National Scan on Improving Care for Black Patients:
Key Findings and Opportunities

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Speakers

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Why CAPC? Why Now?
Ethos of Palliative Care

- **Belief** in intrinsic value of each human life.
- **Goal:** To restore agency, meaning, purpose, and quality of life to people with serious illness.
  - Regardless of who they are, what they look like, where they live, or how they are viewed by society.
- **Racism** is counter to these principles
- **CAPC is committed** to bringing an anti racist perspective to our work by building tools, training, and technical assistance - and a diverse and inclusive community - to support equitable delivery of palliative care.
Countering the impact of racism on the quality of serious illness care is a priority for CAPC.
Why focus on Black people with serious illness?

- Evidence base documenting ubiquitous disparities in the care received by, and experiences of, Black patients
- A targeted approach > maximize the impact of CAPC’s efforts
What we will cover today:

- **Environmental scan**: CAPC initiative to characterize care disparities, and identify promising health equity interventions

- **CAPC Change Model**: What are opportunities to reduce racial disparities in palliative care for Black people with serious illness?

- **Call to Action**: How can you and your organization engage with CAPC resources to improve care for Black patients and their caregivers?
Thank you to the CAPC Equity Steering Committee and Funders

Findings from Literature Review
Literature Review

To understand current disparities for Black people living with serious illness →

Research Questions:

1. What goes wrong within the US healthcare system for Black people living with serious illness and their families?

2. What interventions have been tried to improve access to high-quality care, and what is known about obstacles and facilitators to their implementation?
Pillars of Literature Search

Serious Illness

Serious Illness, Palliative Care, Advanced Illness, Hospice, End of Life

(Based on NCP Guidelines Systematic Review search terms)

Patient Population

African Americans, Black, Minority, Race

Adult Only

United States

Aspects of Care

Communication, Caregivers, Symptom Management, Pain Management, Culturally Competent Care, Spirituality, Psychosocial Support
Literature Review Findings: Compared to white patients, Black patients with serious illness experience:

- Poorer pain/symptom management
- Poorer communication with clinicians
- Lower utilization of hospice
- More adverse impact on caregivers and finances
Promising Interventions
Identifying Promising Interventions

- ~160 interventions identified
  - Catalogued interventions from peer-reviewed and gray literature and questionnaire
  - Fielded a national questionnaire to more than 100,000 health care professionals to ascertain existing interventions

“Has your team planned or implemented an initiative to improve care specifically for Black patients with serious illness and their caregivers?”

Several hundred responded, “We treat all patients the same.”
## Identifying Promising Interventions

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<td><strong>1. Staff Education and Workforce Diversity</strong></td>
<td><strong>2. Data Collection + Identifying Unmet Patient Need</strong></td>
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<td><strong>3. Community Health Workers and Care Navigation</strong></td>
<td><strong>4. Improving Knowledge and Use of Palliative Care and Hospice</strong></td>
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<td><strong>5. Faith and Community Engagement</strong></td>
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Highlighting Promising Interventions:

- Overview
- Impact/Data outcomes
- Feasibility
- Scalability
- Sustainability
- Key Advice
- *Team contact information*

https://www.capc.org/innovation-hub/
Patient Perspectives and CAPC Change Model
Patient and Caregiver Feedback

- 18 participants identified; 2 focus groups conducted

“Given your lived experience, would these interventions have meaningfully changed your experience with serious illness?”

**Patient Priorities:** faith and community engagement, staff education and workforce, and **financial toxicity**
Patient Perspectives

Workforce Diversity
Because of historic mistrust of the medical and scientific arenas that many in the Black community hold, having a qualified, professional HCW/advocate of the same racial/cultural background tends to put patients, caregivers and family members more at ease to trust the care they are receiving.

Faith-based Communities
As a culture, we spend time in faith based organizations. And sharing stories, going through care for loved ones this can be new, unknown, very scary. Being able to tell stories, educate and enlighten people in a safe, faith based setting can be helpful.

Financial Toxicity
There should be a model that proactively educates people on how to ask for financial assistance. If you don’t have somebody to ask for you, you go into debt.
Socio Ecological Model: What contributes to lower quality serious illness care for Black patients?

**Structural Racism**

- Policy/System Level
  - Inequities codified in law, housing, education, income, judicial system, healthcare financing

- Community Level
  - Unequal allocation of resources leading to access barriers

- Organizational Level
  - Unconscious bias, discrimination, segregated workforce, trustworthiness, financial disincentives

- Interpersonal Level
  - Financial, Educational Barriers

- Individual Level

**Inequitable Serious Illness Care Across Domains**
What can be done to mitigate impact of racism? CAPC’s Approach

**Structural Racism**

- **Policy/System Level**
  - Community Level
  - Organizational Level
  - Interpersonal Level
  - Individual Level

**Health Care Organizations and Clinicians**
- **Training** - on racism and its impact on health care; unconscious bias
- **Measurement** - documenting disparities and impact of quality improvement efforts
- **Workforce** diversification and pipeline
- **New model** implementation

**Policy/Advocacy:**
- Workforce
- Payment
- Standards/Quality
Policy Recommendations
## Health Equity Policy Examples

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<th>Problem:</th>
<th>Examples:</th>
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| Pain and symptom management | ● Standardize use of symptom assessment in Medicare Advantage (federal regulation)  
● Enable exceptions to opioid restrictions for people with serious illness (state regulation) |
| Clinician-patient communication | ● Utilize the “heard and understood” measure (NQF 3665) in Medicare value-based purchasing programs (federal regulation) |
| Caregiver Support | ● Standardize the use of caregiver burden assessment in Medicare Advantage (federal regulation)  
● Promote caregiver respite and support in Medicare Advantage supplemental benefits (federal regulation) |
| Access to palliative care | ● Require access to palliative care in order to participate in accountable care models (federal regulation) |
| Financial Toxicity | ● Expand access to aging service programs (federal and state budgets) |

Health Equity Policy Recommendations (full list) [https://www.capc.org/documents/1064](https://www.capc.org/documents/1064)
A Call to Action

1. Review the models in CAPC’s Innovation Hub (what is feasible in your context)
2. Download the Community Asset mapping activity
3. Review policy priorities for addressing disparities
4. Attend a CAPC Virtual Office Hour to discuss equity initiatives with peers
5. Join CAPC’s online discussion board for equity champions
6. Review FAIR Health Consumer materials (tools to plan for costs of care/make healthcare decisions)
7. Stay tuned for 2023 CAPC resources:
   a. Roundtable discussions on key strategies to address racial disparities
   b. Comprehensive tools and training on how to replicate equity initiatives
THANK YOU!

Questions?

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