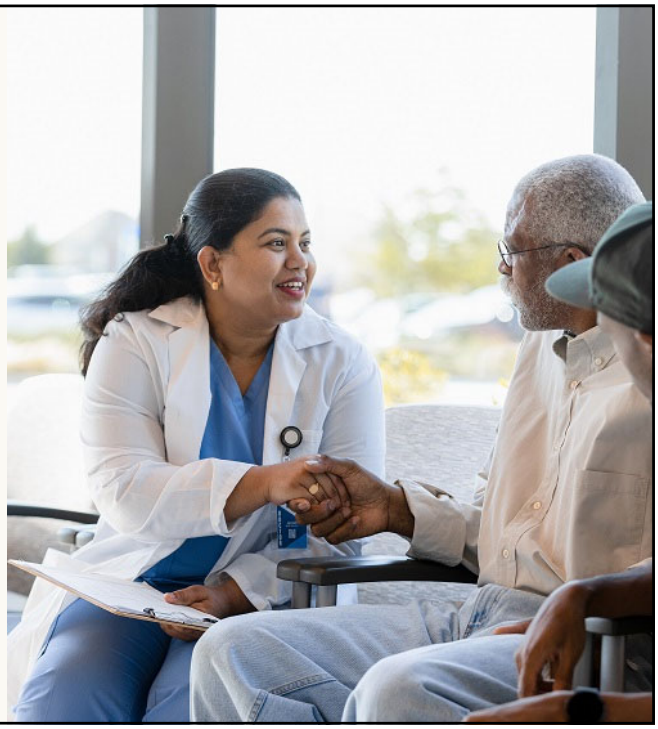
Seattle, WA



1

Learning objectives

At the end of this educational activity, participants should be able to:

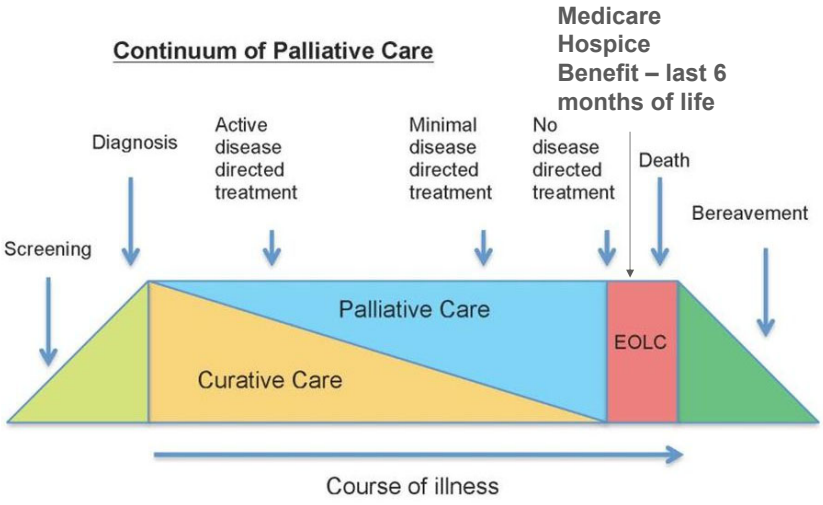
- Characterize the data on racial and ethnic inequities in end-of-life pain management
- Describe the multi-level barriers that contribute to inequities in end-of-life pain management
- Identify strategies to address racial and ethnic inequities and improve care for patients at the end of life

2

Prevalence Of Pain At The End Of Life

3

Definitions – Palliative Care, Hospice, and End of Life



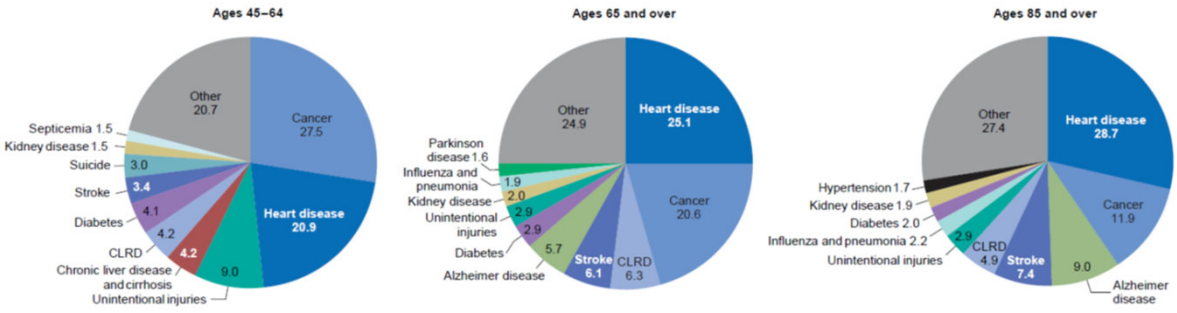
Myatra SN. . 2014. Indian J Crit Care Med. 2014 doi: 10.4103/0972-5229.140155.

