Author Manuscript
Author Manuscript
Author Manuscript
Author Manuscript

HHS Public Access
Author manuscript
SSM Qual Res Health. Author manuscript; available in PMC 2024 July 02.

Published in final edited form as:
SSM Qual Res Health. 2024 June ; 5: . doi:10.1016/j.ssmqr.2024.100440.

"If we don't speak the language, we aren't offered the same opportunities": Qualitative perspectives of palliative care access for women of color living with advanced breast cancer

Nithya Krishnamurthy[a], **Daniel David**[b], **J. Nicholas Odom**[c], **Krystina Mathelier**[d], **Jenny J. Lin**[a], **Cardinale Smith**[a], **Maria Peralta**[a], **Dolores Moorehead**[e], **Melissa Mazor**[a,*]

[a]Icahn School of Medicine at Mount Sinai, New York, NY, USA

[b]NYU Rory Meyers College of Nursing, New York, NY, USA

[c]School of Nursing, University of Alabama at Birmingham, Birmingham, AL, USA

[d]Pace University, Lienhard School of Nursing, New York, NY, USA

[e]Women's Cancer Resource Center, Berkeley, CA, USA

Abstract

Context: Despite efforts to enhance equity, disparities in early palliative care (PC) access for historically minoritized patients with advanced breast cancer (ABC) persist. Insight into patient and clinician perspectives are needed to inform future models aimed at improving equity in PC access and outcomes.

Objectives: To explore qualitative barriers and facilitators to early PC access in an urban setting with Black and Latina women with ABC.

Methods: In this qualitative descriptive study, we conducted one-on-one interviews with Black and Latina women with ABC (N = 20) and interdisciplinary clinicians (N = 20) between February 2022 and February 2023. Participants were recruited from urban academic and community cancer clinics. Transcripts were analyzed using an inductive coding and thematic analysis approach.

Results: Barriers identified by both patients and clinicians included lack of communication between oncology, PC, and primary care teams, limited understanding of PC among patients and non-PC clinicians, language and health literacy-related communication challenges, and racism

This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

*Corresponding author. Department of Medicine, Icahn School of Medicine at Mount Sinai, 17 E 102 St 6th Floor, New York, NY, 10029, USA.ss Melissa.Mazor@mountsinai.org (M. Mazor).

Declaration of competing interest
The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

CRediT authorship contribution statement
Nithya Krishnamurthy: Writing – review & editing, Writing – original draft, Conceptualization, Formal analysis. **Daniel David:** Writing – review & editing. **J. Nicholas Odom:** Writing – review & editing. **Krystina Mathelier:** Formal analysis, Data curation. **Jenny J. Lin:** Writing – review & editing, Methodology, Formal analysis. **Cardinale Smith:** Writing – review & editing. **Maria Peralta:** Data curation, Project administration. **Dolores Moorehead:** Writing – review & editing, Formal analysis, Conceptualization. **Melissa Mazor:** Writing – review & editing, Writing – original draft, Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

and marginalization, including implicit bias and lack of diverse racial/ethnic representation in the supportive care workforce. Facilitators identified by both patients and clinicians included patient-to-patient referrals, support groups breaking cultural stigma on topics including self-advocacy and PC, referrals from trusted providers, and community organizations' abilities to overcome challenges related to social determinants of health, most specifically logistical and financial support.

Conclusions: Patients and clinicians reported similar barriers and facilitators to PC access, most commonly through the lens of care coordination and communication. These findings will inform future adaptation of a culturally and linguistically care model to improve access to early PC services for Black and Latina women with ABC.

1. Introduction

Over 3.8 million women live with breast cancer in the United States, with a growing number living with advanced breast cancer (ABC) (Giaquinto et al., 2022; Siegel et al., 2023). Despite breakthroughs in targeted treatment and improved survival, this population of women often suffer from unaddressed physical, psychosocial, and spiritual needs (Arnaud et al., 2021). These challenges represent a growing area of health disparities where Black and Latina women with ABC experience more severe distress and symptom burden, discordant provider communication, and inadequate symptom management, relative to White women (Fu et al., 2009; Mott-Coles, 2014; Ren et al., 2019; White-Means & Osmani, 2017).

Palliative care (PC) encompasses holistic support throughout the illness trajectory, addressing communication, goals of care, symptoms, and personalized care coordination and is recommended by the American Society of Clinical Oncology for all patients with high symptom burden and advanced cancer (Ferrell et al., 2017). Importantly, *early* PC, a proactive approach to establishing goals of care and symptom management, has been shown to optimize quality of life and cancer outcomes (Bauman & Temel, 2014) and is particularly important in the setting of ABC where women live with incurable disease for an extended period of time (Giap et al., 2023).

Yet, there are major barriers to early access and availability of PC for women of color with ABC (Giap et al., 2023; Hawley, 2017). There is a lack of capacity for PC within cancer clinic and PC research does not focus specifically on the unique needs of women with ABC or historically minoritized populations (Griggs, 2020; Hawley, 2017; Johnson, 2013). Moreover, as a clinical specialty, PC has been predominantly shaped by a white Anglo sociocultural lens, leading to a less clear definition of overall accessibility for individuals with diverse social, cultural, and/or linguistic backgrounds (Nelson et al., 2021). Consequently, among racial and ethnic minority patients, PC access and delivery remains suboptimal. Relative to non-Latino Whites, Latino and Black individuals with metastatic cancer are up to 40% less likely to receive PC (Giap et al., 2023) and report significantly higher unmet, persistent social and spiritual PC needs relative to white women, even after adjusting for social determinants of health (Mazor et al., 2022).

Access to care is complex, encompassing elements like communication, care coordination, accessibility, and prevailing healthcare regulations (Hawley, 2017; Overholser & Callaway,

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

2019; White-Means & Osmani, 2017). Yet, despite evidence of PC related racial and ethnic disparities, historically minoritized populations are underrepresented in early PC research and their experiences regarding access to early PC are not well characterized (Griggs, 2020; Johnson, 2013; Malhotra et al., 2023). Hence, the purpose of our study was to address this gap and qualitatively describe barriers and facilitators to access to early PC from the perspectives of Black and Latina patients and the clinicians who care for them. Insight into these research questions will provide guidance on how to integrate a larger cultural and social lens to the delivery of PC with the aim at improving access for historically underserved patients with advanced cancer.

2. Methods

2.1. Design

Using a qualitative descriptive approach, (Kim et al., 2017) semi-structured interviews were conducted with patients (N = 20) and multidisciplinary clinicians (oncologists, PC physicians, community navigators, social workers, nurses, and chaplains; N = 20)) via HIPPA compliant Zoom. Participants were asked to share experiences with receiving (patients) and or delivering (clinicians) early PC. Findings were reported using the consolidated criteria for reporting qualitative research (COREQ) to maximize transparency and credibility. Box 1 provides information about the study team and how members who performed analysis and/or interviews bracketed and reflected on their power and made room for the participants to share their journey (Tong et al., 2007). This study was approved by the institutional review board (STUDY-21-01250). Verbal informed consent via HIPPA compliant Zoom with a signing un-biased witness were obtained prior to participation.

