



# Exploring cancer care needs for Latinx adults: a qualitative evaluation

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## Abstract

**Purpose** Latinx adults with cancer, as compared with non-Latinx White adults, are diagnosed with more advanced stages and experience worse quality of life. Identifying barriers in cancer care among low-income Latinx adults is crucial to designing and implementing culturally appropriate interventions. The objective of this study was to explore the specific barriers encountered by Latinx adults after a cancer diagnosis and perspectives on the use of community health workers (CHWs) to address these barriers.

**Methods** We conducted semi-structured qualitative interviews with low-income Latinx adults with a past or current history of cancer and/or their caregivers in a community oncology clinic located in an agricultural community in California. Analysis was based in grounded theory and performed using the constant comparative method.

**Results** Sixteen interviews were conducted with patients alone ( $n = 11$ ), a caregiver alone ( $n = 1$ ), and patient-caregiver pairs ( $n = 4$  patients;  $n = 4$  caregivers). Four major themes emerged: (1) low cancer health literacy including cancer diagnosis and treatment, cancer fatalism, navigating next steps after diagnosis, advance directives, and precision medicine; (2) challenges in communicating and receiving supportive services due to language barriers; (3) stress and anxiety regarding financial hardships related to job loss, insurance barriers, and the COVID-19 pandemic; (4) the need for supportive, bilingual, and bicultural personnel to assist in overcoming these challenges.

**Conclusions** Low-income Latinx adults with cancer and their caregivers experience health literacy, communication, and financial barriers that impede quality cancer care delivery. Embedding CHWs in the care team could be one way to address these barriers to culturally concordant, accessible care.

**Keywords** Community health worker · Cancer care · Health disparities · Community-engaged · Language barrier · Advanced directives

## Abbreviations

CHWs Community health workers

PCC Pacific Cancer Care

## Introduction

Cancer incidence and mortality continue to decline in the USA, yet cancer remains the number one cause of death among the Latinx population [1]. Latinx adults with cancer as compared with non-Latinx White adults have more advanced stages of disease at diagnosis [2], are under-represented in clinical trials [3] and precision medicine research [4], and experience worse cancer-related quality of life [5, 6]. These disparities are more pronounced for low-income Latinx adults [7–9]. Finding ways to improve outcomes for this disproportionately affected population remains a critical need. Identifying unmet cancer care needs among low-income Latinx adults and their caregivers to design and implement culturally appropriate interventions is an important step in addressing cancer disparities.

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Studies aimed at understanding cancer care needs from the perspective of Latinx adults have mainly focused on cancer screening [10, 11] and the needs of cancer survivors [12, 13]. One study identified medical, financial, socio-cultural, and mental health needs among Latinx adults undergoing treatment for lung and head and neck cancers [14]. However, to our knowledge, limited studies have explored specific needs that may be contributing to cancer disparities and potential interventions to overcome disparities among low-income Latinx populations.

In prior work, our team developed an intervention using community health workers (CHWs) also known as lay health workers [15], to encourage patients to discuss advance care planning [16] and symptom burden [17] with their cancer care teams. CHWs, nonclinical members of the community trained to promote culturally appropriate health education and facilitate access to health care services [18], have been integrated into preventive care [19, 20] and abnormal diagnostic tests follow-up [21]. Yet, it remains unknown whether low-income Latinx adults with cancer and their caregivers would support the integration of CHWs into their cancer care.

The objective of this formative qualitative study was to explore: (1) the specific cancer care needs and barriers encountered by low-income Latinx adults with cancer and their caregivers, and (2) perspectives of low-income Latinx adults with cancer and their caregivers on the use of CHWs to assist with cancer care delivery in collaboration with a local community cancer clinic.

## Methods

### Study design

We conducted semi-structured, in-depth qualitative interviews with low-income Latinx participants with a past or current history of cancer and their caregivers from September 21, 2020, to October 30, 2020. Due to COVID-19 pandemic safety concerns, participants had the option to schedule an in-person interview at the local community cancer clinic or an interview over the phone. All participants provided verbal informed consent to participate in the study and were advised that their responses could be published as anonymized quotes from multiple interview subjects grouped into themes. The study was approved by the Stanford University Institutional Review Board.

Two bilingual, bicultural trained CHWs conducted the 30-min interviews. Interviewers conducted interviews in the language of preference of the participant (English or Spanish). All interviews were audio-recorded, transcribed, and translated by lead author (GR), a native Spanish speaker.

