

Community Health Workers (CHWs): A Key Ingredient for Culturally Affirming Serious Illness Care

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 **The HAP Foundation**
Hospice and Palliative Care Research & Education





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We are a non-profit, independent mission-driven organization. Our work is centered on education, advocacy, workforce development, and research around serious illness, providing guidance, direction, and support for pain management and a better end of life.

[Visit our website](#)



Objectives

- Discuss hospice care and palliative care and their benefits.
- Examine the current disparities in hospice utilization by racial group.
- Explore CHW programs as an intervention to address disparities.
- Learn about The HAP Foundation's Community Health Workers (CHWs).



Land Acknowledgement



- Chicago is situated on the traditional homeland of the Council of the Three Fires: The Odawa, Ojibwe, and Potawatomi (Bodéwadmi) Nations.
- Many other Tribes like the Peoria, Myaamia, Kaskaskia, Ho-Chunk, Menominee, Sac, and Fox also called this area home.
- Chicago continues to be home to many Indigenous Peoples who continue to practice their heritage, and traditions, and care for the land and waterways.

We ALL live on Indigenous lands. Visit <https://native-land.ca/> to find out on which traditional lands you live.



Labor Acknowledgement

We respectfully acknowledge our debt to the enslaved people, primarily of African descent, whose labor and suffering built and grew the economy and infrastructure of a nation that refused to recognize their humanity.



Hospice Care

- Hospice care is designed to give supportive care to individuals who are in the final phase of a terminal illness.
- Focus is on comfort and quality of life, rather than cure.
- Hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support.



Hospice Eligibility and Coverage

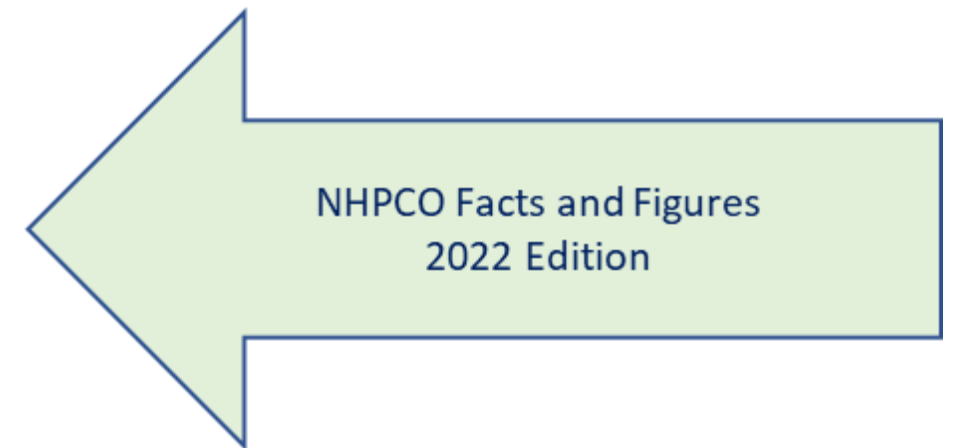
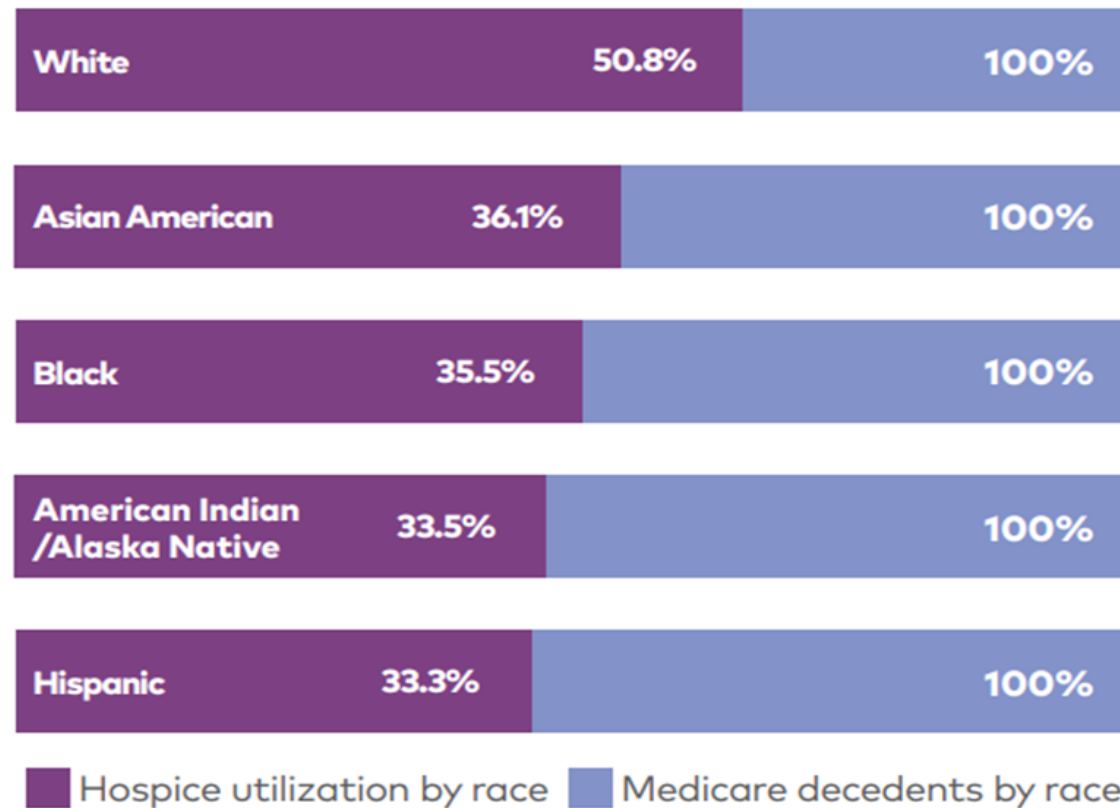