4

Leading Causes of Death in the US Across Age Groups

National Vital Statistics Reports, Vol. 70, No. 9, July 26, 2021

Figure 2. Percent distribution of the 10 leading causes of death, by age group: United States, 2019



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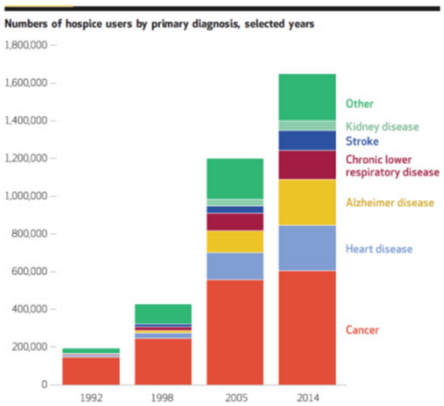
Primary Hospice Diagnoses

For Medicare patients enrolled in hospice: NHPCO 2018 data

Cancer – 29.6%
Heart disease – 17.4%
Dementia – 15.6%

Increase in multi-morbidity



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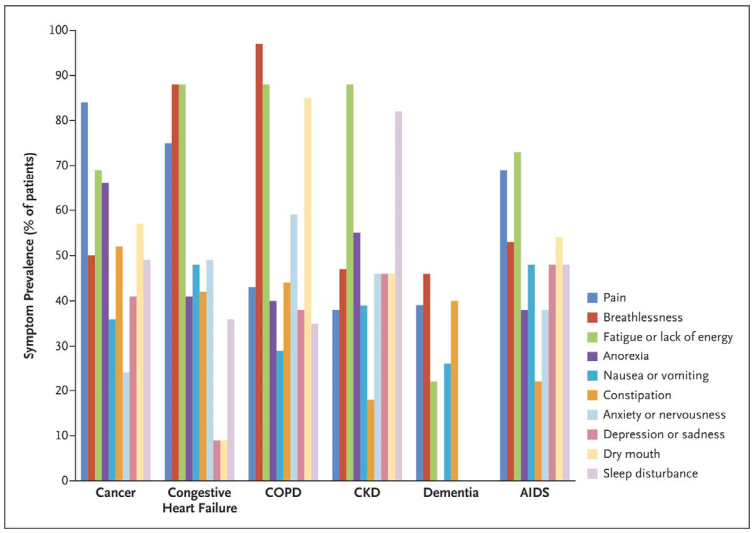
Symptom Prevalence in Advanced Illness



Kelley AS. N Engl J Med 2015; 373:747-755
DOI: 10.1056/NEJMra1404684

Prevalence of Pain for Patients with Advanced Cancer

Table 4
Pain Prevalence in Patients With Advanced, Metastatic, or Terminal Disease (Group 3)

Study	Continent[a]	Setting[b]	Type of Cancer[c]	Mean Age	Sample Size	% Pain				
						No	Mild	Moderate	Severe	Total
Bausewein, 2010[76]	2	2	4	63.8	49					69.0
Black, 2011[77]	1	2	1	75.7	71	21.1	26.8	21.1	31.0	78.9
Bradley, 2005[78]	2	2	1	69.0	1137	22.0	28.0	32.0	17.0	78.0
Clark, 2012[79]	6	2	1	70.5	3005	46.7	27.8	18.5	6.9	53.2
Elmqvist, 2009[80]	2	2	1	66.0	116			57.0[d]		
Gomez-Batiste, 2010[81]	2	2	1	72.2	202					62.3
Hamaker, 2011[57]	2	2	1	73.4	137					64.0
Jimenez, 2011[82]	2	2	1	66.0	406					80.5
Justo Roll, 2009[83]	4	2	1	59.0	91					41.7
Kang, 2013[84]	1	2	1	59.2	1612	8.4	20.3	31.6	39.6	91.5
Kirkova, 2012[85]	1	2	1	65.0	941					84.0
Kwon, 2006[86]	3	2	1	51.3	142	0.7	5.6	15.5	78.2	99.2
Lasheen, 2009[87]	1	2	1	70.0	30					60.0
McPherson, 2008[88]	1	2	1	68.0	66					69.7
Mercadante, 2013[89]	2	2	1	61.6	385	69.1	19.1	8.6	3.1	30.8
Modonesi, 2005[90]	2	2	1	67.0	162			40.0		67.0
Mystakidou, 2007[91]	2	2	1	63.2	82			68.2[d]		
Narducci, 2012[92]	2	2	1	68.0	68	45.6[e]		19.1	35.2	
Oi-Ling, 2005[93]	3	2	1	69.0	30					57.0
Park, 2006[94]	3	2	1	63.5	138				59.4	
Peters, 2006[95]	6	2	1	67.7	58					74.0
Saini, 2006[96]	2	2	1	63.0	11					55.0
Shin, 2011[97]	3	2	1	60.1	102	15.0	27.0	29.0	30.0	85.0
Spichiger, 2011[98]	2	2	1	63.7	103					71.2
Torvinen, 2013[40]	2	2	6	72.2	108					24.0
van den Beuken, 2007[41]	2	2	1	62.8	81			53.1		75.0
Wilberg, 2012[99]	2	2	1	64.0	99					43.3
Wilson, 2009[100]	1	2	1	67.2	381	29.7	36.5	28.6	5.2	70.2