Interviews were completed when thematic saturation was reached.

### Measures

Interviewers used a semi-structured interview guide that included suggested probes (Appendix). The interview guide was co-developed by the principal investigator (MP), community health workers (ML, JO), local community oncologist (ZK), and community advocates (YD, DO). The interview guide was based on the Theoretical Model of Cancer Health Disparities [22] in which barriers to care faced by minoritized populations or populations with low socioeconomic status can lead to worse health outcomes, a literature review, personal experiences in cancer health equity, and from feedback from a pre-established local community advisory board. Questions were designed to solicit perspectives on cancer care needs encountered during diagnosis and treatment and to explore the role a CHW could play in addressing those needs. Additional questions were included to explore the impact of COVID-19 on cancer care as these interviews were conducted during the pandemic.

### Participants and setting

The setting for the study was Pacific Cancer Care (PCC), a community cancer clinic located in Monterey County, CA, a rural agricultural community comprised of 60% Latinx residents. PCC is the largest referral center in the region for patients with cancer and provides care to over 6100 patients with cancer, with at least 12% who self-identify as Latinx and half of whom have public or no insurance coverage. Inclusion criteria included a diagnosis of cancer within the last 3 years, age of 18 years or older, and self-identified Latinx participants from low-income households. Participants were excluded if they lacked capacity to consent to all study procedures. Low-income was defined based on the Housing Authority of the County of Monterey definition for housing assistance programs in Monterey County: \$39,800 or less for a 1-person household and \$56,850 or less for a 4-person household. Participants were screened for eligibility by the primary oncologist and referred to the study coordinator. Caregivers of patients who met the eligibility criteria were also invited to participate and referred to the study coordinator for inclusion. When a patient and their caregiver participated in the interview together, each participant had the opportunity to answer the questions themselves. Each participant received a \$25 gift card for their participation.

### Data analysis

The analysis was based in grounded theory and performed using the constant comparative method [23, 24]. Two

researchers (GR, ML) read the transcribed text using the open coding technique and created codes. The research team used the codes to create a codebook which was used by four coders (GR, ML, JO, MP) who independently applied the focus coding technique and discussed discrepancies and modified the codebook. Three coders self-identify as Latinx. Interrater reliability was ensured by coding the first several transcripts as a group and then individually coding and meeting together regularly to discuss data interpretation. After ongoing and iterative analysis, consensus was reached among multiple investigators with respect to thematic saturation. To measure interrater reliability, we calculated a Cohen's  $\kappa$  using all quotes from the major code categories. The kappa scores ranged from 92 to 97% suggesting excellent interrater reliability.

## Results

Twenty-one potential participants were approached for inclusion in the study, one of whom declined to participate. A total of 16 interviews were conducted with 20 participants: 11 involved the patient alone, 4 involved the patient and a designated caregiver, and 1 involved a caregiver alone. All interviews were conducted in Spanish. Twelve participants identified as female and 8 as male. The median age of the participants was 52 years of age. Table 1 shows participant demographic and clinical characteristics. Eight participants had gastrointestinal cancer, two had breast cancer, one had kidney cancer, one had melanoma, one had ovarian cancer, and one had multiple myeloma. One of the participants did not disclose their cancer diagnosis. Fourteen participants were receiving active treatment at the time of the study.

The analysis revealed four major themes: (1) low cancer health literacy including cancer diagnosis and treatment, cancer fatalism, navigating next steps after diagnosis, advance directives, and precision medicine; (2) challenges in communicating cancer care needs and receiving supportive services due to language barriers; (3) stress and anxiety regarding financial hardships related to job loss, insurance barriers, and the COVID-19 pandemic; (4) the need for supportive, bilingual, and bicultural personnel to assist in overcoming these challenges. Table 2 shows the supporting quotes of the themes and subthemes.

