Jonestown Listening Session Report: Understanding Barriers to Primary and Hospice Care in a Southeast Baltimore

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Introduction

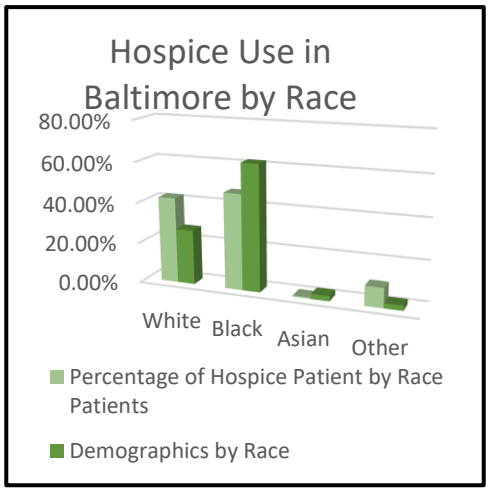
To better understand barriers to hospice and primary care, the Gilchrist and GBMC Health Partners Diversity, Equity, and Inclusion Council's Outreach Committee conducted a listening session series focused on the Jonestown neighborhood in the southeast Baltimore City zip code of 21202, adjacent to 21231. Three listening sessions were held with a total of 31 participants. This report provides findings from the listening sessions, and a literature review provides data that allows a comparison of the Jonestown findings with local and national trends in both hospice and primary care.

Gilchrist, the largest hospice provider in Maryland, and GBMC Health Partners one of the largest providers of primary care in the Baltimore Metro, are part of The Greater Baltimore Medical Center (GBMC) healthcare system. Through Gilchrist and GBMC Health Partners the GBMC Healthcare system renewed its investment in Baltimore City's health care.
With the 2020 opening of the GBMC Health Partners Jonestown Center and the 2021 opening of the new Gilchrist Center Baltimore within zip code 21218 both services are available in Baltimore City and in particular southeast Baltimore GBMC.

During the listening session and through the review of the literature, there emerged themes impacting people's access to health care and their ability to lead a healthy lifestyle. Themes included a lack of understanding around the hospice care and the patient centered medical home (PCMH) model, and a lack of access to healthy food. The literature review and prior local listening sessions revealed a mistrust toward health care providers.

Background

Jonestown is 67% African American [(1)]. Most of the participants identified as Black, with some White and Latino and one Asian. All the listening session participants lived in Baltimore City. All participants lived in Baltimore City and lived or worked in or around the 21202 and 21231 zip codes or in the general southeast Baltimore area.



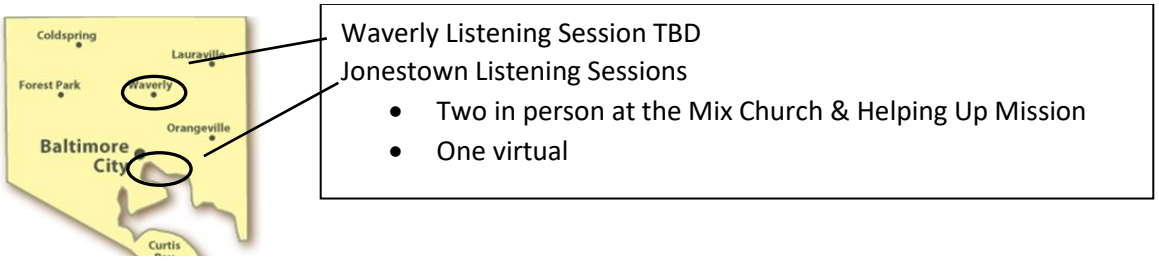
Disparities in primary care [(2) (3) (4)] and hospice [(5)] access and utilization exist at national, state, and local levels. Utilization rates of hospice are lower among communities of color when compared to predominantly white communities [(5) (6) (7)]. These trends persist even in areas where communities of color make up the majority population. [(8)] For example, Baltimore City is over 60% African American and just over 30% white [(9)] . However, the Black community utilizes hospice at a lower rate when compared to white communities. According to a study out of UCLA [(3)] , racial gaps in care utilization and positive

outcomes are present in primary care. The UCLA findings showed that black and Latino patients were 40% and 35% more likely to receive lower quality of care compared to non-Hispanic white patients.

The Jonestown neighborhood is comprised of a majority Black population along with White representing the second largest group. Asian and Latino populations represent the third and fourth largest groups in the community [(1)]. Facilitating listening sessions in Jonestown provided an opportunity to explore barriers and trends of the healthcare experience from people in underrepresented communities.