[a]1 = North America; 2 = Europe; 3 = Asia; 4 = South America; 5 = Africa; 6 = Australia/New Zealand.
[b]1 = in-patient; 2 = out-patient; 3 = at home; 4 = hospice or palliative care unit; 5 = referred to palliative care service; 6 = all; 7 = other.
[c]1 = all; 2 = head and neck; 3 = gastro-intestinal; 4 = lung; 5 = breast; 6 = urogenital; 7 = gynecological; 8 = other.
[d]Moderate to severe.
[e]None or mild.

van den Beuken-van Everdingen MH. JPSM. 2016
doi: 10.1016/j.jpainsymman.2015.12.340.

Palliative Care Quality Domains

Table 2. Palliative Care Domains and Recommendations from the National Consensus Panel Guidelines.*

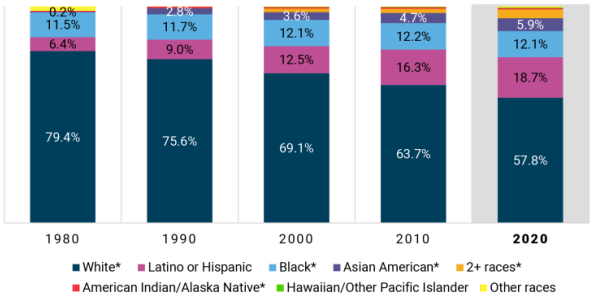
Domain	Key Recommendations
Structure and processes of care	Interdisciplinary team, comprehensive interdisciplinary assessment, education and training; relationship with hospice program
Physical aspects of care	Pain and other symptoms are managed with the use of best practices
Psychological and psychiatric aspects of care	Psychological and psychiatric issues are assessed and managed; grief and bereavement program is available to patients and families
Social aspects of care	Interdisciplinary social assessment with appropriate care plan; referral to appropriate services
Spiritual, religious, and existential aspects of care	Spiritual concerns are assessed and addressed; linkages to community and spiritual or religious resources are provided as appropriate
Cultural aspects of care	Culture-specific needs of patients and families are assessed and addressed; recruitment and hiring practices reflect the cultural diversity of the community
Care of the imminently dying patient	Signs and symptoms of impending death are recognized and communicated; hospice referral is recommended when patient is eligible
Ethical and legal aspects of care	Patient's goals, preferences, and choices form basis for plan of care; the team is knowledgeable about relevant federal and state statutes and regulations

* Adapted from the National Consensus Project for Quality Palliative Care.[2]

Racial and Ethnic Inequities in End-of-Life Care

Changing US demographics – Increasing Racial and Ethnic Diversity

Figure 3. Race-ethnic profiles of US population, 1980-2020



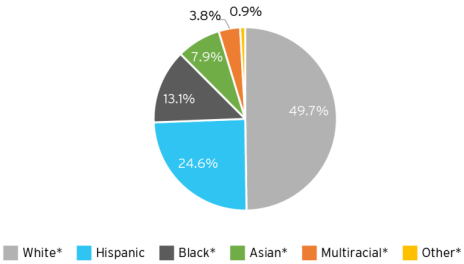
*non-Latino or Hispanic members of race group

Source: William H. Frey analysis of 1980-2020 US decennial censuses. Note: For 1980 and 1990, category 2+ races did not exist and Hawaiians/Other Pacific Islanders were included as part of Asian Americans.

Metropolitan Policy Program at BROOKINGS

FIGURE 1

Racial profile of U.S. population, 2045



* *Non-Hispanic members of race*

Source: William H Frey analysis of U.S. Census population projections released March 13, 2018 and revised September 6, 2018

Metropolitan Policy Program at BROOKINGS

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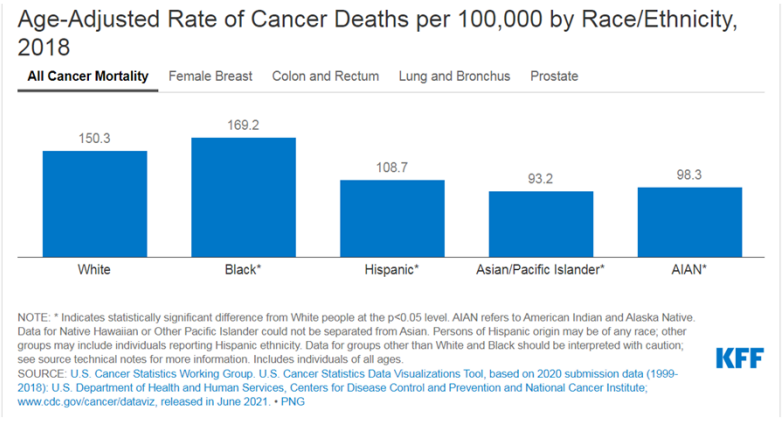
Black Americans are at the Highest Risk for Cancer Death