### Theme 1: low cancer health literacy including cancer diagnosis and treatment, cancer fatalism, navigating next steps after diagnosis, advance directives, and precision medicine

Low cancer health literacy regarding significance of a cancer diagnosis and treatment and how they might impact a patient's quality and length of life was prevalent. In addition,

**Table 1** Demographics and clinical characteristics of participants

Characteristics	Value
Age in years (median, range)	52 (35–80)
Participants (N, %)	
Patients	15 (75.0)
Caregivers	5 (25.0)
Race/ethnicity (N, %)	
Latinx	20 (100)
Gender (N, %)	
Female	12 (60.0)
Male	8 (40.0)
Anatomic site of cancer diagnosis (N, %)	
GI	8 (50.0)
Breast	2 (12.5)
Kidney	1 (6.2)
Melanoma	1 (6.2)
Ovarian	1 (6.3)
Multiple myeloma	1 (6.3)
Unknown	1 (6.3)
Treatment (N, %)	
Receiving active treatment	14 (93.3)
Oral chemotherapy	5 (35.7)
Intravenous chemotherapy	7 (50.0)
Immunotherapy	1 (7.1)
Radiation	1 (7.1)
Not receiving active treatment	1 (6.7)

participants assumed that their cancer diagnosis would inevitably result in their death.

One participant noted, “*When I woke up, I wanted to find something small, but she [the surgeon] told me that she could not save my right kidney and had to remove the entire tumor with it. Then recovery came, and for me it was new. I didn't even know what cancer was. Nor that I had to go to an oncologist, nothing.*”

A participant noted, “*Especially because we tend to have the idea of associating cancer with death. We associate cancer with being completely lethal and incurable.*”

Participants feel lost and unsure about the next steps to take after receiving their diagnosis. Many expressed that they did not know what questions to ask or who to ask. One participant said, “*Yes, I did have a lot of concern. I did not know who to call or where I would make my appointments to be honest.*”

Low health literacy on the significance of advance care planning was a prevalent subtheme. Some participants had designated an emergency contact, and some had discussions with their caregivers, but no participant had discussed their values, preferences, and goals for care with their oncologist or other clinical team members. Participants also were not made aware of advance directives. After explaining

**Table 2** Frequency of themes

Theme and subthemes	Supportive quotes	Number of unique patients expressing themes or subthemes	Number of unique caregivers expressing themes or subthemes	Total number of unique participants expressing themes or subthemes
Theme 1: low cancer health literacy		15/15	5/5	20/20
Subtheme 1: low health literacy on cancer diagnosis and treatment	<i>At the beginning it would be difficult because we didn't understand since we don't know anything about cancer. I did not know what treatments were available for me. I didn't know. I got very scared</i>	10/15	1/5	11/20
Subtheme 2: perception of cancer fatalism	<i>I wanted to cry because when they tell you the word cancer, you start thinking about death.</i>	9/15	2/5	11/20
Subtheme 3: difficulty navigating next steps	<i>I was worried that I would die soon. In my case, I didn't have medical services, so I had to look for help. I didn't know who to turn to. I didn't know where to go. We started to search how we could obtain more information about what the next step would be because the next step would be more complicated.</i>	8/15	2/5	10/20
Subtheme 4: low health literacy of advance care planning	<i>No, no, I've never heard of an advanced directive.</i>	15/15	4/5	19/20
Subtheme 5: low health literacy of precision medicine	<i>No, to be honest, no one talked about it. The truth is that I don't know what a genetic test is.</i>	15/20	4/5	19/20
Theme 2: challenges in communicating cancer care needs and receiving supportive services due to language barriers	<i>Test the DNA? Not that I know. Well, my English is a little bit poor, right, because I do understand but I can't carry a conversation. Sometimes I don't answer or sometimes they speak English, and they don't understand me.</i>	14/15	3/5	17/20
Theme 3: stress and anxiety regarding financial hardships related to job loss and insurance barriers		14/15	1/5	15/20
Subtheme 1: financial hardships due to cancer diagnosis	<i>I start worrying that I can't work—that I can't pay anything. You see, there are different things I need to pay, and unfortunately, I can't do anything. My biggest concern is that I haven't been able to work since May when I ended up in the hospital.</i>	8/20	0/5	8/20

Table 2 (continued)