2.2. Participants and setting

Purposive sampling was used to recruit patients and clinicians from outpatient breast oncology clinics from hospitals and community-based clinics in New York City. Patients were eligible if they: 1) had a history of advanced stage (stage IIIC or IV) breast cancer as documented in the EMR or by self-report if EMR report was not available, 2) were ≥ 21 years of age, 3) able to communicate in English or Spanish, and 4) self-identified as Black and/or Latina. Clinicians were eligible if they 1) were > 21 years of age, 2) were able to communicate in English or Spanish, and 3) self-endorsed that they work in breast oncology or specialty PC and provided care for Black and/or Latina women with ABC for at least one year. Patient participants were recruited through chart review and flyers and newsletters distributed at partnering community-based organizations (i.e., SHARE Cancer Support). Professionals were recruited through local networks and word of mouth. Specifically, interested patient participants either called the research coordinator (RC) directly (flyers, newsletters) or received an opt out letter and subsequent phone call one-week later from the RC (EHR review). For clinician participants, the RC sent an email explaining the study. Interested clinicians emailed the RC to schedule a screening phone call. For all participants, during the screening phone call, the RC provided information about the study, screened for eligibility, and scheduled participants for informed consent and study interview via HIPPA compliant Zoom.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

2.3. Data collection

An interview guide to elicit a discussion around early PC needs (e.g., symptoms, communication, treatment decision making, goals of care discussions), knowledge and beliefs (e.g., cultural preferences), and access (i.e., utilization, availability, referrals, care coordination) was created and reviewed by a team of community advisory board (CAB) and co-authors. The CAB has been meeting monthly for together for 2 years, and consists of 7 patient advocates from diverse cancer and sociodemographic backgrounds, focuses on how to best embed equity and community engagement in research, and is co-led by the PI of the study.

These interview questions were designed to elicit an in-depth description of the participants' experience with outpatient early palliative and/or supportive oncology access and/or delivery. Following the first qualitative interview, the guide was revised and finalized based on CAB and co-author feedback. Box 2 describes the key interview guide comments and questions. Interviews were conducted, via HIPPA compliant zoom, by the PI and/or trained research coordinator both of whom have extensive experience in qualitative interviews and cancer care. The semi-structured interviews began with informed consent and demographic survey. Interviews ranged from 45 to 60 min and were digitally recorded, transcribed verbatim by a trained research coordinator, checked for accuracy and anonymity, and uploaded them onto Dedoose. (Home | Dedoose) Data were collected until theme saturation was reached and no new themes emerged (Saunders et al., 2018).

For clarification purposes, there remains debate about the terms "palliative care" and "supportive care". Per experts in the field, "supportive care" can be used as a broader term encompassing all types of care focused on improving quality of life. Where PC is a medical specialty aimed at alleviating symptoms and stress associated with serious illnesses (i.e., advanced breast cancer in this context), with the goal of improving quality of life for both patients and their families, provided by a multidisciplinary team and appropriate at any stage of illness alongside curative treatment (Fadul et al., 2009). However, the two terms are frequently used interchangeably. Importantly, from the patients' perspective "supportive care" is often preferred due to misconceptions about "palliative care" being associated with giving up on treatment, despite their similar goals. Hence, most outpatient PC clinics at cancer centers are called "Supportive Oncology". Although the purpose of this paper is to discuss barriers to early PC, to uphold integrity of data, we will maintain the terminology (supportive care or palliative care) used by interview participants.

2.4. Data analysis

Data were analyzed using inductive thematic analysis (Braun & Clarke, 2006; Connelly, 2016). A 3-person coding team consisted of the PI (MM) and trained student interns (NK (medical student), KM (nurse practitioner and PhD student). Text of each interview was read by all members of the coding team to gain an overall perspective of the participant's experience. Initial codes were generated using the process of individual open coding (Rogers, 2018). The team then convened to review their individual coding and reach agreement on the initial codes. All transcripts were subsequently re-coded (2 coders/transcript) using the final code book. For this study, codes related to barriers and facilitators

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

of PC access were collated into broader descriptive themes. Themes and subthemes were reviewed by authors with qualitative expertise (DD, DM, JL) and CAB to ensure consistency of interpretation and rigor of analysis (Braun & Clarke, 2006).

2.5. Quality of the data

Trustworthiness was supported through qualitative rigor of maximizing credibility, transferability, dependability and confirmability (Connelly, 2016). Importantly, the RC conducted an ongoing audit trail from documenting the research process through conducting the analysis. Credibility and confirmability was enhanced through investigator triangulation, peer debriefing with PC clinicians and member checking with representative members on our CAB. Thick descriptions of the themes allow for transferability. In addition, the PI met with an expert qualitative researcher (JL) to review findings, analysis, processes, and data interpretation. The varying perspectives of the study team members (nurse and PC researcher, medical student, oncology nurse practitioner, primary physician/cancer survivorship researcher, community navigators/patient advocates) enriched the analysis.

3. Results

3.1. Clinical and demographic characteristics

Forty interviews were conducted with 20 Black and Latina women with ABC and 20 interdisciplinary care clinicians. As described in Table 1, patient participants were a mean (SD) of 61.8 (10.1) years of age with 70% self-identifying as Black and 30% as Latina. All patients were diagnosed with either Stage IIIC (44%) or Stage IV (56%) breast cancer. Clinician participants were a mean (SD) of 49.5 (2.1) years of age, with 45% self-identifying as Black or Latina and 55% as White. Clinicians represented several disciplines within oncology and/or PC including patient navigation (45%), oncology or PC social work (20%), nursing (15%), oncology or PC medicine (20%), and chaplaincy (5%). Clinician participants had been working in their respective roles in oncology for range of 5–35 years.

3.2. Qualitative findings

Patients and clinicians described 4 barriers and 4 facilitators to PC access. Both patient and clinician perspectives were incorporated into our analysis. We integrated all perspectives into our analysis as common facilitators and barriers emerged across patients and clinicians, which provides a more in-depth description of each theme. Although there was consistency of themes across patients and clinicians, some themes were more heavily weighted in the patients versus providers as noted in greater detail below. The summary of themes are shown in Fig. 1 and exemplary quotes for each theme with associated clinician or patient study ID number are listed in Table 2.

3.3. PC access barriers

3.3.1. Barrier 1 – Fractured Communication—Communication barriers included challenges that arose for patients at initial diagnosis along with discomfort and shame with broaching the topic of symptoms, particularly around mental health and sexual side effects. For example, two patient participants shared their stories about “insensitive” communication exchanges with their oncologists upon finding out they had metastatic breast cancer. “I

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

started crying because I didn't know, and he had the audacity to me to stop crying … I had surgery scheduled by that Thursday to have a double mastectomy and came to find out it was already stage four" (PTID 149). Another patient recognized that despite wishing she learned about PC earlier, it may even be worse for others: "And, as you know, a person of color who's educated and the way that I was treated … I can only imagine what it's like for somebody else who isn't too familiar with the medical system or what advocating for yourself actually means" (PTID 141).

