

Community-Based Study: Prioritizing Dignity and Respect in End-of-Life Care for Black Chicagoans



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INTRODUCTION

This report reflects the findings from an alliance between Arreola Research, The HAP Foundation, and NORC at the University of Chicago to understand the knowledge, attitudes, and behaviors of Black Americans regarding serious illness care in Chicago. The project will be referred to as the Dignity and Respect study throughout this document. The team consisted of Sonya Arreola from Arreola Research, an established community-based participatory research consultant, Kandis Draw and Kimberly Downing from HAP, and Stefan Vogler, Jocelyn Wilder, and Grey Pierce from NORC.



Kandis' Remarks

When approached by NORC to use my idea about Hospice and Palliative Care in Black Communities, I envisioned that the impact of this study would reach not only locally, but globally. It is no secret that this country was founded upon the systemic mistreatment and marginalization of Black and brown people. It is not the hearing of this that is alarming, it is the reality of this, which calls on the need for hospital administrators and care providers to address these injustices, beginning as early as medical school.

Dignity, love, and care are the basic needs of any human

being and should not be determined by skin color. Stigmatization and discrimination of people of color have led to barriers to and a fear of health services that create gaps in the access and utilization of care. Establishing trust becomes essential to bridging these gaps. It is my hope that through community-led projects we can become trustworthy, and thereby change how Black people view research; gain momentum for change in partnership with hospitals, clinics, and providers; and, more importantly, give communities of color assurance that while facing the end of life, there is hope.

-Kandis Draw, Community Research Liaison-Chatham & Englewood

"Although as Black People we had a dignity and a love of life, those qualities had to be defended constantly." —Maya Angelou



Why This Work is Important



Acknowledgement

We want to thank the participants of the Dignity and Respect study who shared their experiences with us. We cannot thank them enough for the time and truth they offered. Our goal is to use the knowledge and stories that were so graciously shared to reduce inequities in hospice and palliative care, draw attention to the existing disparities in service provision, and promote inclusiveness in health care.

Palliative care is specialized medical care for people living with serious illnesses like cancer or heart disease. Patients receive this medical care to ease their pain and symptoms, to receive treatment intended to cure their serious illness, and to receive emotional and social support for themselves or for their family members. Palliative care can start when the illness is first diagnosed. Hospice care is for people who can no longer be cured. Both types of care have a team of experts to help patients and their family members through the struggles and experiences associated with a serious illness.

Palliative and hospice services have been shown to be helpful in many medical situations. These services can improve a person's quality

of life, lower the chances of experiencing depression, and support those at the end of life to die with dignity. Studies also found that using these services in the community can save money on healthcare bills, reducing costs by about 36% and cutting down on hospital stays by 48%.

But even though these services are proven to be helpful during a serious illness journey, not everyone uses them equally. In 2020, stats showed that about 51% of white people on Medicare used hospice services, while only 35% of Black people did. Research has found several reasons for this, like Black patients' distrust of healthcare providers and discrimination in regards to hospice referrals.

The Dignity and Respect study shares stories from African Americans living in Chicago to show how these disparities affect real lives.



Research Framework for the Dignity and Respect study

➤ **Community-Based Participatory Research**

Community-based participatory research is when people from a community and an academic setting work together as equals in a research project. They make decisions together and share everything about the research. The goal is to form a partnership that uses all the wisdom to address a community need, while the information and results are shared equitably among all involved.

➤ **Qualitative Research**

Qualitative Research is a way of studying and understanding real-world problems by collecting personal stories and experiences from people; making sure that the viewpoints of all participants are respected. The main goal is to gain a deeper understanding of a given concern based on individuals' subjective experiences. Qualitative research looks at "how" and "why" certain things happen.

➤ **Recruitment**

Recruitment is how the research team asked people to join the study. In this project, we used informational flyers that we posted in many places in Chicago like libraries, e-newsletters, health fairs, and community groups. Each participant chose to join the Dignity and Respect study.

➤ **Inclusion Criteria**

Research studies usually have specific qualities or traits that a person must have to be part of the study. In the Dignity and Respect study, the researchers only included Black individuals who either had a serious illness or had taken care of a Black person with a serious illness. Also, to be in the study, you had to be at least 18 years old and live in Chicago.

➤ **IRB Oversight**

IRB stands for Institutional Review Board. It's a group of people who are chosen to check and make sure that a research plan is safe and fair for the people who are taking part in it. This project was carried out while being monitored by the IRB to ensure that the rights and well-being of the participants were carefully looked after.