Theme and subthemes	Supportive quotes	Number of unique patients expressing themes or subthemes	Number of unique caregivers expressing themes or subthemes	Total number of unique participants expressing themes or subthemes
Subtheme 2: financial hardships exacerbated by COVID-19 pandemic	Well, it has affected us financially. It has affected us a lot, and we are scared... thinking what we are going to do next? Well, first they gave them a small break from work, but then they laid them off definitively. I did have some difficulty because at times I did have to go and ask for help to pay those large payments because I didn't have insurance. The insurance is not covering me right now. I have to pay for it [treatment]. We don't know where or how to get help.	10/20	0/5	10/20
Subtheme 3: financial hardships due to insurance barriers		8/15	2/5	10/20
Theme 4: need for supportive, bilingual, and bicultural personnel		15/15	5/5	20/20
Subtheme 1: a CHW role is unfamiliar	Oh, is she like the person who helps you at home? Well, is she a social worker?	15/15	5/5	20/20
Subtheme 2: a CHW can assist with cancer education	[A CHW can help] giving us much more information because the information is sometimes diffuse and complicated. If there was someone to advise you, to help you and tell you...look after the cancer surgery you need to have a treatment, so it does not get worse.	7/15	2/5	9/20
Subtheme 3: a CHW can assist with navigation	Someone who held me by the hand like to show me how to do everything, who to turn to, what programs to apply for, and when to do what needs to be done. Yes, if they [a CHW] provide you that help in the beginning... someone to guide you where you have to go. It's not easy.	11/15	2/5	13/20
Subtheme 4: a CHW can offer emotional support	It [having a CHW] would be helpful because you would have another person with you during the process. They would also be a huge moral support for the person receiving treatment. They [a CHW] can help you a lot on how to deal with the stress you get when dealing with cancer.	7/15	2/5	9/20

**Table 2** (continued)

Theme and subthemes	Supportive quotes	Number of unique patients expressing themes or subthemes	Number of unique caregivers expressing themes or subthemes	Total number of unique participants expressing themes or subthemes
Subtheme 5: a CHW can offer resources	Well, helping get my treatment, get my Medi-Cal, help me get phone numbers of other people to help me get my treatment. Give us several options on what we could do, the different foundations that could help me, help us with paperwork and to submit some forms to apply for several benefits.	9/15	2/5	11/20

advanced directives, during the interview, a participant acknowledged the importance of them.

One participant stated, “No, no, no. I only placed, for example, my daughter and my sister as emergency contacts but not that [advance care planning].”

A caregiver stated, “A will? What is a will? If my wife is unable to respond I would manage it.”

Participants, specifically, noted lack of discussion and comprehension of precision medicine. Participants stated that they had not been made aware of the reason for tumor testing nor heard of such testing, but several associated genetic testing with searching for hereditary cancers. Some participants assumed they had tumor testing performed but were unsure.

A participant stated, “No, no I don’t know much about these tests. Like is the cancer hereditary?”.

**Theme 2: challenges in communicating cancer care needs and receiving supportive services due to language barriers**

Participants regularly encountered communication barriers with their cancer care team and noted difficulties due to limited English proficiency. Participants were more comfortable speaking in Spanish and requested an interpreter to help communicate with their oncologist even if they had basic English proficiency levels. One participant stated, “I sometimes use an interpreter because even though I speak every-day English, when we get to the medical part, I get stuck.”

Another participant said, “I did not talk to her [the doctor] because she is an American, and she did not speak Spanish at all. She had a nurse, a translator, but well I just asked the basic questions, just the basics that they can answer, and that’s it...it’s over, and you can’t stay there chatting about your problems or asking questions.”

Language barriers prevented participants to ask complex follow-up cancer-related questions, actively engage in treatment discussions, or join cancer support groups because these services were all conducted in English.

One participant stated, “Yes, yes, yes, they would get together and speak to me. But now...it’s like...it’s like if they ask you something and you don’t understand what can you say? Whatever they think is best...give me that.”

Another participant reported, “There are existing support groups, psychological support, moral support which we should have more access. Not all of them are in Spanish. Not all of them are in different languages. That would be helpful.”

During the COVID-19 pandemic, participants preferred in-person visits over telemedicine partly due to feeling they could communicate better in person. Having an English-speaking caregiver accompany them to their appointments was helpful.

One respondent mentioned, *“Well I prefer it much better in person because I write down...with the chemo you know how you can have a lot of aches, so I am the type of person that writes down questions on my notebook, and since I do not speak English, I prefer to go in person.”*

### **Theme 3: stress and anxiety regarding financial hardships related to job loss, insurance barriers, and the COVID-19 pandemic**

Participants described stress and anxiety related to financial concerns after receiving a cancer diagnosis or after initiating cancer-directed treatment. Participants reported they had to decrease their working hours or stop working due to treatment side effects and noted the impact on their anxiety regarding paying for treatment and supporting their households.

A respondent stated, *“I have to go to the places like the salvation army where I didn’t go before to look for clothes or shoes.”*

Many depended on their family members or friends for financial support and help with paying rent and bills.