Additionally, symptom communication was a barrier for almost all patient participants. One patient illustrated that "older women might not feel comfortable bringing it [vaginal dryness] to the attention to the doctor … They would just not take the medicine" (PTID 152). Another patient participant noted how challenges around discussion of symptoms were exacerbated through "an incredible deference paid to doctors … [which] could be to a detriment in terms of gathering emotional information from the patient" (PTID 152), leading to patients waiting for clinicians to initiate uncomfortable symptom-related conversations, which often never occurred.

From the clinicians' perspective, fractured communication was discussed less and most often occurred across interdisciplinary teams. Most commonly these barriers prevented follow up with supportive oncology, resulting in unaddressed symptom concerns and a lack of "circle-back communication" with PC team members (PID 13, Breast Psychologist). Collectively, these factors reduced the quality of communication between clinicians and patients, particularly for patients experiencing high symptom burden.

3.3.2. Barrier 2 – Health literacy—Patients and clinicians discussed how minimal understanding and appreciation about the scope and role of PC, especially early PC, limited PC access. For example, PC clinicians discussed how "there are oncologists who feel that they are capable of doing all of the things that we can do, the physical, psychosocial support, advanced care planning. And they don't necessarily see the need to have us involved." (PID 17, social worker). Clinicians noted that, in the context of ABC, this is particularly challenging since "breast cancer is viewed as a chronic cancer … and PC really only comes up when they are ready to make a hospice referral." (PID 1, PC social worker).

Similarly, patient participants discussed how throughout their care, PC was confused with hospice or end-of-life care. Patient participants shared that even among their oncologists, there was confusion about the role of PC among women with ABC. One participant shared that her oncologist said "palliative is like when you're ready to go to hospice … you're not there yet". She mentioned that if she didn't advocate for herself the doctor "would have waited till I have months to live" (PTID 104). Notably, this sentiment is supported by the PC clinician participant's statement "people who have higher healthcare literacy, more education, better socioeconomic status are probably more likely to be referred to us …. but nearly 90% of patients have no idea why they are coming to see us" (PID 2, PC nurse).

3.3.3. Barrier 3 – Language discordance—The inability to converse with patients in their native language served as a significant impediment to adequate PC access. As one patient eloquently stated, "If we don't speak the language or ask questions, we aren't offered

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

the same opportunities." (PTID 103; *Of note, this patient was one of the only bilingual individuals among her friend group and hence, acted as peer navigator for her support group of Spanish speaking women with breast cancer.*) This phenomenon was noted by patients and clinicians, especially by the English/Spanish bilingual navigators and clinicians who had extensive experience working in the community with Spanish-speaking women. Consequently, an understanding of prognosis, goals of care, and/or treatment options were often lost in translation. Unfortunately, even potential system-level solutions such as phone-mediated translation services were focused on concrete care, failing to address any psychological and/or spiritual PC needs (PID 18; community navigator). One patient noted how women with ABC in her Spanish speaking support group "were facing a serious diagnosis and they had no idea what the doctor was talking about. They only knew they had cancer and they were going to die" (PID 9; patient navigator).

3.3.4. Barrier 4 – Bias and representation—Participants discussed how perceived implicit bias led to delays in diagnosis and referrals for pain management. One patient recounted facing bias during her initial diagnosis, recalling "Black women a lot of times. We don't get the help that we need, you know … because I really didn't feel like I wasn't being heard" (PTID 112). Patient navigators further shed light onto these biases through a discussion of how deeply rooted racism may impede adequate PC delivery through clinician internalization of stereotypes. One navigator explained: "we need to address barriers from the oncologist who has unconscious and implicit bias. Through their behaviors, they imply that somehow if you're black, you have the ability to handle pain at a much greater level than someone who's not" (PID 4; community navigator). Another community navigator illuminated on this experience in her discussion of patient's feeling like their needs are not being heard: "A lot of the patients have had that experience That is the number one thing. They're not listening to you, truly, listening to you. I get a lot of cancer patients that I hear that from … they say the doctor is just ignoring me. That's like the biggest barrier of all." (PID 20; Nurse Practitioner).

One factor that perpetuated this problem was the lack of representation of Black and Latino clinicians, which served as a critical system-level barrier in PC coordination. As one nurse practitioner noted, "Since I'm White and most of the doctors are White, we really didn't get her questions answered for her. That situation just upset me and I felt really bad for the patient and she was like 'no one looks like me in this practice'" (PID 14; oncology nurse). Patients also noted that finding clinicians of a similar race and/or background would help facilitate trust, yet they were unable to find them: "Right now I'm in my community looking for an African American doctor, and I cannot find one because it's just not here" (PTID 150).

3.4. PC access facilitators

3.4.1. Facilitator 1 – Individual peer support—Patients felt empowered by advocating for other women with ABC through sharing information about the benefits of PC through conferences, support groups, and even clinic waiting rooms. These often-serendipitous discussions helped patients feel aware and activated. One patient heard about services from a woman in the waiting room, explaining she learned "they have a social

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

worker I can talk to" (PTID 149), enabling her to reach out to the supportive care team. Likewise, clinicians emphasized the value of peer to peer networks in motivating patients to seek out specific care for symptoms and side effects. One oncology chaplain participant explained that these networks often generated "self referrals or patients, going back to the oncologist and saying you know I'm really having a horrible neuropathy from my therapy for my breast cancer … would you refer me? I'd like to see if they can help me" (PID 11; oncology chaplain).

3.4.2. Facilitator theme 2 - Group support—Support groups, including groups offered through social media, church, or community-based organizations, were particularly helpful in promoting trust and dismantling stigma surrounding self-advocacy and PC. Equipped with information and experiences from support group peers, patients "became more informed … felt better making decisions … and somewhat hopeful" and subsequently self-advocated for more information from their doctors (PTID 150). One navigator discussed how one of her patients "learned from [her] support groups what really palliative care is" (PID 8; patient navigator) and then felt comfortable asking her doctor to refer her to a PC provider. Through these groups, patients were able to hear from other women with similar diagnoses, overcome stigma, and generate self-referrals for symptom management. One PC clinician noted that once patients were seen, they recognized the value of PC yet were frustrated they experienced unnecessary suffering through a delay in referral: "The degree to which patients say 'Oh, I wish I would have come sooner' … in some ways it's gratifying, in some ways it's disheartening" (PID 10; PC physician).

3.4.3. Facilitator theme 3 - Trust—Trusted clinicians facilitated timely referrals to early PC services allowing for adequate management of physical and psychosocial symptoms. Participants noted a distinction between clinicians and 'trusted' clinicians, where the latter provided space to build rapport and understand the whole patient: "African Americans, Blacks and Latinos have been mistreated … in these patients, they may take a little longer to connect" (PTID 15). Another patient described how she finally felt safe with her oncologist and became open to mental health support, "… after a meltdown, I finally emailed my oncologists and said I don't know what I need … she referred me to somebody … This was the first time ever I had gone professionally for something like this [mental health support]" (PTID 104).

