



New Focus Group Work Examines Perceptions Surrounding End of Life Care in Black Communities in Chicago

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NORC at University of Chicago, in partnership with The HAP Foundation, announces a research project that aims to better understand perceptions surrounding serious illness care in Black communities in Chicago. The intent of this study is to collect and then disseminate information to the community that might improve access to care and quality services at or near the end of life.

“We are very excited to launch this study that allows us to advocate for the needs of Black American community members,” said Kandis Draw, Community Health Educator and Research Liaison at The HAP Foundation. *“Health Disparities are a Public Health crisis. It is essentially critical that we are hearing the voices of those most affected by access to care with end-of-life issues. It is the goal of this study to discover the barriers related to hospice & palliative care from the perspective of Community Members and Caregivers. We anticipate that this study will provide insight into the lived realities of minority populations in the Chicagoland Area, and that the voices of those who participate might echo shared concerns beyond Chicago and even globally.”*

Prior research has consistently indicated disparate access to end-of-life care for older adults in Black communities (as compared to their white counterparts) regardless of diagnosis, geographic area or care setting. Multiple prior studies confirm not only access issues, but also lower quality hospice and palliative care for minority patients across multiple domains, including patient satisfaction, meaningful communication and pain management. While there are likely multiple, systemic, historical, personal, geographic and other reasons for this disparate access and quality of care, NORC and HAP are seeking to understand perceptions and experiences of the Black communities in Chicago, in hopes of applying and sharing this information to impact the issue in tangible ways. The information collected from the community through this project will be disseminated back into the community for continued conversation and brainstorming around potential actions to spur meaningful change.





Kim Downing, Executive Director of Program Evaluation and Research at the HAP Foundation, expressed gratitude saying, *“We are so appreciative of NORC and the team of researchers we have engaged with for their commitment to advancing important issues in the Chicago region through community-based participatory research. The opportunity to better comprehend one element of end-of-life care experiences in Black communities will contribute meaningfully to our continued efforts to create change. It is a sliver of a much larger pie we need to more deeply understand but NORC’s investment in this work is an important step forward.”*

This study will be implemented using focus groups and interviews with Black residents over the age of 18 living in Chicago and those who were caregivers for a Black community member at or around the end of life. If you are interested in participating in this research study, please email hapstudy@NORC.org. In gratitude for time shared, each community member who participates in a focus group will receive a \$50 Amazon gift card.

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The HAP Foundation

HAP Foundation is a non-profit, independent mission-driven organization. Its work is centered on education, advocacy, workforce development and research around hospice and palliative care, providing guidance, direction and support for pain management and a better end-of-life.

NORC at University of Chicago

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