A respondent said, *“I do get depressed because I feel a little worried because I have to pay bills. I have to pay several things and the truth is ... sometimes there are people or friends who give me 100 dollars, they give me 200 dollars, and with that I have been hanging in there, but I really worry right now because I can’t work... and then I can’t get money to pay my bills.”*

During the COVID-19 pandemic, family members also experienced job loss and decreased earnings causing additional stress and anxiety regarding financial hardships. Participants noted that financial resources, such as financial counseling, would be valuable.

One participant noted, *“Yes, almost all [my children] lost their job...since there are three, they were here in my house, and we struggled with the rent and all of that. Like I was telling you, right now I am not contributing anything. I have requested unemployment benefits, but look, right now my card has not arrived and it’s already the 30th and we pay the rent the 3rd so I am going to start seeing who can pitch in for my rent.”*

Participants also experienced concerns regarding loss of insurance due to loss of employment.

One participant said, *“Then she [the doctor] asked me if I wanted to stop working and I wanted to continue to work because of my insurance. I wanted to continue to work, and she was surprised. Do you really want to continue working? And I said yes. I would go to work at night, and I was not eating well. I was not feeding myself well.”*

### **Theme 4: need for supportive, bilingual, and bicultural personnel to assist in overcoming encountered challenges**

None of the respondents had known a CHW or their intended roles prior to this interview, and many assumed this role to be one of a social worker. However, after describing the definition and the role of a CHW, participants reported that having the support of a bicultural, bilingual CHW would be valuable.

A participant mentioned, *“But when you’re just starting, if there is someone to advise you, for example, in the hospital when you have cancer surgery and you quickly [need to] have an oncologist, you have someone to help you and tell you this can happen to you ... or if someone new like me comes here to the clinic and they know they have cancer it would be good for a worker to say you know ... this can happen to you if you don’t stop working... this can happen to you regarding the chemo.”*

Specifically, participants described that CHWs can guide and educate them after a cancer diagnosis.

A respondent stated, *“Well, yes, like helping us understand...you think all the cancer are dangerous, but then I thought there are some a that are more difficult than others... like pancreas compared to skin.”*

In addition, participants described that CHWs can help connect them with cancer support groups, assist with clinic follow-up appointments, offer emotional support, and be available for questions that arise during their cancer care.

One stated, *“During the first visit when they told me that in fact what they saw on the tests was a cancerous tumor...hmm... my wife was with me, and they allowed one person to come in, but the impact is very big...it’s a very big psychological impact. And it would be helpful that on the following visits a person [a CHW] could be there especially...especially because the sick person in under a lot of psychological pressure.”*

One participant said, *“No, I don’t expect her to know everything that is happening to me or how I am feeling, but to have the most information possible to funnel my...with whom to funnel my questions, whether they are medical, psychological, or economic, and she should have access to that.”*

## **Discussion**

In this study among low-income Latinx adults with cancer and their caregivers, we identified specific and modifiable unmet needs in cancer care delivery that contribute to disparities among low-income populations with cancer. Many of the needs identified by participants could be overcome through the incorporation of CHWs into their cancer care.



Specifically, our study uncovered low cancer health literacy, financial hardships, language discordance between clinical team members and patients that preclude appropriate and adequate communication, and the overwhelming need for supportive, bicultural, bilingual personnel, such as CHWs, to assist in overcoming these challenges.

In this study, similar to prior studies [25, 26], participant experienced low health literacy of many aspects of cancer, including basic cancer care. Low health literacy of precision medicine, a fundamental component of cancer diagnostics that can impact treatment options, was especially pronounced. These findings are consistent with prior studies noting that the majority of Latinx adults were not made aware of precision medicine [27, 28] which may contribute to the lower rates of genomic testing [29] and underrepresentation of Latinx adults in precision medicine research [30] as compared to White adults. Furthermore, consistent with prior literature, Latinx adults reported limited understanding of advance care planning and advanced directives [31] which may contribute to the known lower rates of advance care planning discussions, advance directive documentation, and hospice use among Latinx adults compared with White adults [32].

Our study identified that language-concordant communication is a key factor in overcoming disparities in cancer care among low-income Latinx adults. Prior literature has documented that limited English proficiency can affect cancer screening [33], clinical trial enrollment [34], and communication with clinical teams [35]—all essential factors in cancer care. Participants in the present study described communication challenges in the cancer care setting with lack of clinic-based language-concordant resources and staffing that inhibited participation in important cancer care conversations, such as advance care planning, with their providers due to limited English proficiency. Furthermore, participants' desires for greater access to care delivered in Spanish also highlight the importance of ancillary care services such as supportive care groups to be offered in Spanish.