- Two doctors must certify that the patient has a prognosis of six months or less to live.
- Unlike palliative care, hospice is for those who are no longer pursuing curative treatments.
- Medicare Part A covers all aspects of hospice care and services, and Medicaid offers similar coverage.



Hospice Utilization Disparities by Race in 2020

Figure 9: Share of Medicare decedents who used hospice, by race



Source: MedPAC March 2022 Report to Congress, Table 11-3



Why Do Utilization Rates Matter?



Patients enrolled in hospice live an average of 29 days longer than those not enrolled in hospice.



Hospice patients experience better management of pain and other symptoms.



Patients receiving hospice care are more likely to remain at home and report having a better quality of life.



“Perhaps it goes without saying that the inequities historically underserved communities face throughout life continue through the end of life.”

(Addressing Inequities in End-of-life Planning and Care: Advancing Equity at Life's End Summit Report 2021)



Research Examining Disparate Use of Services in the Serious Illness Space

“Studies consistently document lower rates of hospice use for minority older adults than for whites across diagnoses, geographic areas, and settings of care, including nursing homes.”

--Johnson, K. “Racial and Ethnic Disparities in Palliative Care.” *J of Palliative Medicine*, 2013; 16(11) 1329-1334.

Advanced Care Planning study revealed that among the population surveyed, only 18% of minority participants had completed advanced directives while 34% of white respondents had done so

--Hong M. et al. “Facilitators and barriers for advanced care planning among ethnic and racial minorities in the US: A systematic review of the current literature,” *J of Immigrant and Minority Health*. 2017; 20(5) 1277-87

Black veterans with CKD experienced racism in the clinical setting that produced physical and emotional stress and a strong sense of distrust in the healthcare system

--Jenkins K, et al. “Perspectives on Racism in Health Care Among Black Veterans with Chronic Kidney Disease,” *JAMA Network Open*. 2022; 5(5): e2211900.