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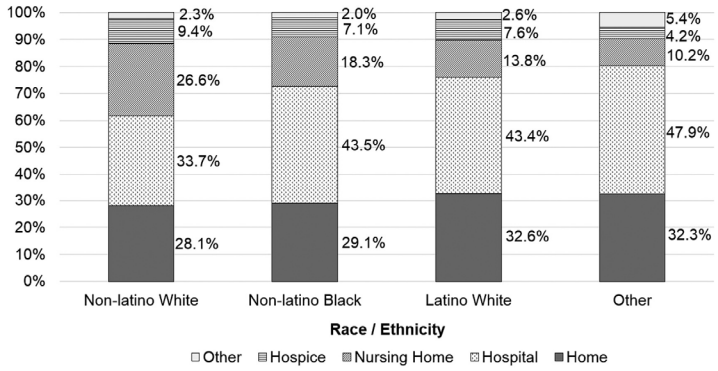
Racial and Ethnic Differences in Place of Death

Data from the Health and Retirement Study – Americans who died between 2002 and 2014



Orlovic M. SSM Popul Health. 2018 Nov 30;7:100331. doi: 10.1016/j.ssmph.2018.100331.

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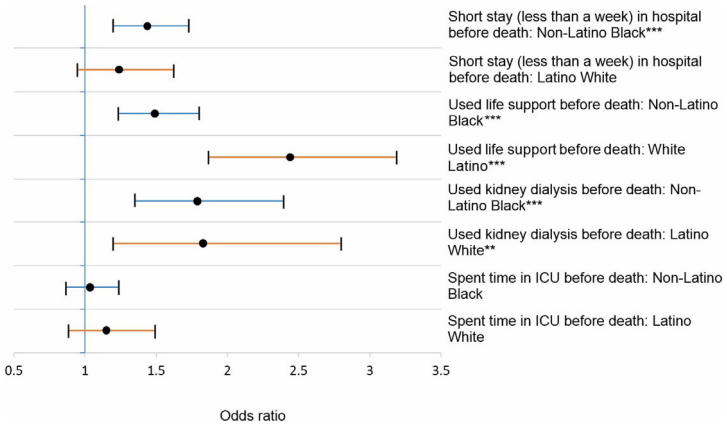
Racial and Ethnic Differences in Healthcare Utilization

Data from the Health and Retirement Study – Americans who died between 2002 and 2014



Orlovic M. SSM Popul Health. 2018 Nov 30;7:100331. doi: 10.1016/j.ssmph.2018.100331.

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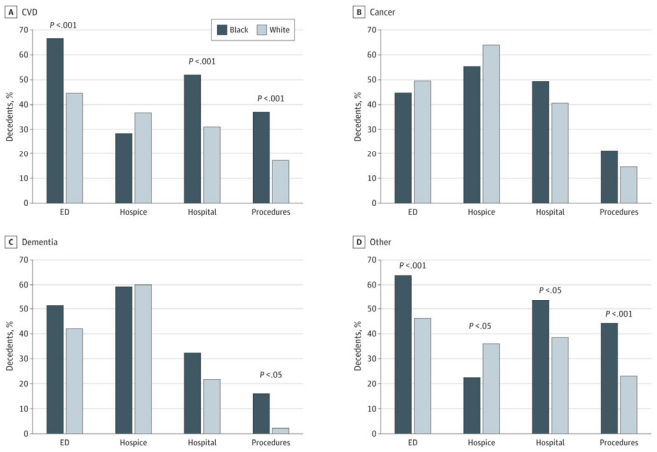
Racial Disparities in Hospice Use and Treatment Intensity

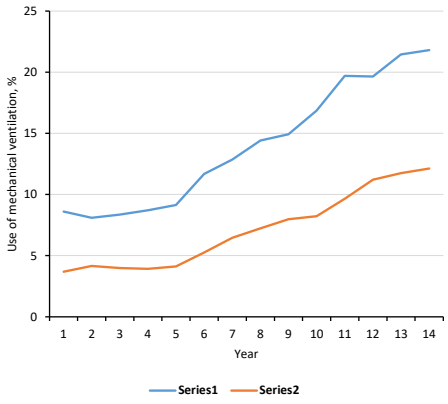
End-of-Life Health Care Use in the Last 6 Months of Life by Race and Cause of Death



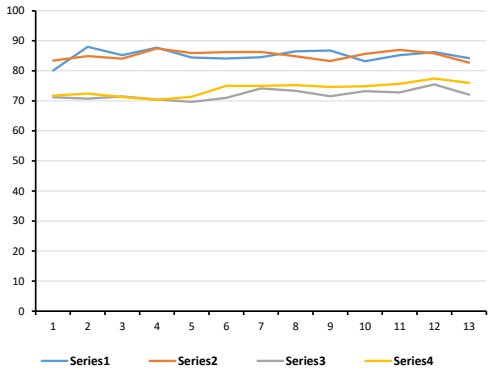
Ornstein KA et al. JAMA Netw Open 2020. doi:10.1001/jamanetworkopen.2020.14639

Black patients more likely to receive Higher Intensity EOL care

[A] Use of mechanical ventilation



[B] 1-year mortality



Sharma RK et al. J Am Geriatr Soc. 2020 Sep;68(9):2106-2111. doi: 10.1111/jgs.16635.