Clinician participants, particularly the community navigators, emphasized how trust was essential to establish prior to introduction and acceptance of PC, in particular for patients of color. They highlighted the impact of historical racism on trust of the medical system. Specifically, they noted that clinicians need to provide time and space to allow for the development of rapport to enable acceptance of early PC, "It's hard to gain trust … with time patients start to trust … especially by the time we get control of the cancer and they're not in pain" (PID 13; psychologist).

3.4.4. Facilitator 4 – External support that addresses social determinants of Health—Most of the patient, social work, and navigator participants discussed how community organizations served a vital role in overcoming barriers to accessing early PC through addressing social determinants of health (SDOH), particularly financial concerns

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

and allowing for the opportunity to connect to supportive care services. As one social worker noted, “There are cases where we had women who had very advanced cancer, so they needed an oxygen tank, but they didn’t have Medicaid, they were undocumented … so we were able to identify resources that provided oxygen and a hospital bed.” (PID 7; social worker) Many of the participants shared their experiences with a specific community organization for women with metastatic disease that provides support for unmet SDOH including financial resources and linkage/referrals to supportive care. Patients discussed the cascading effect of access to free, community-based supportive care, “You’re you connect with one person or organization then you get connected with others” (PTID 130).

4. Discussion

Our study found that fragmented communication, health literacy, language barriers, and downstream factors of historical racism (i.e., implicit bias and lack of representation) posed unique challenges in understanding the role of PC in the advanced cancer setting and hindered PC access. Notably, many of these factors are related to inadequate care coordination, a key aspect of access to care (Hawley, 2017; Overholser & Callaway, 2019). Patients and clinicians underscored the value of patient-patient networks, support groups, and community organizations to help improve access to PC through overcoming stigma related to mental health, promoting self-advocacy, and overcoming financial and logistical barriers related to SDOH, all of which facilitated access to earlier integration of PC for Black and Latina women with ABC. These findings are line with recent findings that cross-cultural incongruity, especially in communication, may limit PC among non-Western populations (Cain et al., 2018; Nelson et al., 2021). Addressing these cultural differences is crucial for providing culturally appropriate PC across diverse patient groups.

It is well known that PC is often poorly understood, particularly regarding its misinterpretation as hospice and/or end-of-life for not just minoritized but diverse individuals with cancer (Hawley, 2017; Zimmermann et al., 2016). In our study, both patients and clinicians noted that low PC health literacy prevented timely referrals, yet the context by which the PC literacy challenges ensued varied slightly between patient and clinician participants. Patients spoke on challenges and discomfort in bringing up a referral to early PC. While clinicians commented on how societal views of breast cancer as a chronic but essentially curable illness posed a barrier to early PC referrals. More specifically, studies have shown that clinicians avoid PC referrals for reasons of uncertainty about prognosis and fears that a referral will lead to the destruction of hope (Sarradon et al., 2019). Hence, in the context of BC, which is often perceived as curable or chronic, but not life threatening, along with idea that PC is equivalent to terminal care, clinicians fear that referral to PC may alarm patients and their families and thereby avoid the conversation and referral (Giap et al., 2023; Smith et al., 2012). As posited by others, these factors may lead to the low rate of PC utilization (25%) among women with ABC, (Giap et al., 2023) and are potential targets to improve early PC access and utilization.

Low health literacy regarding PC and advanced cancer is not only common (Lipman, 2016) but also leads to poor care coordination (Hawley et al., 2010) and lower patient acceptance of PC particularly among patients who have been historically minoritized

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

(Barnato et al., 2009; Enguidanos et al., 2021). Hence, mechanisms by which we can promote understanding of PC in a culturally sensitive and widely disseminated manner is essential (Henderson et al., 2011; Perry et al., 2021). Our findings suggest that facilitators such as support groups, and peer-to-peer communication may be a feasible option by which to improve PC and advanced cancer health literacy across more diverse and medically underserved populations with the goal of improving early PC awareness and acceptance.

Similar to facilitators to health care access in general, (Lor & Martinez, 2020) language concordance and optimal clinician-patient communication and connection play a vital role in improving access to PC services. Patients and clinicians both noted that an inability to converse with the patient in their native language hindered a nuanced discussion on treatment prognosis and further isolated minority populations. Additionally, cultural factors influenced communication (Cain et al., 2018) where symptom related communication barriers were often rooted in stigma, muted deference, and institutional fractures between interdisciplinary clinicians.

While interpreter services helped mitigate some language-related barriers, they were far from adequate in conveying body language and empathy. Hence, inability to translate complexities of living with locally advanced or metastatic cancer in their native language led patients to either fear dying or live in the dark about the long-term implications of their condition. Still, studies show that limited English proficiency speakers experience poorer quality of care at the end of life when interpreters are not employed (Silva et al., 2016). Our findings encourage clinician-initiated communication with appropriate use of in-person interpreters, as well as supportive care clinicians speaking to patients in their native languages. Such interventions can improve patients' perception of quality of care and adoption of PC (Silva et al., 2016).

Our qualitative analysis underscores the harmful role of downstream consequences of structural racism including implicit bias and lack of representation (Hall et al., 2015; Payne et al., 2019). Importantly, these factors cast a pervasive shadow on early integration of PC for Black and Latina patients with ABC (Giap et al., 2023; Johnson, 2013). In our study, Black women described feeling that their health concerns were dismissed, resulting in care delays. Other studies have demonstrated that implicit biases led to the perception of higher tolerances yet under-treatment of pain medication in Black patients, and that doctors exhibited fewer positive, rapport-building nonverbal cues with Black patients during goals of care discussions (Fiscella et al., 2021; Hoffman et al., 2016). Of note, Black and Latina patients in our study reported that despite searching, they rarely saw a clinician of the same race. A salient feature of our observations was that clinicians also felt some discordance in relationships with patients of a different race/ethnicity.

4.1. Implications

Despite deeply rooted barriers, our findings indicate that community and peer groups are a promising method to facilitate PC access potentially through enhancing access to financial and SDOH related services, emboldening self-advocacy, challenging cultural deference to healthcare providers and encouraging open communication and referrals to supportive and early PC (Ashing-Giwa et al., 2012). Importantly, there is a ripple effect, where one referral

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

can create subsequent palliative and supportive oncology referrals as needed. Moreover, concordant racial/ethnic patient provider relationships increase care comfort and acceptance and can lead to more effective therapeutic relationships (Ma et al., 2019). Increasing minority representation in the supportive care fields and expanding education on anti-racism and cultural humility may help increase minority patient trust and participation in PC (Fitz-Gerald & Hurst, 2017).