Research Framework for the Dignity and Respect study

➤ Data Collection: Focus Groups and Interviews

Information was gathered by having small group discussions called “focus groups” and also by talking to participants one-on-one in interviews. The researchers did this in four focus groups (two were online, and two were in person) and two interviews (one was online, and one was in person). In total, 18 individuals shared their stories and experiences for this project.

➤ Research Aims

The research aims are the main goals of the study. In this study, there were two:

1. To understand what Black Americans living in Chicago with serious illnesses, along with their families and healthcare providers, know, think, and do when it comes to hospice and palliative care.
2. To find out what things make it more difficult or easier for Black Americans in Chicago to receive the care they need for serious illnesses.

➤ Analysis

In the Dignity and Respect study, the conversations in the focus groups and interviews were recorded and written down word-for-word, which is called “transcribing.” After that, several members of the research team looked at the transcripts to find common themes or patterns in the discussions. They grouped these patterns together into categories, which are called “codes.” This way of analyzing the data is called an “iterative collaborative inductive approach,” which means they kept reviewing and discussing the data to uncover new insights.

➤ Study Results:

“Participant demographics” refers to information about each participant, such as their age, gender, ethnicity, where they live, and other personal characteristics. This data helps researchers understand more about the backgrounds of the individuals involved in the research.

	FOCUS GROUP		IN-DEPTH INDIVIDUAL INTERVIEWS
	≤50	>50	>50
Women	4	11	2
Men		1	
Age Range	32-50	62-78	65-73



Research Framework for the Dignity and Respect study

➤ Themes and Codes Utilized in Transcript Review

“Themes and codes utilized in transcript review” means that when the researchers looked at the written records of the conversations, they identified specific themes or topics that were mentioned in the discussions. They also assigned codes or labels to these themes to help organize and categorize the information, making it easier to analyze and understand the key points and ideas that emerged from the conversations. This process helps researchers identify patterns and important information within the data.

THEMES	CODES
HAP KAB	Providers
	Family
	Person with Serious Illness
MEDICAL CARE SYSTEM	Institution
	Quality of Care
	Competing Priorities
CARE GIVING	Who / Why
	Burden of Care
DEATH & DYING	Fear
	Passing / Transition
	Communication
	Peferences
	Decision Making
RACE	Race
	Culture
SPIRITUALITY / RELIGION	Spirituality
RECOMENDATIONS	Recomendations

*HAP KAB means Hospice and Palliative Knowledge, Attitudes and Behaviors



Key Findings

Key Findings - 1

Participants knew different things about palliative and hospice care.

1. Participants knew different things about palliative and hospice care.
2. Some participants said they couldn't receive hospice and palliative care when they needed it.
3. People who were seriously ill and those taking care of them had to deal with many important issues and events happening at the same time.
4. Some participants experienced racism and noticed they were treated differently than white people.

Summary

Individuals who participated in the Dignity and Respect study, just like most Americans—weren't entirely sure about the details of hospice and palliative care. Regardless of whether they could name these types of care, they all believed that everyone deserves to be treated with dignity when they're near the end of their life. This means having open, honest, and respectful communication between the patient, their family, and the healthcare team.

Some of the stories that were shared in the study showed that when there's poor communication between a seriously ill patient, their family, and the healthcare team, it can lead to a lack of dignity during the patient's final moments. This also leaves the family members with a heavy burden of knowing their loved one didn't have a peaceful passing.



Quotes Related to Finding 1

- I don't know much about either one, I know people who have had [hospice in] their living room and had a hospital bed moved into their house, so that they would still be at home, and relatives could care for them, while they were at home. That's all I know about it. I guess.
- I just want to say one other thing. One thing that when they offer palliative care, they have to be very careful that it's really not hospice care. Because sometimes people say we're just going to do palliative care, but then all of a sudden you see it's not palliative care, it's hospice care. I mean it could be a very thin line with that. Because look, hey, sometimes they need more, and the doctor has already recommended that this person is not going to make it and we need to move them into hospice.
- I don't want to bash doctors. Some of them need to take some customer service class. [laughter and talking] I'll tell you. You're [the] patient and you're [a] customer, and without the customer you don't have a job, so they do need to learn--some of them--a little bedside manner and you know smile, and patting you on my hand? You know, it doesn't take anything away from them to be kind.
[all agree]
- I'm not familiar with what palliative care is or who determines when palliative care is needed and for how long. So I guess I'm more curious how that is determined, what the limit of palliative is, how does palliative care move from that phase to the next phase.
- To me it means maintaining an individual's quality of life as much as you possibly can. From the time [they] become that ill until the time they transition, and particularly important to me is maintaining that person's dignity. Because that's what they really want to be left with, as long as they can be left with that, I think they are really okay.