Methodology

The 12/19/2022 Listening Session was held at THE MIX church with 12 attendees, and the 12/21/2022 Listening Session occurred online through Zoom with five attendees. Due to a winter spike of COVID-19, the third session occurred later and was held on April 26 at Helping Up Mission with 13 participants. Even with limited numbers of participants, consistent correlations with secondary data validated the findings. [(10)] [(11)] [(13)] [(12)] [(2)] [(3)] [(14)]. Members of the Gilchrist and GBMC Diversity, Equity, and Inclusion Council administered all listening sessions.



Each listening session was under 90 minutes and consisted of an informational portion at the beginning where information was shared about hospice and primary care PCMH center model. A member of the outreach team was able to meet with leaders in the two supporting organizations THE MIX Church and Helping Up Mission before the sessions took place to explain the purpose of the project. Participants were told about the purpose during the information portion at the beginning of the listening session. Participant names were not recorded. Personal health information was not elicited during the listening session or recorded in the notes. No video or audio recordings were taken during the listening sessions the team instead opted for two team members to take notes by hand.

Twenty-three questions were asked and divided into 4 four sections, on the topics of PCMH, hospice, openness, and outreach. Most of the questions were open-ended, with poll questions at both the beginning and the end of the Listening Session.

After the listening session series was complete a review of the literature gave us additional insights into the barriers at both a national and local level. This provided our team with information that

both validated our listening session findings and identified information not picked up in the listening session findings.

Findings

Three priority issues were identified in the listening session series and literature review. Potential responses to these specific needs are aligned with or connected to the Gilchrist and GBMC systems strategic plan.

1. Lack of information about hospice and Patient Centered Medical Home (PCMH) model
   a. Understanding hospice coverage/cost options (i.e., Medicare or insurance) [10] [11] [12]
   b. Availability of home hospice care [10]
   c. Access to points of contact for more information about hospice
   d. Understanding the meaning of the PCMH
2. Mistrust of doctors and the healthcare system [10] [11] [12] [4] [5]
3. Lack of access to healthy food [11] [12] [13]

Addressing issues one and two could mitigate barriers to access. Addressing three could meet a need and create positive associations of the Gilchrist and GBMC Health Partners work system among the community.

The findings of the listening sessions are divided into six areas: of awareness, experience, barriers, perspectives of healthcare, outreach preferences, and openness. These results consist of answers from polls, lists and open-ended questions. Additionally, secondary data from the literature review compare findings in from the listening sessions to local and national trends.

<u>Awareness</u>

In our review of the literature, we found that Black, Asian, and Latino communities have a lower understanding of hospice when compared to White communities [5] [15] [16] . This is true even when adjusting for income and location [10]. Our listening session data found that a lower level of information and understanding about hospice was common among people in communities of color. In 2021, a Howard County listening session series focused on barriers to care among communities of color. Many participants believed that hospice was a place where patients would go or that it requires out-of-pocket spending.

A lack of information and understanding about hospice was common in the Jonestown series. 59% of respondents reported being aware of hospice care; however, only 48% were aware that hospice care is covered by insurance. These figures were 10 to 19 percentage points lower than the responses from the African American listening sessions sponsored by HPCNM in Howard County. [10] These findings on awareness levels are consistent with the current literature review. [5] [15] [16]

Barriers to accessing healthcare
"Too much red tape between Medicare and Medicaid and it makes it harder for me to get primary care"
"I don't want to wait 2-3 days for an appointment"
"Scheduling is a barrier."
"If you have an urgent need, you want urgent care…Needs to be more convenient"

Results of the listening session suggests that a lack of awareness applies to elements of primary care. Less than 13% of listening session attendees were familiar with the definition of a Patient-centered Medical Home (PCMH). This finding is consistent with our literature review. A recent Qualitative study out of North Carolina and Washington, DC found that few participants were aware of the PCMH model and concept, even when they were patients at a PCMH, and were pleased with the service [17]. A University of Chicago and UNC School of Medicine study indicated that the PCMH model was associated with lower racial disparities in experience [14]. All the Jonestown listening session attendees who were patients at GBMC Health Partners Jonestown were favorable about their care; however, many were not familiar with the term PCMH.

Experience – "*Great place for your last days"*

67% of respondents reported having had a loved one, friend, or someone they knew utilize hospice. Respondents with prior experience of hospice expressed a favorable view.

What your experience was like for you, or your loved one, or someone in the community who received hospice care?
"Peaceful experience homecare experience with music and activities." "A very good program"
"It was peaceful atmosphere, nurses were nice," "great place for your last days"

Barriers

Barriers reported in the listening sessions were consistent with our literature review. [10] [5] [15] [16] [18]. One-third of all participants were patients of Jonestown Center; however, only 64% of participants reported a PCP visit in the past 12 months. 8% reported that there were barriers to hospice care.