Community navigators from similar backgrounds and/or experiences as minoritized patients can play a crucial role in delivering patient-centric supportive care in minority populations, but their effectiveness relies on securing require adequate funding (Mazor et al., 2023). Fortunately, with the integration of new Medicare physician fee payment schedule policies, community and non-licensed navigators will be able to bill for services rendered, greatly improving the feasibility of integrating navigators into interdisciplinary care. (Calendar Year) A pilot study demonstrated that community health workers successfully ameliorated psychological distress and provided quality supportive care to Black patients with advanced solid organ cancers (Villamar et al., 2022). However, another trial showed that bicultural navigators helped Latina patients with advanced cancer planning, yet their involvement did not significantly affect pain mitigation or hospice use (Fischer et al., 2018). Future trials should prospectively analyze the role of culturally sensitive and/or community-based navigation on early PC coordination in minority populations.

4.2. Limitations

This study carries several limitations. First, the findings are limited by the sample of participants from an urban environment, limiting generalizability to rural environments with different access challenges. Although the participants were of diverse racial and ethnic backgrounds, many had health care backgrounds and access to research and supportive oncology clinics, which may provide advantages regarding health literacy and care. Additionally, participants came from varying personal and professional backgrounds, which may limit attributing specific themes to participant characteristics. However, the purpose of the study was to understand diverse perspectives from individuals less represented in research, including Spanish speaking participants, which adds to the uniqueness and richness of findings. Additionally, rather than attributing specific themes to racial/ethnic populations, our findings highlight the point that Black and Latina women are not homogonous. Hence, addressing their care needs requires recognizing individual backgrounds, cultures, and preferences, and considering how health care systems and professionals can best mitigate barriers that stem from a predominantly White, western care model to improve access to early PC.

5. Conclusions

Our study outlines key patient and clinician-identified barriers and facilitators of early PC access for women of color with ABC. These findings will contribute to the development of a new, innovative method of PC delivery for underserved patients. More specifically, these findings will inform the development of a future lay navigator-led PC intervention for Black

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

and Latina women with advanced breast cancer, focusing on acceptance of early PC and linkage to community and clinical resource.

Acknowledgment

The authors remain grateful for the generosity of time and experiences shared by all participants.

Disclosures and acknowledgements

We certify that this work is novel clinical research. Availability of data and material: The data that support the findings of this study are available from the corresponding author upon reasonable request.

Funding

This work was supported by the National Institute of Health [NCI 1K08CA267309-01] and Alex and Rita Hillman Foundation.

References

Arnaud A, Grenier J, Boustany R, Kirscher S, Mege A, de Rauglaudre G, et al. (2021). Role of supportive care in improving the quality of life and reducing unscheduled hospital care in patients with metastatic breast cancer. Supportive Care in Cancer, 29(7), 3735–3742. [PubMed: 33205324]

Ashing-Giwa K, Tapp C, Rosales M, McDowell K, Martin V, Santifer RH, et al. (2012). Peer-based models of supportive care: The impact of peer support groups in African American breast cancer survivors. Oncology Nursing Forum, 39(6), 585–591. [PubMed: 23107852]

Barnato AE, Anthony DL, Skinner J, Gallagher PM, & Fisher ES (2009). Racial and ethnic differences in preferences for end-of-life treatment. Journal of General Internal Medicine, 24, 695–701. [PubMed: 19387750]

Bauman JR, & Temel JS (2014). The integration of early palliative care with oncology care: The time has come for a new tradition. Journal of the National Comprehensive Cancer Network, 12(12), 1763–1771. quiz 1771. [PubMed: 25505216]

Braun V, & Clarke V (2006). Using thematic analysis in psychology. Nullx, 3(2), 77–101.

Cain CL, Surbone A, Elk R, & Kagawa-Singer M (2018). Culture and palliative care: Preferences, communication, meaning, and mutual decision making. Journal of Pain and Symptom Management, 55(5), 1408–1419. [PubMed: 29366913]

Calendar Year (CY) 2024 Medicare Physician Fee Schedule Final Rule [Internet]. [cited 2023 Dec 14]. Available from: https://www.cms.gov/newsroom/fact-sheets/calendar-year-cy-2024-medicare-physician-fee-schedule-final-rule.

Connelly LM (2016). Trustworthiness in qualitative research. Medsurg Nursing, 25(6), 435. [PubMed: 30304614]

Enguidanos S, Cardenas V, Wenceslao M, Hoe D, Mejia K, Lomeli S, et al. (2021). Health care provider barriers to patient referral to palliative care. Americanx Journal of Hospice and Palliative Medicine®, 38(9), 1112–1119.

Fadul N, Elsayem A, Palmer JL, Del Fabbro E, Swint K, Li Z, et al. (2009). Supportive versus palliative care: What's in a name? A survey of medical oncologists and midlevel providers at a comprehensive cancer center. Cancer, 115(9), 2013–2021. [PubMed: 19235253]

Ferrell BR, Temel JS, Temin S, Alesi ER, Balboni TA, Basch EM, et al. (2017). Integration of palliative care into standard oncology care: American society of clinical oncology clinical practice guideline update. Journal of Clinical Oncology, 35(1), 96–112. [PubMed: 28034065]

Fiscella K, Epstein RM, Griggs JJ, Marshall MM, & Shields CG (2021). Is physician implicit bias associated with differences in care by patient race for metastatic cancer-related pain? PLoS One, 16(10), Article e0257794.

Fischer SM, Kline DM, Min SJ, Okuyama-Sasaki S, & Fink RM (2018). Effect of Apoyo con Cariño (Support With Caring) Trial of a Patient Navigator Intervention to Improve Palliative

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Care Outcomes for Latino Adults With Advanced Cancer: A Randomized Clinical Trial. JAMA Oncology, 4(12), 1736–1741. [PubMed: 30326035]

FitzGerald C, & Hurst S (2017). Implicit bias in healthcare professionals: A systematic review. BMC Medical Ethics, 18(1), 1–18. [PubMed: 28077127]

Fu OS, Crew KD, Jacobson JS, Greenlee H, Yu G, Campbell J, et al. (2009). Ethnicity and persistent symptom burden in breast cancer survivors. Journal of cancer survivorship: Research and Practice, 3(4), 241–250. [PubMed: 19859813]

Giap F, Ma SJ, Oladeru OT, Hong YR, Yu B, Mailhot Vega RB, et al. (2023). Palliative care utilization and racial and ethnic disparities among women with de novo metastatic breast cancer in the United States. Breast Cancer Research and Treatment, 1–8.

Giaquinto AN, Sung H, Miller KD, Kramer JL, Newman LA, Minihan A, et al. (2022). Breast cancer statistics, 2022. CA: a cancer journal for clinicians, 72(6), 524–541. [PubMed: 36190501]

Griggs JJ (2020). Disparities in palliative care in patients with cancer. Journal of Clinical Oncology, 38(9), 974–979. [PubMed: 32023155]

Hall WJ, Chapman MV, Lee KM, Merino YM, Thomas TW, Payne BK, et al. (2015). Implicit racial/ethnic bias among health care professionals and its influence on health care outcomes: A systematic review. American Journal of Public Health, 105 (12), e60–e76.

