



**For Immediate Release:**

July 23, 2024

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**The HAP Foundation begins new research study: “Black Caregivers in Chicago: Informing Resource Development for Community and Care Providers through Storytelling”**

*Grant funded through RRF Foundation for Aging; Collaborative project with NORC at the University of Chicago*

[The HAP Foundation](#) is conducting a qualitative research study to more deeply understand the experience of Black caregivers in Chicago. In this collaborative project with NORC at the University of Chicago, we aim to conduct focus groups and interviews to identify caregiver perspectives, needs, and burdens. This research study is funded by the [RRF Foundation for Aging](#) (RRF), a steadfast supporter of programs and research that significantly improve the quality of life for older people.

“As we aim to create an equitable health care system, we need to better understand racial disparities,” said Joseph Matty, President of The HAP Foundation. “Through community-based research, such as this study, we wish to better understand the experiences of caregivers in Cook County’s predominantly Black communities. Then, The HAP Foundation will use and share what we have learned from this research to create tools and engage with the community to stimulate change.”

The findings of the study will be shared with the community and clinicians with the creation of two tools, which aim to build and foster equity. The first tool, Caregiving Guidance, will include information to empower and support the health and wellness of those who care for someone with a serious illness. The second tool is Healthcare Teaching Resources, which will use the language and storytelling from the focus groups to enhance cultural humility and empathy in the healthcare environment.

Data from “[Community-Based Study: Prioritizing Dignity and Respect in End-of-life Care for Black Chicagoans](#),” a research collaboration between HAP and NORC, which examined attitudes and behaviors on hospice and palliative care among Black individuals in Chicago found that Black caregivers routinely faced lack of information and culturally insensitive communication. The poor communication and impact on caregiver experience was detrimental to their well-being. The magnitude of caregiver burden related to culturally insensitive communication and racism, along with the complex grief associated with an unsupported death of a family member has significant, long-lasting health impacts for caregivers.



[thehapfoundation.org](http://thehapfoundation.org)



“By providing education and fostering community-based partnerships, I am addressing a vital aspect of health care that often goes unspoken—end-of-life issues and the families affected by them,” said Kandis Draw, Community Health Worker, Southside of Chicago with The HAP Foundation. My interactions with caregivers and those facing the challenges of serious illness have highlighted significant needs and perspectives within my community. My lived experiences of being a caregiver for my mother and sister has provided a lens and perspective that is often lacking to more deeply understand structural racism. My experience has turned into passion that is driving research to create change for other families like mine in Black communities.”

The projected timeline for completion is December 2025.

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***About The HAP Foundation:***

*The HAP Foundation is an independent nonprofit that provides education, advocacy, workforce development, and research on hospice, palliative care, and grief for all ages. With four decades rooted in direct patient care, it currently focuses on educating communities and professionals on hospice and palliative care; engaging in community-based research to better understand and impact disparities in hospice, palliative care, and grief support; increasing the Community Health Worker workforce to strengthen and share serious illness resources and education in the community; and advancing policies that assist individuals and families during end of life. Also, The HAP Foundation offers association management and consulting services. [www.thehapfoundation.org](http://www.thehapfoundation.org)*