Why do you think there are lower hospice utilization rates among African Americans?
"Before Gilchrist, I didn't know about hospice"
Lack of resources and knowledge
Cultural differences
A lot of cultures don't know about hospice, and family cares for them
Family takes care of the elderly
Not sure doctors know about Hospice

What are the barriers to receiving hospice care?
Lack of having the information to make a good decision
Need knowledge of who to contact and where to go

Some participants cited challenges navigating insurance providers as a barrier creating increased difficulty. A 2020 Baltimore City community health needs assessment from Morgan State University [13] and a 2021 needs assessment from Mt. Washington Pediatric Hospital both cited
difficulties with insurance as a top barrier to accessing primary care [11]. According to the 2018 National Healthcare Quality and Disparities Report, uninsured adults were three times more likely to have trouble accessing care, tests, or treatments [2].

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GBMC Jonestown Center is working toward becoming a PCMH. Interestingly, the information gained in this listening session study shows that the center has already adopted some attributes of a PCMH. Many of the attendees who were also patients of GBMC Jonestown Center indicated that the increased accessibility and availability allowed for more consistent utilization. This is consistent with the Chicago study which linked enrollment in a PCMH with better quality of care and clinical outcomes [14] . Most of the people who reported not visiting their PCP in 12 months were not patients of GBMC Jonestown Center

Perspectives on Health

Many attendees attributed poorer health outcomes in the city when compared to surrounding counties to a lack of access to healthy food, economic disparities, and stress-related to blight and crime.

What does being healthy mean to you?
Being happy
Good mental health state
"No mental health stressors, no anxiety."
"Good weight – I can fit in my clothes."
"Take care of body, mind, and spirit, balance."
"Being able to physically, mentally, and spiritually function each day. Do chores and my job without discomfort."
"Just a feeling in your body of being healthy"
"Going to the Doctors every 6-12 months."
Feeling good
"Taking care of aches and pains."
"Any emergencies are taken care of"

Where do you go for routine healthcare services
The VA because I'm a Veteran
GBMC Health Partners
Healthcare for the Homeless
Emergency Room

What would a healthy community look like to you
"Access to: Healthy foods, Health care, Parks, Things that make you feel good b. Access to the right types of food" *mentioned multiple times
More accessible mental health *mentioned multiple times
Safe housing/lower crime
Lower death rate
Exercise, yoga, programs for seniors and kids
Use of Parks for exercise

Why is hypertension more prevalent in Baltimore City compared to the surrounding counties?
More food deserts. Eat more processed food, chips for breakfast, lunch, and dinner. Eat more fast food. More sodium. *Mentioned multiple times
more fast food/food desert/no grocery store or fresh markets, lack of nutritional education, s
People of color have higher disparities and tend to have hypertension/high blood pressure. There's stress in the city - trauma. Poor diets. It's cyclical in nature.
More stressors in the city.
lack of safety, low socio-economic status – lower education and lower-income
Blight in the city. Constantly seeing dilapidated row homes is stressful.
Lack of knowledge and resources.

Outreach

Where do you get healthcare information?	
Family	Dental practitioner
Doctor	Primary care
Internet	Research on internet

Best Places to receive important information
NextDoor App. Community groups and newsletters.
Church, school, library

Openness

In the final poll, 92% of respondents considered themselves highly likely to share information about hospice with their family and friends.

When polled, most participants were open to attending the following outreach programs
Learning forum or panel on primary care or hospice
Walk with a Doc
Community health fair

Themes

Common themes emerged during the listening session series. The lack of information or understanding about hospice and a lack of awareness about the PCMH model was consistent in both listening sessions and came up in answers regarding barriers [10]. Awareness of hospice care insurance coverage availability was 10% lower in the Baltimore group than in the Howard County listening sessions with a similar demographic [10] . Red tape and insurance difficulty came up as a barrier to primary care

Multiple Baltimore City community needs assessments report that medical insurance issues are cited as a top barrier to healthcare access [11] [12]. Access to healthy food was cited at all the listening sessions and in multiple community needs assessments [13] [11] [12] . While mistrust did not come up in the Jonestown sessions, mistrust toward the healthcare system or practitioners came up in the Howard County African American listening session, all of the Baltimore City Community needs assessments, and is present in national literature [10] [11] [12] [5] [4] [13].

Limitations

This study had an overall small number of participants; however, the educational value was in hearing details and stories about obstacles and barriers. Additionally, many of the findings were consistent with data found in our primary care and hospice literature review which could indicate an acceptable level of validity. The third listening session only focused on primary care because of time constraints.

Next Steps

Data gained through the Jonestown listening session series suggests that outreach efforts should be focused on increasing understanding of both hospice and the PCMH model and building trust between GBMC providers and residents of the Jonestown. These outreach efforts could bridge barriers to care in local underserved communities. Partnering with schools, neighborhoods, and faith communities [5] [7] [18] could positively affect outreach efforts. Incorporating healthy food access into these efforts would respond to a community need outlined in listening sessions and community needs assessments. [11] [12] [13].

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