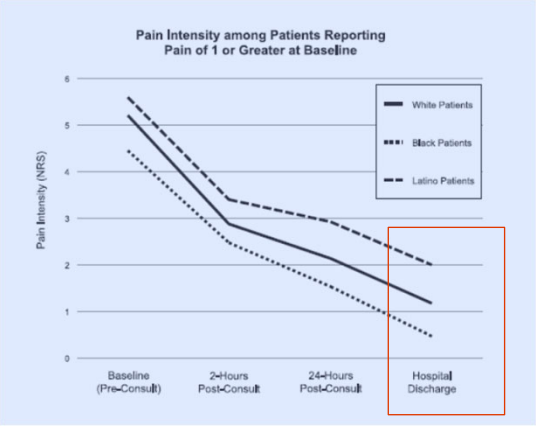
Racial and Ethnic Inequities in Assessment and Management of Pain

Pain Severity in Patients Undergoing Palliative Care Consultation

Patients undergoing initial palliative care consultation

	African Americans (N=681)	Whites (N=100)	P value
Palliative Performance Scale			0.49
0-30	35.6%	23.6%	
40-60	56.7%	66.2%	
≥70	7.8%	10.2%	
Pain			
Any	66.0%	56.1%	0.06
Moderate/severe	40.0%	34.5%	0.28

Kamal AH et al. Am J Hosp Palliat Care. 2017 doi: 10.1177/1049909116632508.



RR 0.38
95% CI 0.15-0.97

Laguna J. et al. J Amer Geriatr Soc. 2014 doi: 10.1111/jgs.12709

Pain Assessment and Management in Hospice

Data from 2007 National Home Health and Hospice Care Survey – Older Adults Receiving Hospice Care

	Pain assessment on hospice admission		Valid pain tool used	
Race/ethnicity	AOR	95% CI	AOR	95% CI
Black, non-Hispanic	0.26	0.11-0.65	0.95	0.66-1.39
Hispanic	1.19	0.16-8.78	1.18	0.60-2.31
Other	0.58	0.07-4.66	1.14	0.27-4.90

	Opioids		Non-pharmacologic	
Race/ethnicity	AOR	95% CI	AOR	95% CI
Black, non-Hispanic	0.82	0.59-1.14	0.80	0.55-1.18
Hispanic	0.62	0.40-0.97	1.18	0.72-1.94
Other	0.96	0.48-1.92	0.97	0.51-1.83

Cea ME et al. J Pain Symptom Manage. 2016 Nov;52(5):663-672. doi: 10.1016/j.jpainsymman.2016.05.020.

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Receipt of Opioids for Pain in Hospice Setting

Medicare beneficiaries 65+ enrolled in hospice between 2014-2016

Prevalence of opioid medication prescribing among older hospice beneficiaries				
Race/ethnicity	N	% prescribed opioid	AOR	95% CI
White, non-Hispanic (ref)	484,557	64.1	ref	ref
Black, non-Hispanic	42,656	57.9	0.75	0.72-0.77
Hispanic	10,694	54.3	0.74	0.70-0.78
Other	16,115	60.6	0.84	0.80-0.87

Gerlach LB et al. J Am Geriatr Soc. 2021 Jun;69(6):1479-1489. doi: 10.1111/jgs.17085.

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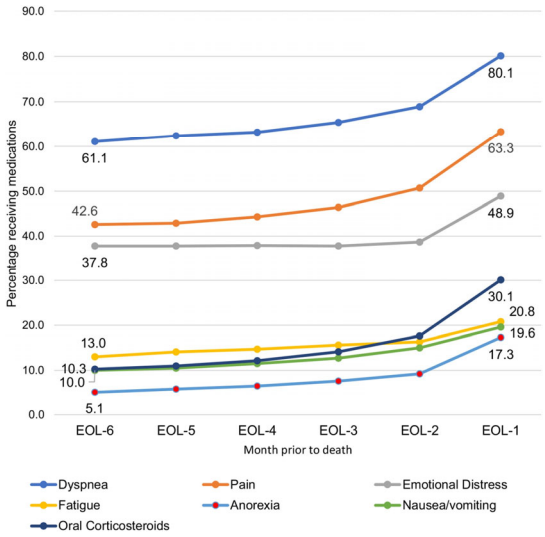
Receipt of Pain Medications in Patients with Advanced Lung Cancer



Adjusted RR of Medication Receipt Among Medicare Beneficiaries with Advanced Lung Cancer at EOL-1

	Any Pain Medication		
Race/ethnicity	RR	P	95% CI
Black, non-Hispanic	0.79	0.001	0.69-0.91
Hispanic	0.74	<0.001	0.63-0.87
Asian, other	0.57	<0.001	0.49-0.65

Saphire ML et al. J Pain Symptom Manage. 2020 doi: 10.1016/j.jpainsymman.2019.11.015.