Research Examining Disparate Use of Services in the Serious Illness Space

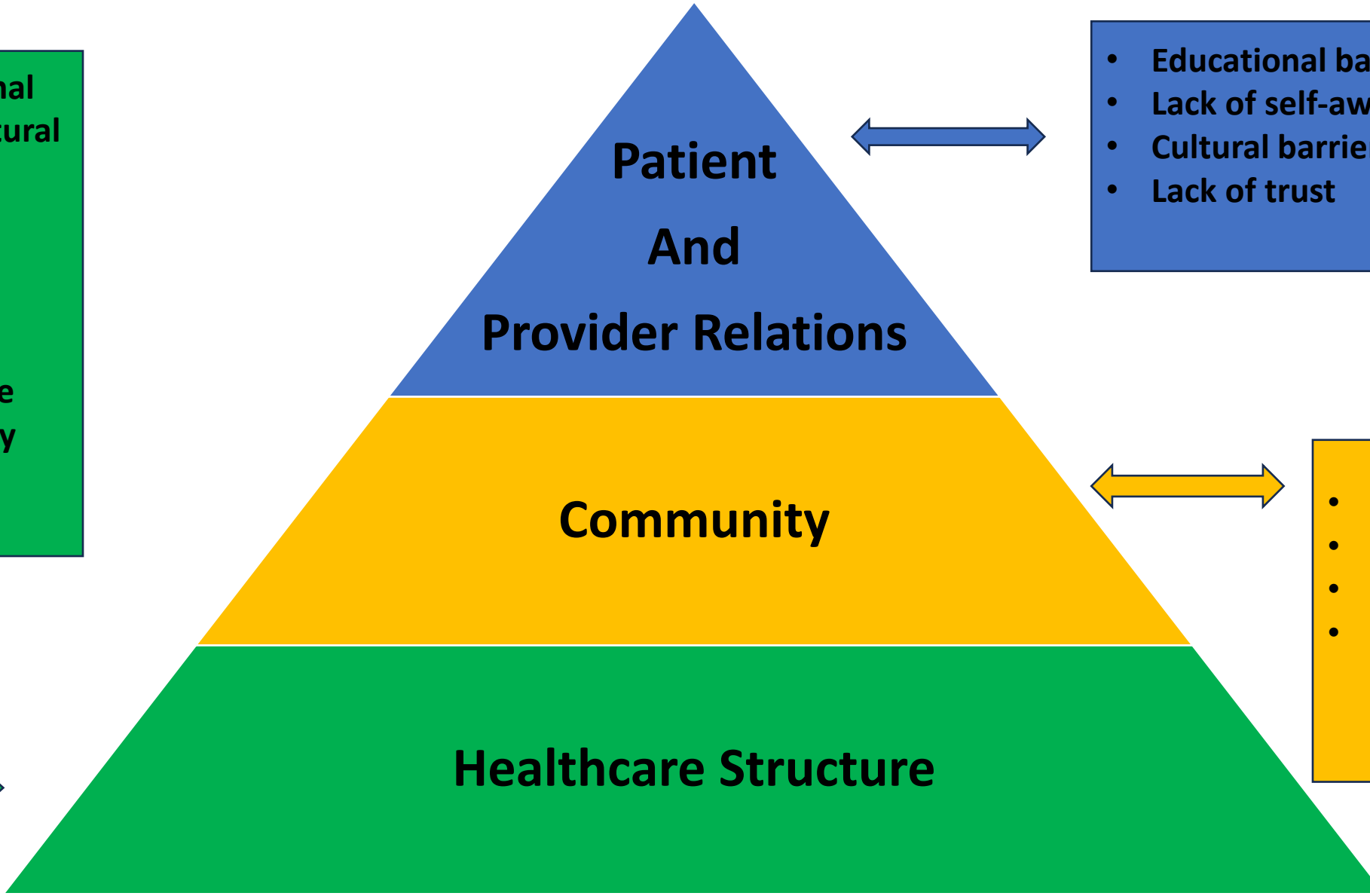
*The critical role of
communication in
disparate access to and
use of services*

© Randy Glasbergen for RapidBI.com



**"I'm inviting you to my seminar on Improving Your
Communication Skills. If you'd like to attend,
grunt once for yes or twice for no."**

- Institutional and structural racism
- Regional diversity
- Resource allocation
- Healthcare complexity



- Educational barriers
- Lack of self-awareness
- Cultural barriers
- Lack of trust



- Lack of resources
- Disinvestment
- Barriers to care
- Lack of prioritization

Implicit and Explicit Bias



Implications for Hospice Care

“I challenge us to change because as Charles Darwin once observed, ‘It’s not the strongest species that will survive, nor the most intelligent, but the one most responsive to change.’”