Hawley P. (2017). Barriers to access to palliative care. Palliat Care, 10, Article 1178224216688887.

Hawley ST, Janz NK, Lillie SE, Friese CR, Griggs JJ, Graff JJ, et al. (2010). Perceptions of care coordination in a population-based sample of diverse breast cancer patients. Patient Education and Counseling, 81, S34–S40. [PubMed: 21074963]

Henderson S, Kendall E, & See L (2011). The effectiveness of culturally appropriate interventions to manage or prevent chronic disease in culturally and linguistically diverse communities: A systematic literature review. Health and Social Care in the Community, 19(3), 225–249. [PubMed: 21208326]

Hoffman KM, Trawalter S, Axt JR, & Oliver MN (2016). Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. Proceedings of the National Academy of Sciences, 113(16), 4296–4301.

Home | Dedoose [Internet]. [cited 2022 Sep 8]. Available from: https://www.dedoose.com/.

Johnson KS (2013). Racial and ethnic disparities in palliative care. Journal of Palliative Medicine, 16(11), 1329–1334. [PubMed: 24073685]

Kim H, Sefcik JS, & Bradway C (2017). Characteristics of qualitative descriptive studies: A systematic review. Research in Nursing & Health, 40(1), 23–42. [PubMed: 27686751]

Lipman AG (2016). Health literacy and palliative care: Workshop summary. Journal of Pain & Palliative Care Pharmacotherapy, 30(3), 237–239. [PubMed: 27559633]

Lor M, & Martinez GA (2020). Scoping review: Definitions and outcomes of patient-provider language concordance in healthcare. Patient Education and Counseling, 103 (10), 1883–1901. [PubMed: 32507590]

Ma A, Sanchez A, & Ma M (2019). The impact of patient-provider race/ethnicity concordance on provider visits: Updated evidence from the medical expenditure panel survey. Journal of Racial and Ethnic Health Disparities, 6(5), 1011–1020. [PubMed: 31236800]

Malhotra S, Christopher M, Chowdry RP, Mossman B, Cooke A, Deblieux J, et al. (2023). Barriers, blocks, and barricades: Disparities to access of palliative care in cancer care. Current Problems in Cancer, Article 101024.

Mazor M, David D, Moorehead D, Merriman JD, & Lin JJ (2023). Community navigation and supportive care experiences of low-income black and Latina cancer survivors: Patient and navigator perspectives. J Oncol Navig Surviv, 14(4).

Mazor MB, Li L, Morillo J, Allen OS, Wisnivesky JP, & Smith CB (2022). Disparities in supportive care needs over time between racial and ethnic minority and non-minority patients with advanced lung cancer. Journal of Pain and Symptom Management, 63(4), 563–571. [PubMed: 35031503]

Mott-Coles S. (2014). Patients' cultural beliefs in patient-provider communication with African American women and Latinas diagnosed with breast cancer. Clinical Journal of Oncology Nursing, 18(4).

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Nelson KE, Wright R, Peeler A, Brockie T, & Davidson PM (2021). Sociodemographic disparities in access to hospice and palliative care: An integrative review. American Journal of Hospice and Palliative Medicine®, 38(11), 1378–1390. [PubMed: 33423532]

Overholser L, & Callaway C (2019). Improving care coordination to optimize health outcomes in cancer survivors. Journal of the National Comprehensive Cancer Network, 17(5.5), 607–610. [PubMed: 31117043]

Payne BK, Vuletich HA, & Brown-Iannuzzi JL (2019). Historical roots of implicit bias in slavery. Proceedings of the National Academy of Sciences, 116(24), 11693–11698.

Perry LM, Sartor O, Malhotra S, Alonzi S, Kim S, Voss HM, et al. (2021). Increasing readiness for early integrated palliative oncology care: Development and initial evaluation of the EMPOWER 2 intervention. Journal of Pain and Symptom Management, 62(5), 987–996. [PubMed: 33864847]

Ren JX, Gong Y, Ling H, Hu X, & Shao ZM (2019). Racial/ethnic differences in the outcomes of patients with metastatic breast cancer: Contributions of demographic, socioeconomic, tumor and metastatic characteristics. Breast Cancer Research and Treatment, 173(1), 225–237. [PubMed: 30293212]

Rogers R. (2018). Coding and writing analytic memos on qualitative data: A review of johnny saldaña's the coding manual for qualitative researchers. Qualitative Report, 23 (4), 889–892.

Sarradon-Eck A, Besle S, Troian J, Capodano G, & Mancini J (2019). Understanding the barriers to introducing early palliative care for patients with advanced cancer: A qualitative study. Journal of Palliative Medicine, 22(5), 508–516. [PubMed: 30632886]

Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. Quality and Quantity, 52, 1893–1907. [PubMed: 29937585]

Siegel RL, Miller KD, Wagle NS, & Jemal A (2023). Cancer statistics, 2023. Ca-A Cancer Journal for Clinicians, 73(1), 17–48. [PubMed: 36633525]

Silva MD, Genoff M, Zaballa A, Jewell S, Stabler S, Gany FM, et al. (2016). Interpreting at the end of life: A systematic review of the impact of interpreters on the delivery of palliative care services to cancer patients with limited English proficiency. Journal of Pain and Symptom Management, 51(3), 569–580. [PubMed: 26549596]

Smith CB, Nelson JE, Berman AR, Powell CA, Fleischman J, Salazar-Schicchi J, et al. (2012). Lung cancer physicians' referral practices for palliative care consultation. Annals of Oncology, 23(2), 382–387. [PubMed: 21804051]

Tong A, Sainsbury P, & Craig J (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care, 19(6), 349–357. [PubMed: 17872937]

Villamar DM, Huard C, Nicholson LA, Moreno P, & Tan M (2022). Training community health workers to increase advanced care planning in African American women with breast cancer. Journal of Clinical Orthodontics, 40(16_suppl), Article e18549.

White-Means SI, & Osmani AR (2017). Racial and ethnic disparities in patient-provider communication with breast cancer patients: Evidence from 2011 MEPS and experiences with cancer supplement. Inquiry: The Journal of Health Care Organization, Provision, and Financing, 54, Article 0046958017727104.

