Published in final edited form as:

Am J Hosp Palliat Care. 2017 July ; 34(6): 510–517. doi:10.1177/1049909116631776.

The Desires of Their Hearts: The Multidisciplinary Perspectives of African Americans on End-of-Life Care in the African American Community

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Abstract

Background: Studies have identified racial differences in advance care planning and use of hospice for care at the end of life. Multiple reasons for underuse among African American patients and their families have been proposed and deserve further exploration.

Objective: The goal of this study was to examine perceptions of advance care planning, palliative care, and hospice among a diverse sample of African Americans with varying degrees of personal and professional experience with end-of-life care and use these responses to inform a culturally sensitive intervention to promote awareness of these options.

Methods: Semistructured interviews and focus groups were conducted with African Americans who had varying degrees of experience and exposure to end-of-life care both personally and professionally. We conducted in-depth qualitative analyses of these interviews and focus group transcripts and determined that thematic saturation had been achieved.

Results: Several themes emerged. Participants felt that advance care planning, palliative care, and hospice can be beneficial to African American patients and their families but identified specific barriers to completion of advance directives and hospice enrollment, including lack of knowledge, fear that these measures may hasten death or cause providers to deliver inadequate

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Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

care, and perceived conflict with patients' faith and religious beliefs. Providers described approaches they use to address these barriers in their practices.

Conclusion: Findings, which are consistent with and further elucidate those identified from previous research, will inform design of a culturally sensitive intervention to increase awareness and understanding of advance care planning, palliative care, and hospice among members of the African American community.

Keywords

African Americans; end-of-life care; advance care planning; hospice; palliative care

Introduction

African Americans have traditionally been found to complete advance directives and enroll in hospice less often than their white counterparts.^{1–6} Several theories for these racial differences have been proposed, and a number of studies have examined these racial differences in completion of advance directives, hospice enrollment, perceptions of hospice quality, and even hospice revocation.^{3,4,7–21} For instance, some studies suggest that an overall lack of knowledge or misunderstanding about advance care planning, palliative care, and hospice may play a role.^{7,12,17} Others suggest completion of an advance directive or enrollment in hospice can be construed as losing faith in God or conflict with patients' and family members' spiritual or religious beliefs.^{2,3} Mistrust in the medical system among members of the African American community has often been cited as a cause for disparities in health care that persist even at the end of life.^{2,7,11} While these studies certainly add to a growing body of literature on end-of-life (EOL) care among African Americans, very little research has been done to transform these findings into interventions to enhance consideration of EOL options.

The goal of our study was to not only examine perceptions of advance care planning, palliative care, and hospice from the perspectives of African American providers, caregivers, and patients but also to use our findings to inform development of a culturally sensitive intervention that will increase awareness of these options among a segment of the population that has historically underutilized them. We believe that this study is one of a few that uses qualitative methods to examine racial differences in EOL care from a multidimensional view of African Americans—those who have provided EOL care, are recipients of EOL care themselves (as patients or caregivers), and those who have done both.

Methods

We conducted semistructured interviews with an African American hospice and palliative medicine physician, an African American palliative care nurse practitioner, an African American minister who had also served as a hospital and hospice chaplain, 2 African American caregivers of hospice patients, and a current African American hospice patient to gauge their perceptions of EOL care, barriers to EOL care, and specific strategies the providers use to counteract those barriers among members of the African American community. To ensure that we examined perceptions of EOL care from diverse group, we

followed these interviews with focus groups that included community-dwelling African Americans who received care at one of our University-affiliated clinics or hospitals, served as a caregiver for someone who received care at one of our University-affiliated clinics or hospitals, or were recommended by others to participate based on their personal experiences with EOL care. We followed the approach of purposive sampling among a diverse set of persons who had experience with the provision and/or receipt of palliative care, hospice care, or provision of counsel to seriously or terminally ill persons and their families. All respondents gave verbal consent to participate per UT Southwestern Medical Center Institutional Review Board-approved protocol.

Question Guide

The interview templates were made up of 18 questions that explored respondents' personal and/or professional experiences with EOL care or the care of a seriously ill loved one. Participants were asked about their perspectives on advance care planning, palliative care, and hospice care in the African American community and to identify what they believed were barriers to completion of advance directives and hospice enrollment among members of the African American community. Respondents were also asked how they would counsel a patient, congregant (if applicable), friend, or loved one about completion of an advance directive or enrollment in hospice. Similarly, focus group templates were made up of questions that expounded on participants' experiences with EOL care, their knowledge of treatment options (i.e., advance care planning, palliative care, and hospice), and ways that barriers to participation in these treatment plans could be addressed. The semistructured interview and focus group templates were developed with input from all members of the study team.

Data Collection and Data Coding

The study period was from November 18, 2014, to October 2, 2015. Interviews and focus groups were transcribed, and they were coded by 2 individuals (Ramona L. Rhodes and Bryan Elwood). At periodic intervals, data were discussed, and the coding scheme was refined. Disagreements were resolved by discussion, and although a third individual was available (Simon C. Lee) to resolve any disagreements, the 2 coders were able to come to consensus on the coding scheme. The codes identified fell under the categories of benefits and barriers to completion of advance care planning and hospice enrollment, strategies to increase awareness of options for EOL care, and personal and professional experiences with EOL care in the African American community. Participants were enrolled until thematic saturation was reached, and no additional emerging themes were identified.