--Harriet Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*



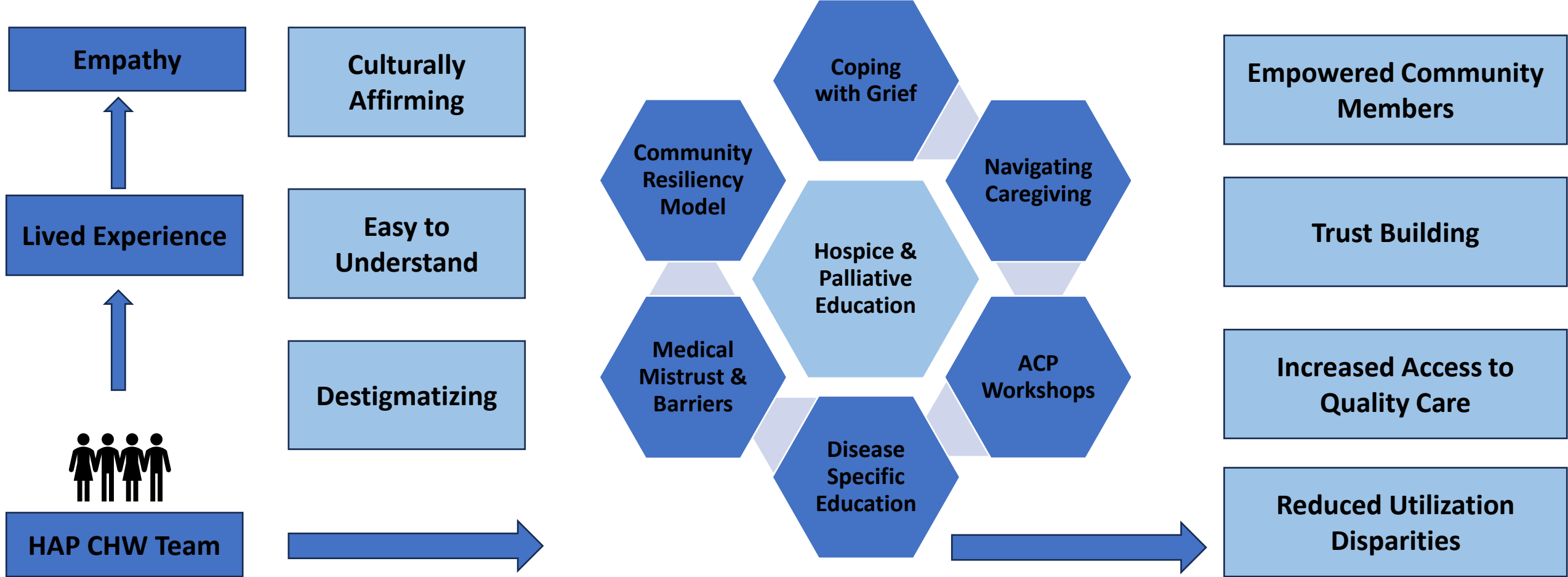


Utilize Community Health Workers (CHWs) to

- Expand the serious illness continuum of care.
 - Offer culturally affirming education.
 - Address barriers to care



CHWs as Serious Illness Educators



The Life and Times of a HAP Community Health Worker

Community Education Programs

- Offering education programs on topics including serious illness, hospice and palliative care utilization disparities, advance care planning, grief, caregiving self care and wellness

Community Outreach and Collaborations

- Connecting to community through health fairs, newsletters, conferences and partnerships with community-based organizations

CHW Networks and Communities

- Furthering the voice of serious illness access and care through collaboration, community and involvement with CHWs and CHW allies in the region and beyond