Interviewer: And why do you think that [hospice and palliative care] is something our community does not know about?

Participant: Because we haven't had access to that. I'll say the obvious, racism. Even fools will say that. We haven't been given...the respect even in death. Because black lives don't matter. I mean in short, even in death they don't think that we matter.



Key Findings

Key Findings - 2

Some participants said they couldn't receive hospice and palliative care when they needed it.

1. Some healthcare providers continued medical treatment even when the patient with a serious illness wanted to stop curative treatment.
2. Some patients with serious illnesses didn't get enough help with managing their pain.
3. Some patients with serious illnesses had to wait a long time before they were offered hospice care.

Summary

Many articles talk about problems around the world that make it difficult for people to access hospice and palliative care. Some of these problems include people's negative thoughts about hospice, doctors who feel uncomfortable talking about terminal illnesses, and physicians who worry about losing control or guessing incorrectly about how long someone will live.

But in the Dignity and Respect study, another problem was mentioned. Many participants told stories about how they talked with their healthcare team about their changing care goals—from trying to cure their illness to focusing on comfort and quality of life. However, their healthcare team didn't always listen to these new goals. This raises questions about how well

Black patients, their families, and healthcare teams communicate with one another, especially when they decide not to continue very aggressive treatments.

Research has also shown that Black individuals often get treated unfairly in healthcare, especially in regards to managing pain. Some of the stories in this research reinforced the reality of this experience for Black people with serious illnesses.

Lastly, some stories mentioned that people didn't receive referrals for hospice care until very late or not at all. This led to receiving care that didn't match what they wanted for themselves or their family member. Late referrals also made people less happy with the quality of the care they received.



Quotes Related to Finding 2

- *Tell me more about the patient wanting palliative care when the surgeons and the physicians were pressuring to continue treatment.* “I decided I didn’t want what the doctor was offering. They really got mad, saying ‘we are going to put a crash cart outside your door because this is going to happen.’ They wanted to give her surgery, knowing that she was dying. We said no. It’s cruel to prolong her life maybe for another week to get the money.
- “It’s when you know the end is near and you want to have comfort in your final days; it’s about dignity... not being in a hospital or a nursing home, where you might not have the care you need, or the love, the attention. ... your family members, sitting with you. That’s dignity; not to die in a cold room somewhere.”
- “And couple of weeks ago, my neighbor passed and she’s been my neighbor for over 52 years, and her daughters were there every day, all day, with her. At the very end when she was so sick they kept taking [her] back and forth to the hospital; they never got a hospice nurse at the house.”
- I was actually sitting next to my grandmother, and it was happening [she was dying], and I knew it was happening [but] I didn’t know to call the nurse to call the ambulance. [My grandmother] was in so much pain that night all I could do was play music [and] sit next to her bed. I had called the hospice nurse, is there anything else I can give her? [But] I had given her the maximum morphine. I just listened to her crying and wailing in pain and [when] she started seeing deceased family members, I knew it wasn’t going to be long.
- Doctors ...will let them hang on in the hospital, maybe doing different tests or something that’s unnecessary, instead of saying, “Okay, they got a few months to live”. We need put them into hospice care now, where they can enjoy and get the pleasure of the last few months being cared for by caring people.

Participant: I went there one day and they had him in there giving him dialysis, [he was] already in a comatose state or whatever. [A provider] had him hooked up and everything, and he was drooling and he had no control over anything. Drool all down his face and everything, I told them right then and there, you can disconnect him right now. I don’t want him to have any more dialysis while he’s here. I don’t want him to have him to have anymore because that was very disrespectful of what he had wanted. He was laying there unconscious and drool all this and down, running out of his mouth and everything. You know that really upset me.

Interviewer: I can see how that would be very upsetting. What did they offer you? Did they offer you hospice or palliative care?

Participant: They never offered hospice or anything. I imagine they knew it wasn’t going to be many days, he only lasted about five days there...They knew he wasn’t going last too long with the condition he had, with the sepsis.



Key Findings

Key Findings - 3

People who were seriously ill and those taking care of them had to deal with many important issues and events happening at the same time.