Zimmermann C, Swami N, Krzyzanowska M, Leighl N, Rydall A, Rodin G, et al. (2016). Perceptions of palliative care among patients with advanced cancer and their caregivers. Canadian Medical Association Journal, 188(10), E217–E227. [PubMed: 27091801]

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Box 1

Background and Reflections from Team Members who Participated in Coding and/or Analysis

Initials	Professional Role	Reflections
DD	PC Nurse Researcher	I identify with being a nurse rather than a researcher, recognize as qualitative interviewer, I am part of the measurement and provide as much space as possible to allow the participant voice to emerge.
DM	Supportive Care Clinician and Navigator	I am a mental health clinician from the African American/Black community, yet I recognize the power imbalance, and the need to provide safe and brave space for patients to tell their story. I do this by being curious, listening, and validating their experiences.
KM	Nurse Practitioner/PhD Student	Personal note taking was a beneficial tool for breaking down complex ideas that the participants mentioned. After critically thinking about their stories, I could also identify my biases. One repeated thought I kept close was that my background in health care provides knowledge that would make my experience navigating the health care system vastly different from our participants. Understanding that people have various levels of health literacy was at the forefront of my mind during this study phase.
JL	Primary Care and Survivorship Physician	As a physician I am always acutely aware of the power differential in my relationships with patients. It is similar in research—as investigators, we often drive the research questions but we all do much better when we take a step back and have our participants help steer the direction of our work together.
MM	Oncology Nurse and Equity Researcher	As a nurse researcher, I address healthcare power dynamics, mindful of biases in data interpretation. Through self-reflection, mentorship, and collaboration, I develop transparent guidelines and hold debriefing sessions. Personal note-taking aids in dissecting participant narratives, prompting critical reflection on biases. I acknowledge my healthcare background's influence and varying health literacy levels among participants, aiming to elevate marginalized patients' palliative care experiences.
NK	Medical Student	I reflect on systemic power dynamics in medicine and their impact on my unconscious biases and data interpretation. Self-reflection, mentorship, and collaboration with development of a transparent codebook and debriefing sessions throughout the writing process were employed to examine biases and privilege with the goal of eliciting and amplifying minoritized patients' experiences with palliative care.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Box 2

Interview Guide Key Comments & Questions*

- o Definitions of Early Palliative care and Primary and Specialty Palliative Care in Context of ABC
- o Prompts to elicit experience with:
- o ABC Diagnosis and Treatment
- o ABC related symptom and communication experiences
- o Early primary and/or specialty PC awareness, access, and/or experiences (if any)
- o Supportive care management both in the clinic and community
- o Communication with care team
- o Cultural and/or linguistic factors that influenced care access or communication with their care team
- o Other barriers or facilitators to early palliative care access that were not asked about specifically.

*Interview guide exact phrasing was modified based on the interviewee professional and personal background and experience with and previous knowledge of PC.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

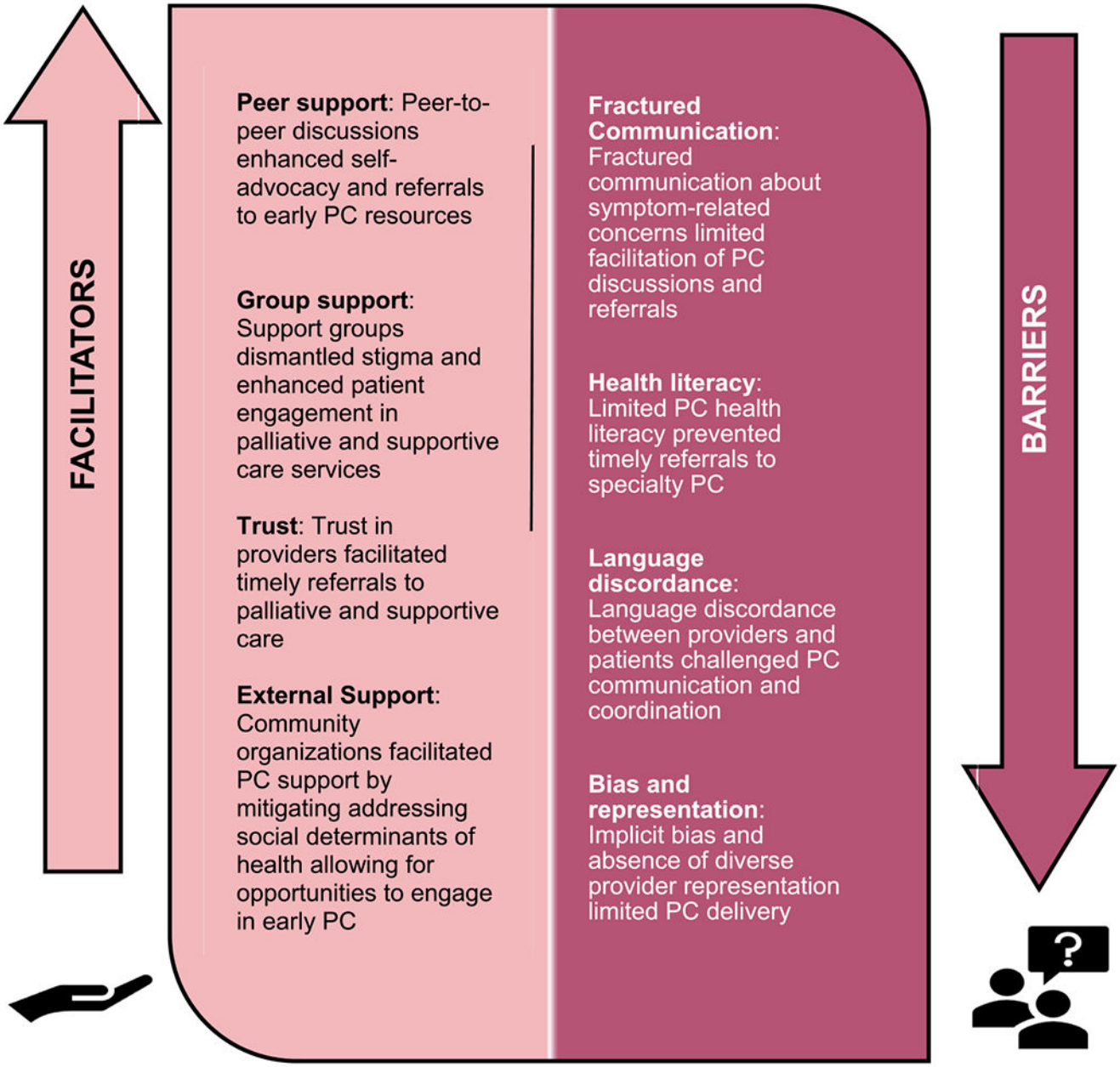

Fig. 1.
Summary of barriers and facilitators to early palliative care access for black and latina women with advanced breast cancer.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Table 1

Patient and clinician clinical and demographic characteristics.

Patient Characteristics (N = 20)	
Age (mean (SD)	61.8 (10.1)
Cancer Diagnosis	
Stage IIIC	44%
Stage IV	56%
Race/Ethnicity	
Black/Non-Latina	70%
Latina/White	30%
College Graduate	45%
Clinician Characteristics (N = 20)	
Age (mean (SD)	49.5 (2.1)
Race/Ethnicity	
Black/Non-Latina	35%
White/Non-Latina	55%
Latina/White	10%
Professional Role	
Navigator	45%
Social Worker	20%
Nurse	15%
Medical Oncologist	10%
Palliative Care Physician	10%
Oncology Chaplain	5%

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Table 2

Themes and exemplary quotes - palliative care access barriers and facilitators.