Our study revealed high levels of concern and anxiety due to financial hardships. These findings are consistent with prior studies that have shown high financial burden among adults with cancer including employment loss after diagnosis [36] and challenges in paying bills [37]. Among Latinx adults with cancer, higher financial burden persists more than a year after diagnosis as compared to non-Latinx White adults with cancer [38]. Lower social economic status and the type of insurance coverage (private versus public) can further exacerbate financial hardships [38] as was evidenced by our study results. The COVID-19 pandemic worsened the financial burden among Latinx adults, as described by participants in our study and other studies [39], due to disproportionate job loss and lower

wages among Latinx populations compared with other racial and ethnic groups [39]. Other studies have reported increased anxiety [40] and food insecurity [41] due to the pandemic. These results are an important area of current and likely future unmet needs among Latinx populations with cancer that require attention and intervention.

In this study, bilingual, bicultural personnel such as CHWs were encouraged as an approach to improve cancer care delivery. Specifically, all study participants expressed desire for integrated, bicultural, and bilingual personnel to assist with delivery of culturally tailored and language-specific education regarding cancer diagnosis and prognosis, precision medicine, navigation of care, insurance applications, and connection to financial support resources. In our prior work, CHW-led interventions increased engagement of patients with cancer in their care, specifically increasing goals of care documentation and reducing symptom burden [16]. Expanding the role of CHWs to ensure culturally tailored, personalized cancer care in patients' preferred languages in the context of precision medicine may be one approach to support Latinx adults across the cancer continuum.

This study had several strengths and limitations. First, through qualitative semi-structured interviews, we elicited rich data regarding the experiences of low-income Latinx adults in their cancer care that can inform interventions aimed to improve care delivery among these populations. Second, although we had low participation from patients with hematologic malignancies who may have different cancer care needs than the ones we identified, we had representation of the most prevalent cancer diagnoses in the Latinx population such as gastrointestinal and breast cancer. Third, as inherent to qualitative studies, this study may have experienced respondent bias, in which participants may have given answers that they think would be better accepted, especially for sensitive or personal questions. However, we reached thematic saturation and, of the 21 participants who were identified as eligible for the study, only one declined. Fourth, we had an unbalanced number of caregivers and patients which could have led to sampling bias. Fifth, all the participants in the study chose to complete their interviews in Spanish, which could reflect a less acculturated sample. It is possible that their experiences may differ from more acculturated Latinx adults with cancer. Finally, this study is exploratory in nature and the experiences of Latinx adults with cancer and their caregivers living in a rural, agricultural county may differ across different settings.

In conclusion, we identified systems-level, modifiable needs among low-income Latinx adults and their caregivers after a diagnosis of cancer. The findings highlight barriers that contribute to disparities and approaches that can be integrated into clinical care delivery to overcome disparities among these populations.



## Appendix. Stem questions for the semi-structured interviews

### Interview guide

1. What were your main concerns when you were told you had cancer?
2. How did you cope with these concerns?
3. How could a community health worker help address these concerns?
4. What did your healthcare provider tell you about genetic testing/tumor testing, if any?
5. Tell us what you know about advanced directives.
6. What was important to you when you started your cancer treatment?
7. What were some concerns or challenges during your cancer treatment?
8. How could a community health worker help address these concerns?
9. Tell us how COVID-19 has impacted your cancer care.
10. How else can a community health worker help address your cancer needs?

**Author contribution** G.M.R. wrote the main manuscript text and prepared Tables 1 and 2 with the help of E.H.W., G.V., M.P. G.V., and L.G.R. M.L. collected the data. G.M.R., M.L., and J.O. analyzed the data with the help of M.P. M.P. designed the study and conceived the idea in collaboration with Z.K., Y.D., and D.O. All authors discussed the results, provided critical feedback, and contributed to the final manuscript.

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### Declarations

**Ethics approval** Stanford University Institutional Review Board #53093.

**Consent to participate** Informed verbal consent was obtained from all individual participants included in the study.

**Consent for publication** The authors affirm that human research participants provided informed consent to have their responses published as anonymized quotes from multiple interview subjects grouped into themes.

**Competing interests** The authors declare no competing interests.

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