Community Partnerships formed with

- CBOs
- Regional Chambers of Commerce
- Academic Medical Centers
- Connections with other regional CHWs



Innovative Approaches to Community Engagement



LEGISLATIVE AND
ADVOCACY OUTREACH



ENGAGEMENT IN
RESEARCH



JOIN BUSINESS
ASSOCIATIONS



STRONG COMMUNITY
ENGAGEMENT



BUILDOUT AND
STRENGTHENING OF
COMMUNITY EDUCATION



BROAD PUBLIC
COMMUNICATION AND
OUTREACH

Evidence of CHW's Impact in the Community

Scientific Literature

Public Health
Surveillance Data

Qualitative Data
(from community
members and other
collaborators)

Media

Personal
experience

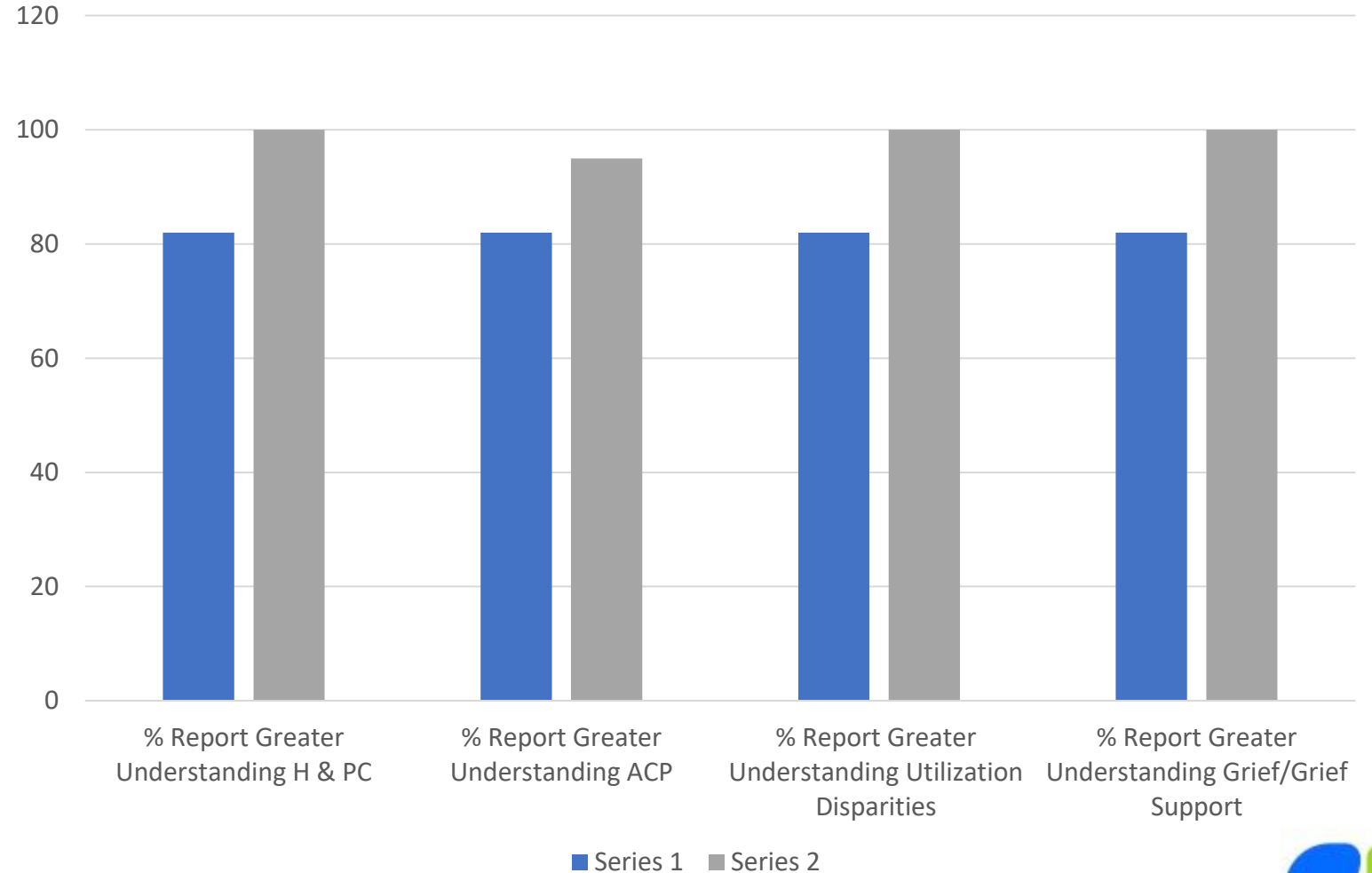


CHW: Program Evaluation

Total 2023 Outreach: 17,013

- Education Programming (sessions in community): 1,318
- Education through community partner meetings and events: 5,508
- Outreach through community events and tabling: 5,258
- CHW education (presentations to CHW groups, including CHLC, NACHW, etc): 4,929

2023 Education Program Evaluation



Comments from Evaluations About CHW Education Programs

CHW: Program Evaluation