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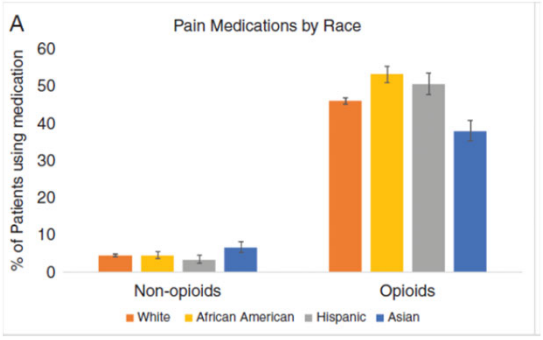
Receipt of Pain Medications in Patients with Brain Metastases

Table 3 Adjusted[a] use of supportive care medications following diagnosis of BM by race (OR = odds ratio)

	White	African American OR [95% CI]	P	Hispanic OR [95% CI]	P	Asian OR [95% CI]	P
Pain medications							
Non-opioid analgesics	Ref	0.89 [0.66–1.20]	0.44	0.69 [0.46–1.05]	0.08	0.97 [0.70–1.34]	0.86
Opioids	Ref	0.96 [0.85–1.08]	0.48	1.09 [0.94–1.26]	0.24	0.86 [0.75–0.99]	0.04



Lamba N et al. Neuro Oncol. 2020 doi: 10.1093/neuonc/noaa054.

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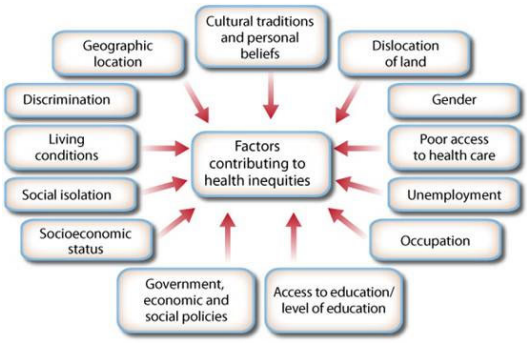
Drivers of Racial and Ethnic Inequities in End-of-Life Care

What Causes Health Inequities?

Structural inequities

Social determinants of health

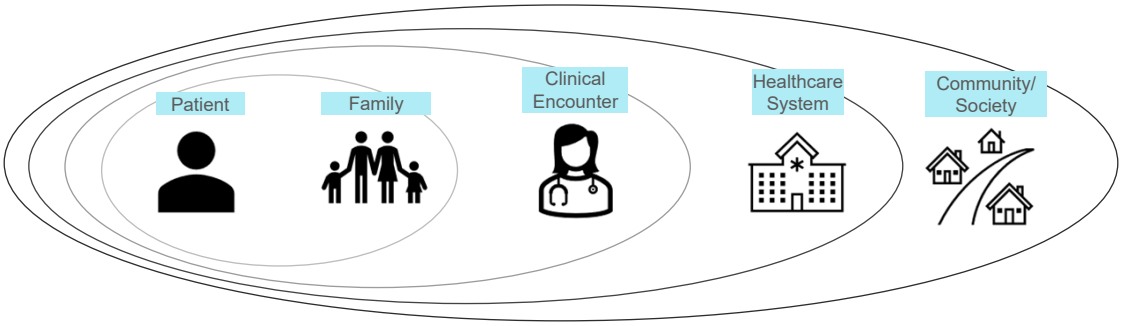
Healthcare disparities
- Clinician behavior
- System-level factors



RWJF Report - *Communities in Action: Pathways to Health Equity*

https://erol.side.wa.edu.au/

Multiple Levels at Which Inequities Occur



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Inequities in Access to Serious Illness Care

BARRIERS

Personal
- Acceptability
- Race/Ethnicity/Culture
- Language
- Literacy/education/income
- Knowledge/attitudes/beliefs
- Preferences
- Involvement in care
- Health behavior

Structural
- Availability
- Appointments
- Organization
- Transportation

Financial
- Insurance coverage
- Reimbursement levels
- Public support

Societal
- Historical discriminatory practice

HEALTHCARE MEDIATORS

Quality of Providers
- Cultural competence/humility
- Communication skills
- Clinical knowledge
- Technical skills
- Bias/stereotyping

Provider Characteristics
- Age
- Gender
- Race/ethnicity/culture
- Religion
- Knowledge/attitudes/beliefs
- Specialty