1. Some seriously ill patients wanted to stop their treatment, but they felt torn. They thought that choosing hospice or end-of-life care meant they were giving up, losing hope for healing, or leaving their families behind.
2. Caregivers had mixed feelings about supporting the seriously ill patient's decision to stop treatment, especially when it came to their spiritual beliefs.
3. Healthcare providers also seemed to have conflicting feelings. They had to balance recognizing a patient's choice to stop treatment with their own wish to cure the patient.

Summary

In our society, talking about death and dying is really difficult, even though it's a natural part of life. The medical system often uses words that make families feel like they're giving up when they consider hospice care, saying "there's nothing else that can be done." But hospice is just a different kind of care for people with serious illness. Hospice care is not the same as doing nothing.

Being able to talk openly and without judgment about death and dying, called "death literacy," is important for everyone, especially doctors, who often lead end-of-life care or discussions about end-of-life care.

Hospice care should respect the beliefs and goals of care of the patient and their family, and should never take away hope, even if that hope is no longer about curing the illness. There can still be other important moments that give hope to individuals and families.

Talking about death and making hospice care centered around the patient are challenges that affect everyone, but when you add in racism, it makes these conversations even more difficult and painful for communities trying to make the best choices for patients and families.



Quotes Related to Finding 3

- But I've found that just my own experience, some of the doctors around even want to [continue aggressive therapies], especially if you are talking to surgeons. They want to operate. Let's take it out.
- A lot of the time there is a lot of resistance there though, because they don't want to accept the fact that they are going to die. Even though the doctors have told them, they want to hold out hope that prayer changes things. And yes, prayer changes things, it also changes you in the process.
- What she just described, the patient themselves--if they are spiritual--already talked to their maker. They are ready to go. That's my first point. When they said they don't want anymore they really don't want anymore. They're tired. [agreement] We want more for them, we're not ready, but sometimes we just have to let their will be. It's between them and their maker.
- **Interviewer:** You know we talk about fear too. I wonder, for your friend at the hospital, with a different doctor every day telling her different thing to do or a different medicine to try, what she expressed to you? I'm curious if she spoke to you about her experience?
Participant: Yes, she was afraid that she was taking too much medication, that she was taking medication and [it] was being changed before the last medication was allowed to even work. Then all of a sudden, she was taking a test. I'm like, what was that test for? Nobody even explained what the test was. I just guess in my mind was thinking at one time, "Oh boy, you're just a guinea pig." Right here, they are testing different things they haven't really used on anyone else. Yeah, it was a fear. She wanted to leave the hospital, but she wasn't well enough to go home.
- **Participant:** I had another lady from my church that I was kind of seeing after, you know. She was at [a local hospital], and it was awful. It was just awful to me the way that she was treated. She wasn't the easiest person to deal with, okay, but still she needed to be, you know, respected.
Interviewer: Tell me about that, what did you observe about her treatment about what the doctors were saying?
Participant: I thought they were always very short with her. They didn't explain anything to her. They were very short, very rude. I've always thought when you're in the hospital, you know the doctors and the nurses have the control. Okay, so you really have to, you know, listen to them. And I think she was angry, but she was sick too. But yeah, I just couldn't handle--you know-- the way they were so short with her.

But I think with palliative care, with end of life care, even the communication between the doctors--the medical side of it with the family--is not always there, or [it] is not as concrete as it should be.



Key Findings

Key Findings - 4

Some participants experienced racism and noticed they were treated differently than white people.

1. Black patients with serious illnesses and their families were treated differently when it came to managing pain compared to white patients.
2. Healthcare providers approached and talked about treatment differently with Black patients and their families compared to white patients.
3. Black patients with serious illnesses often felt like the burden was on them to understand the complicated language and terms used by healthcare providers.
4. In hospice care, there wasn't always room for a person's faith or spirituality.

Summary

Systemic racism is described in a report by the Robert Wood Johnson Foundation as the hidden, deadly base of an iceberg. Many times, it's not obvious to people who aren't affected by it. It includes laws, rules, practices, cultural norms, and everyday things in life that make racism a part of our lives. For example, unfair lending practices, schools that don't receive enough resources, neighborhoods where people of different races live separately, and unequal access to good healthcare.

Studies have clearly shown that structural racism affects the health of both groups of people and individuals. In the world of serious illness, there's

clear evidence of unfair access to hospice and palliative care in communities of color. These disparities can be seen in many illnesses that could be helped by palliative care, like certain cancers, kidney disease, heart disease, and prostate cancer, among others.

The participants in the Dignity and Respect study discussed how racism was a part of their healthcare experience. They noticed that they were treated differently, offered different care options, and had a difficult time receiving care in comparison to white people.