I feel more empowered to talk with my family members about their healthcare plans.

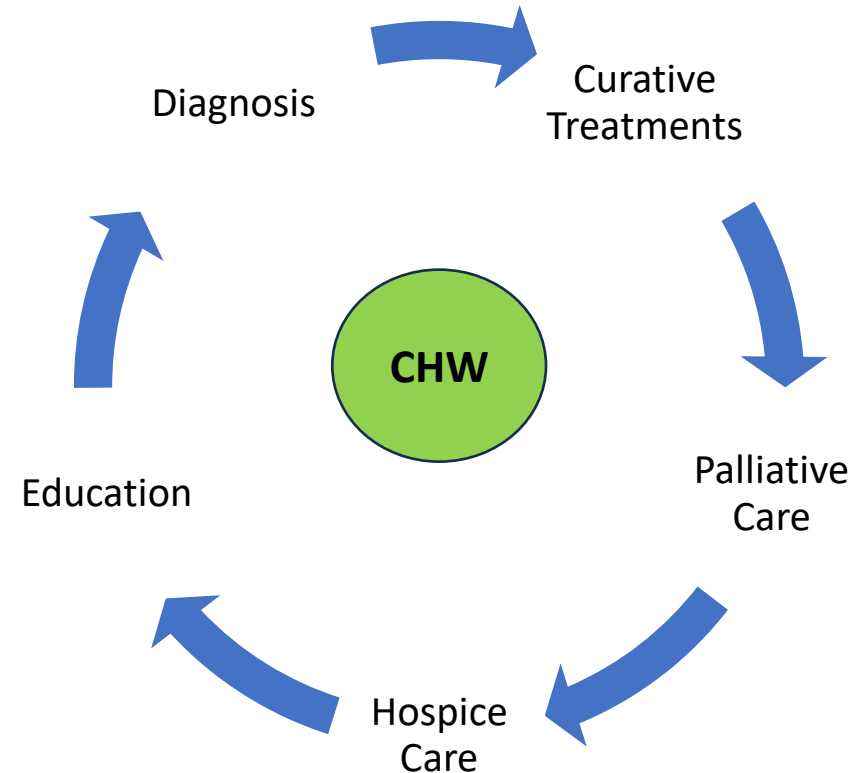
Thanks for an awesome life-changing presentation!

As an African American woman, I have both experienced and witnessed such disparities. Thank you for advocating for the change and raising awareness of hospice and palliative care options.



CHWs Expanding the Continuum of Care

- Increase touch points & and education before patients have a terminal illness.
- Palliative care education expansion is key to building relationships and trust.
- Increasing utilization of palliative care will impact hospice utilization.



Conclusion

- Current and past racism in medicine and healthcare has damaged trust for communities of color.
- Trust in healthcare providers is especially important when it comes to hospice care.
- Medical mistrust and other barriers drive the low hospice utilization rates for racial minorities.
- Addressing disparities in hospice utilization, requires rebuilding trust.
- Community Health Workers offer an innovative approach to rebuilding trust, empowering patients, and addressing barriers to care.