END-OF-LIFE CARE

Model of Care
- Palliative care
- Hospice
- Acute medical care

Care Intensity

Care Duration

OUTCOMES

Health Status
- Mortality
- Quality of life
- Symptoms (Pain)

Patient Experiences
- Satisfaction
- Goal-concordant care

Laguna J. et al. Home Health Care Serv Q. 2012. doi:10.1080/01621424.2011.641922

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Patient-Level Barriers – Perceptions of Black Patients with Cancer

Barrier	% agreeing with statement	Mean, SD
People get addicted to pain medication easily	85.6	3.5 ± 1.8
I do not like taking pills	81.0	3.4 ± 2.0
Constipation from pain medicine is really upsetting	76.0	3.4 ± 2.1
If you take pain medicine when you have some pain, then it might not work as well if the pain becomes worse	63.5	2.4 ± 2.1
It is more important for the doctor to focus on curing illness than to put time into controlling pain	60.2	2.4 ± 2.2
Drowsiness from pain medication is really a bother	59.0	2.2 ± 2.1
Nausea from pain medicine is really distressing	53.8	2.0 ± 2.1

Barrier	% agreeing with statement	Mean, SD
Having pain means the disease is getting worse	53.3	1.8 ± 1.9
Confusion from pain medication is really a bother	48.6	1.7 ± 2.0
It is important to be strong by not talking about pain	43.8	1.4 ± 2.0
Pain medication cannot really control pain	42.9	1.5 ± 1.9
It is easier to put up with pain than with the side effects that come from pain medicine	39.0	1.3 ± 1.9
Pain medicine often makes you say or do embarrassing things.	10.5	0.7 ± 1.5

Yeager KA et al. JPSM. 2019 doi: 10.1016/j.jpainsymman.2018.10.491.

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Concerns about Pain Medications Among Black and Hispanic Patients with Metastatic Cancer

TABLE 4
Percentage of African-American and Hispanic Patients with Disease-Related Pain Expressing Concerns about Opioid Analgesics

	African-American patients (%)		Hispanic patients (%)	
Concerns about pain medicines[a]	A lot	A little	A lot	A little
Be strong and not lean on pain medications	36	57	41	35
Concerns about tolerance	43	36	29	29
Worry about addiction	36	21	53	18
Worry that pain medicine will not work	38	31	12	59
Reluctance to complain about pain	29	43	29	29
Family concerned about pain medications	29	7	41	24
Concerns about side effects of analgesics	43	14	12	35
Wonder why doctor does not know about pain	31	46	18	18
Taking strong analgesic means death is near	43	0	18	18
Distract physician from treating the disease	21	21	12	41

Anderson KO et al. Cancer. 2002 doi: 10.1002/cncr.10414.

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Disparities in Opioid Analgesic Availability

Sociodemographic Characteristics	N	Pharmacies in Minority Zip Codes (N = 93)	Pharmacies in White Zip Codes (N = 95)	P Value*
Median zip code age (mean yrs ± SE)	188	32.3 ± 0.9	36.5 ± 0.5	<.01
Median zip code household income (mean $ ± SE)	188	$32,034 ± $2,076	$49,434 ± $2,160	<.01
Proportion of residents ≥65 yrs within each zip code (mean proportion ± SE)	188	.109 ± .008	.129 ± .005	<.05
Rural zip code (% yes)†	132	0.0	13.2	.28
Pharmacy type (% corporate)	188	64.3	59.9	.61
Hospital in the zip code (% yes)	188	31.7	43.2	.42

Table 3. Results From the Multivariate Models for Sufficient Supply

	Income Group*			
	≥ Mean Zip Code Income		< Mean Zip Code Income	
Predictor	Odds Ratio	95% CI	Odds Ratio	95% CI
White	13.36	(1.09-164.17)	54.42	(6.27-472.02)
Noncorporate	24.92	(3.03-205.18)	3.61	(1.11-11.77)
Median age	.77	(.60-1.00)	1.06	(.99-1.14)
Hospital in the zip code	.63	(.12-3.44)	2.01	(.62-6.52)

Green CR, et al. J Pain. 2005 doi: 10.1016/j.jpain.2005.06.002.

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Patient/Family-Level Barriers to Pain Management

- Fears/concerns:
  - side effects (common across racial/ethnic groups)
  - tolerance/dependency (possibly greater among minorities)
- Wanting to be self-reliant, not having to depend on meds to cope with pain
- Misconceptions; needing more information
- Hesitancy to report pain unless it's severe (stoicism)
- Wanting more individualized approach to pain management (not just guideline-based)

Clarke G et al. BMC Palliat Care. 2022 Apr 6;21(1):46. doi: 10.1186/s12904-022-00923-6.

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Clinician/Healthcare System-Level Barriers to Pain Management

- Clinical encounter level
  - Role of communication barriers: limited-English proficiency, low literacy
  - Inconsistent or limited use of pain assessment scales
  - Implicit bias – hesitancy to prescribe opioids, waiting until near end of life

- Healthcare system
  - Lack of system-level interventions to routinely assess pain
  - Barriers to navigating healthcare system (e.g., getting refills, etc.)