Quotes Related to Finding 4

- **Interviewer:** So do you think that race, that being non-white plays a role in a doctor's discussion of palliative care with patients?
Participant: Yes I really do.
Interviewer: How does that play out?
Participant: Like with my dad. It's the way they [took] care of [him]. The way they take care of you and the way they take care of the White patients—more of the consideration they give. It's time they spend in the room making sure that they [White patients] are comfortable, making sure that it's nothing. The pillows they fluff, or the room temperature is just the way it's supposed to be. Like around the clock service that they give to [White patients] to make them comfortable. Then you're [referencing a Black individual] sitting in the room with your family member and you're here every day, and...you have to tell a doctor "Can you come in and check this, can you come in and make sure he or she has this and this and this." They tell you "okay," [but] then you have to come out of the room and run around and look for them, and you turn around they are in the room with a White patient...they are constantly attentive to their needs.
- If you look for blatant differences [by race] you might not find them....if a [black] patient says "My stomach hurts," and the thought is ... 'we won't operate on this person, I'll get you something', but another person [White] they say 'let's take a scan, let's take the next step'. I think that's where[you] have to look.
- Why can't I get this medication, you've given that same person over [there]." Then a doctor will try to flip around like you don't understand what he's saying, like you're dumb. 'We can't give you this & this.' ...they have stereotypes ... if it's African Americans they assume they are going to get addicted or they are going to sell it.
- **Participant:** I think that also the one thing the medical profession does need to get over or release the stereotypes of – they do not treat all folks equal because that's exactly what the lady said just before that there's the thought that certain ethnicities will go into hospice or even go into the hospital and will not be treated the same, nor get the best medication or care.
Interviewer: Are there specific race and ethnic groups that get the short end of the stick?
Participant: Data would support that it happens with Black communities. That data has been out there for the last few years. Typically, even in emergency situations this has been very well established, it's not just an urban myth.

I think, and this is why it was important for me to go into this work, because I feel like— the care is not the same. We can establish that...The healthcare system [thinks] that we [referencing Black individuals] have a higher threshold for pain, so they don't medicate us as they should. That I saw up close with [my boyfriend]. Because certainly we can tolerate some things, not just because we're Black. [scoffs]. Pain is pain. But there's an assumption that, and this is my opinion, and this is neither this nor that, but it's because there's an assumption we can tolerate it and we don't need as much [pain management].

You [providers] are cutting our [referencing Black individuals'] health & our life expectancy short because of what [you] feel, not because of what is medically [needed]. A lot of doctors don't go by what they should do, they go by how they feel.





The participants made some suggestions for improving the experiences of Black individuals with serious illness.

1. Everyone, no matter their skin color, should be treated with kindness and respect. While it's important for healthcare providers to learn about different cultures, the most important thing is to be kind to everyone.
2. Some participants said they were treated badly or disrespectfully, but they didn't have anyone to talk to about it. If there was someone like a social worker or patient advocate who could listen to their concerns and help them, it might make their situation better.
3. Healthcare providers should be responsible for treating all patients the same, no matter their race. There should be clear rules and consequences if they don't treat people fairly, equitably, or respectfully.

Quotes related to Recommendations:

- I don't think there is enough cultural humility, & awareness taught in medical school. ...I don't know if they are mandated to take these classes or what type of classes folks can take to be more informed about how to work with a Black person. ... I'm not seeing the willingness to learn & adapt properly. Care for Black folks--maybe it's not valued.
- **Participant:** I think if [the medical system] had had an outreach person that could have come to the home, sort of like people would call a "well check" kind of thing, I think that would have been a real support. Would have come to visually see that person and see what kind of condition they are [in]. Kind of like, you know...maybe like a social worker, but I think that would be a big help.
Interviewer: Yeah, that makes sense.
Participant: Because a person like a social worker might see other things going on that the medical system is not looking at.



Closing Thoughts



In conclusion, the Dignity and Respect research project strongly highlighted to The HAP Foundation that structural racism is a significant issue in the already complex world of palliative and hospice care, whether in the hospital or community settings. The stories shared by the research participants give a personal and vivid perspective to support previously published scientific findings about disparities in hospice and palliative care. The Foundation hopes that this work will directly influence education in communities and clinics, and, most importantly, raise awareness about the vital importance of empathy, dignity, and hope for everyone.

On behalf of the research team, we invite you to keep discussing the impact of this work in your workplaces and communities. We are happy to share lessons learned and resources we are using to improve access to culturally sensitive, dignity-focused hospice and palliative care services.

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