Theme	Exemplary Quotes
BARRIERS	
Fractured Communication: Fractured communication about symptom-related concerns limited facilitation of PC discussions and referrals	"*I was in this discussion group where it talked about older women of a certain age who might not feel comfortable bringing it [vaginal dryness] to the attention of the doctor, that they're having this problem. They would just not take the medicine.*" (Patient 152). "*… like a deference to the medical care, so that they won't ask the questions, and they'll say, pues. pues …. and I think it could be a detriment.*" (Patient 159) "*It's not like there's a circle back communication from the social worker of 'Oh, I met with this patient, they are having so much anxiety about their diagnosis and I've connected them with this support group … you know that kind of just falls off by the wayside.*" (PID 13; Breast Oncology Psychologist)
Health literacy: Limited PC health literacy prevented timely referrals to specialty PC	"*My old oncologist.. she just said like palliative is like when you're ready to go to hospice … she said you're not there yet. She would have waited till you know I have months to live or whatever days.*" (Patient 104) "*There are oncologists who feel that they are capable of doing all of the things that we can do, the physical, psychosocial support, advanced care planning. And they don't necessarily see the need to have us involved. Even among patients who did receive referrals, nearly 90% of patients have no idea why they're coming to see us or who we are.*" (PID 17; Oncology Social Worker) "*I also think how breast cancer is viewed as chronic, and for many people, a curable illness … And I think you know supportive oncology and palliative care really only comes up for their population when they're ready to make a hospice referral and we're really trying to move the needle there.*" (PID 1; Palliative Care Social Worker)
Language discordance: Language discordance between providers and patients challenged PC communication and coordination	"*If we don't speak the language or ask questions, we aren't offered the same opportunities as someone who is able to do more research in the English language. about what is available to us.*" (Patient 103) "*I find it's challenging, though, when you use an interpreter and you're trying to do emotional support, it's really not great … when I say something it's nothing mimicked by an interpreter on a video the same way, maybe that I intend it to be.*" (PID 18; Patient Navigator) "*There was a big table of a 15 or more women there, all from different countries and the one thing they had in common was they were here alone, they were facing a diagnosis that no idea really what the doctor is talking about because they couldn't speak English they didn't understand it. They only knew the cancer, and they were going to die.*" (PID 9; Community Navigator)
Bias and representation: Implicit bias and absence of diverse provider representation limited PC delivery	"*I try not to feel like everything is black and white or race related. But in that moment, like later on, when I was diagnosed with the cancer. I felt like wow, like not enough was done … I don't know if it was because I was black, but I feel like they really didn't take my concerns seriously, like they were just like 'Oh, it's nothing, 'whereas you may not think it's anything, but if you do the proper testing, we can find out what it is sooner.*" (Patient 112) "*Barriers from the oncologist who has unconscious and implicit bias … somehow if you're Black, [providers believe] you have the ability to handle pain at a much greater level than someone who's not.*" (PID 4; Community Navigator) "*Right now I'm in my community looking for an African American care position, and I cannot find one because it's just not here.*" (Patient 150) "*A patient was interested in cold capping.. but she's Black and she wanted to know for African American hair how that would work. And so, since I'm White and then most of the doctors are White, we didn't really get that answered for her, but one of my colleagues … she was Black and so she was able to find some resources, but she really had to do some digging behind it … it makes me sad that it's not for all patients and it's mainly directed towards more White patients … that situation just upset me and I felt really bad for the patient and she was like 'no one looks like me in this practice.*" (PID 14; Registered Oncology Nurse)
FACILITATORS	
Peer support: Peer-to-peer discussions enhanced self-advocacy and referrals to early PC resources	"*I learned about people who could help me I wasn't introduced to them I heard about them from other people talking about them in the waiting room. Like oh they have a social worker I can talk to or they have a dietician that I can talk to.*" (Patient 149) "*People appreciate peer support because they want to talk to someone who is going through it or who has been there. There's an instant kind of trust and understanding and rapport that's developed … a lot of metastatic breast cancer patients feel as though others just really don't understand what they're going through.. with peer support you know that's taken off the table.. it's a place where they can talk about their most personal deepest issues without being told that you know they should have a positive attitude or you'll be fine you know, or you know.*" (PID 7; Community navigator) "*[Peer] groups often generate self-referrals or patients, going back to the oncologist and saying you know 'I'm really having a horrible neuropathy for my therapy for my breast cancer, I heard this talk at a group meeting would you refer me. I'd like to see if they can help me.*" (PID 11; Oncology Chaplain)
Group support: Support groups dismantled stigma and enhanced patient engagement in palliative and supportive care services	"*One patient learned from [her] support groups what really palliative care is, and then felt comfortable asking her doctor to refer her to a palliative care provider.*" (PID 8; Patient Navigator) "*A big support is Facebook … groups for triple negative metastatic breast cancer or HER2 positive metastatic breast cancer. I became more informed [through my Facebook support group], and felt better making active decisions for myself, and it made me feel somewhat hopeful about my medication.*" (Patient 150) "*The degree to which patients say 'Oh, I wish I would have come sooner' when they do finally come is. In some ways it's gratifying, in some ways it's disheartening.*

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Theme	Exemplary Quotes
	I've done a fair amount of speaking at patient support organizations … just trying to help people understand how palliative care can help people when they're getting disease directed therapy and that it's not like the on off switch that you turn us on when you turn off disease directed care." (PID 11; Oncology Chaplain)
Trust: Trust in providers facilitated timely referrals to palliative and supportive care	"*African Americans black and Latinos have been mistreated … So you know, we know that, to address a lot of mistrust in the system right and, in these patients, they may take a little longer, you know, to kind of connect.*" (Patient 15) "*I had a meltdown I finally emailed my oncologist and I said I don't know what I need. But I need something and it's not in my head … And she immediately referred me to somebody and I started talking to someone on the phone … this was the first time ever that I had gone professionally for something like this.*" (Patient 104). "*Obviously different cultures have varying opinions about medical professions. It's hard to gain trust, sometimes, and I think with the advanced diagnosis of breast cancer that's a different conversation and with time patients start to trust us. and especially by the time we get control of the cancer and they're not in pain, we have their trust like that you know.*" (PID 13; Oncology Psychologist)
External Support: Community organizations facilitated PC support by mitigating addressing social determinants of health allowing for opportunities to engage in early PC.	" [*Community Organization*] *provides support for metastatic women throughout their entire life, giving them things that people would otherwise have to spend money on. So like I don't have a nutritionist benefit through my insurance. I'd have to pay for that. So I can meet with her. Talk about my nutrition issues or what I have questions on … once you connect with one person or one organization then you get connected with others.*" (Patient 130) "*A lot of our women don't have sick time, don't have vacation time … they need to pay their rent and so helping patients identify those financial services … Trying to identify those very specific services for women who have advanced cancer. There are cases where we had women who were very advanced cancer, and so they needed an oxygen tank but they didn't have Medicaid they were undocumented, and so we were able to identify resources that provided oxygen to some women we identified resources that provided hospital bed.*" (PID 7; Community navigator)

Abbreviations: PTID: Patient Study ID Number; PID: Provider Study ID Number.