- Policy/Societal level
  - Barriers to access to healthcare (insurance, etc), cost of treatment
  - Disparities in opioid stock at local pharmacies

Clarke G et al. BMC Palliat Care. 2022 Apr 6;21(1):46. doi: 10.1186/s12904-022-00923-6.

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Addressing Racial and Ethnic Inequities in EOL Pain Management

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Patient-Level - Dimensions of Pain

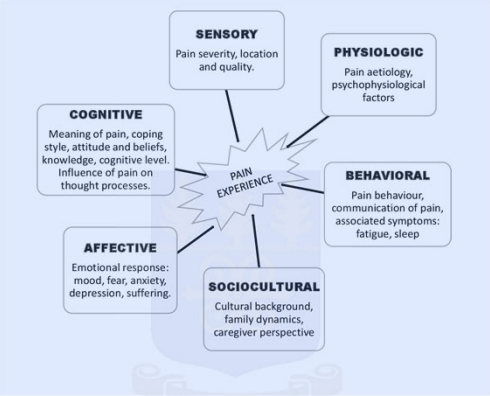
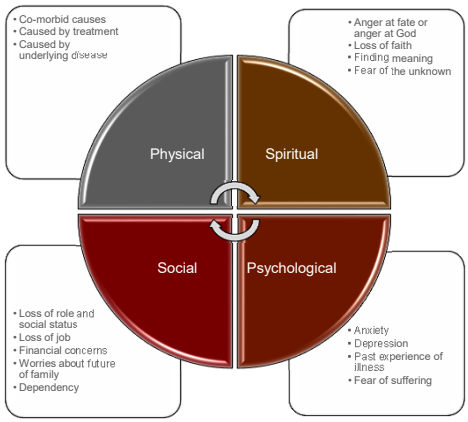


Figure 2. 1: ***Multidimensional Model of Cancer Pain***

Amenorpe, F.D. (2017). Chronic Pain Experiences Among Advanced Cancer Patients In The Accra Metropolis.

Cicely Saunder's Concept of Total Pain



Approaches to Equitable Pain Management

- **Conduct comprehensive assessment of all dimensions of pain**
  - Use standardized tools to assess physical pain (Numeric rating scale, visual analog scale, behavioral scales for patients who can't rate their pain)
  - Use cultural humility approach to explore sociocultural, psychological, and spiritual aspects
  - Explore ways in which structural racism, past healthcare experiences, lack of trust may be contributing to dimensions of pain
- **Individualize pain management and consider pharmacologic and non-pharmacologic treatments**
- **Explore and address patient and family caregiver fears/concerns (e.g., side effects, dependency), misconceptions about pain management, gaps in understanding**

Approaches to Clinical and System-Level Barriers

- Use of standardized pain assessments for physical pain, assess routinely
- Clinician education about role of palliative care, moving palliative care upstream
- Implicit bias training, clinician education to address misconceptions about racial differences in pain and suffering
- Leading clinical interactions with respect (e.g., addressing patients by their surname, asking permission to engage and to touch, etc.)

Rosa WE et al. Health Affairs 2022. doi 10.1377/forefront.20220207.574426

Approaches to Clinical and System-Level Barriers

- Good patient- and family-centered communication practices
  - Explain information clearly, repeat as often as needed to ensure understanding
  - Use trauma-informed care approaches
  - Clarify values/goals

    "No one decision is right for everyone, as you think about your options, what's important to you?"

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Approaches to Community/Societal Barriers

- **Policy/Payment reform**
  - Improving health insurance coverage, Medicaid expansion
  - Decreasing cost-sharing for high value services such as palliative care
- **Addressing structural racism and its role in:**
  - Inequitable distribution of opioids to local pharmacies
  - Financial toxicity for patients with serious illness
    - Consider screening tools like the Comprehensive Score for Financial Toxicity, PRAPARE, Health Leads' Social Needs Screening Toolkit
- **Diversification of the healthcare workforce**
- **Support research that engages minoritized communities, increase systematic collection of race and ethnicity data for people with serious illness**

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Summary Points

- Pain is one of the most common symptoms for patients with serious illness and at the end of life; many patients experience moderate to severe pain
- Assessment and management of pain is an essential component of high quality palliative and end-of-life care
- Racial and ethnic differences occur in multiple domains of end-of-life care; these differences likely reflect inequities that occur at the patient/family, clinical encounter, healthcare system, and community/societal levels
- There is mixed data about the extent of racial and ethnic inequities in assessment and treatment of end-of-life pain; certain populations experience inequitable care
- Multi-level interventions are needed to address drivers of racial and ethnic inequities – key strategies include: standardized pain assessment, patient- and family-centered communication, addressing clinician implicit bias, and policy reform to address structural racism and improve access to healthcare

Thank you!

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