Results

Semistructured Interview Participants

Of the 17 participants, 6 completed semistructured interviews. The interview participants consisted of a convenience sample of women who self-identified as African American and had varying degrees of involvement with hospice and/or palliative care: a board-certified hospice and palliative care physician who served as medical director for a local hospice agency, a palliative care nurse practitioner who worked for a local safety-net hospital

system, a minister who had served as a church pastor and hospice/hospital chaplain, 2 caregivers of patients (with advanced dementia and cancer diagnoses) who received hospice care, and 1 current hospice patient. The hospice and palliative medicine providers and ministers who were interviewed had personal experience with the care of a loved one who was either terminally or seriously ill in addition to their professional work. The interviews ranged from 25 to 64 minutes in duration, were video recorded for potential use in development of a culturally sensitive educational intervention for EOL care for African Americans, and transcribed for analysis.

Focus Group Participants

Eleven participants participated in 1 of 2 focus groups. Four participants (2 men and 2 women) were members of our UT Southwestern Center for Patient Centered Outcomes Research (PCOR) Community Advisory Panel (CAP), a panel of community members with a connection to Parkland, our local safety-net hospital, as patients or family members of patients who receive care there. Two participants were African American men who served as ministers in local churches with predominantly African American congregations. The remaining 5 participants were women who received care from one of our university-affiliated clinics, served as caregiver for someone who received care from one of our university-affiliated clinics, or were recommended based on their personal experiences with EOL care. The focus groups lasted 90 minutes and were audio-recorded and transcribed for analysis. Selected themes and additional quotations from the semistructured interviews and focus groups are included in Table 1.

Themes

Sharing Personal Experiences With EOL Care

The health care providers, ministers, and caregivers who were interviewed shared their personal experiences with EOL care. They admitted that making decisions and being involved in EOL discussions about their own loved ones was difficult, but they understood the importance of focusing on their loved ones' experiences instead of their own feelings about their loved ones' care and, ultimately, their passing. A minister, who participated in one of the semistructured interviews, described her feelings about her mother's care at the end of life in the following way:

When my mom died, I didn't want her to go, but she was not in good shape. She was in a lot of pain, and she had been praying for at least three years, that she would say, "Lord, I'm tired. I just want to go home. I'm ready to go home." At first I couldn't pray that prayer with her, because, I was like, "No, my mom. I don't want my mom to go." But I saw her about three months before she died, and she was in so much pain. At that point, I could say, "God, give her the desires of her heart, because I don't want to see my mother laying there suffering like that." It just felt, for me, to continue to hold on ... just felt selfish. I miss her, but am so happy for her. I am.

The respondents also described conflicts experienced with other family members—particularly those who were not as closely involved in caregiving and preferred aggressive

treatment at the end of their loved one's life but stated that their family members eventually became more accepting of the process over time.

The Importance of Completing an Advance Directive

Several participants in the interviews and focus groups felt that having an advance directive was important and emphasized that everyone should have one regardless of current health status or age. Some felt that having an advance directive in place would take pressure off of family members to make decisions regarding care of the seriously ill. A caregiver of a hospice patient and semistructured interview participant said:

I think that it's important for the purpose of, if nothing else, but keeping down a lot of anxiety. If you've got siblings ... or other family members who come in because they think you don't make the right decision or you're not taking care of their loved one ... you can always present them with a copy, and say, this is what we discussed and this is what Momma wants ... They don't have to take your word for it. Here it is, right here.

Barriers to Completion of Advance Care Planning Among African Americans

Respondents identified certain barriers to completion of advance care planning among members of the African American community. Some felt that a lack of understanding about what advance care planning is and should include (ie, completion of a living will or do-not-resuscitate order, identification of a medical power of attorney, etc) was a barrier. They said lack of knowledge about advance directives created a fear of completing them. Others felt that some would think that completion of an advance directive or other document would mean that health-care providers would no longer care for them or it would hasten death. A hospice provider said, "That's the other reason why people just don't want to sign advance directives. It's like you're saying, 'Well, bring it [death] on.'"

Faith in God was also perceived as a barrier to advance care planning. A minister said:

... I think faith is a factor as well. I think in our tradition God has the first word and the last word, and I think there are some who feel that using an advance directive takes something away from God, that it makes God not the all-powerful being that we know God to be or expect God to be. And so I think we tend to shy away from it ... because we feel that it somehow goes against our faith, you know. It's not a matter of losing faith ... we're all going to die at some point.... Our Christian faith teaches us that there is a life beyond this life ... and our hope, our belief, is that the life beyond this life is a better life.

Another minister and focus group participant said:

There is nothing that I can do in my human capacity that will limit God. God is limitless. God is omnipotent, an all-powerful, allknowing God. If He decides that He wants to heal me, whether I decide to have a directive or not, you know, that's His will ... I can still plan and put things in order and believe God at the same time. It doesn't mean that I'm giving up.

The Benefits of Palliative Care

The respondents who were palliative care providers realized that many patients and families are not familiar with the concept of palliative care, and other participants acknowledged little understanding of the concept of palliative care. When asked how they would describe palliative care to patients and families, the providers emphasized that palliative care is provided by an interdisciplinary team that will not only treat symptoms related to underlying illness but also provide much needed support during a very challenging time. A palliative medicine provider said:

... A lot of times we ignore the fact that the patient is a person—a person with feelings. A person with symptoms that could be, you know, pain, anxiety, and depression. There could be physical issues, psychosocial and spiritual issues that need to be addressed at this time ... I'll be there to help them navigate through the diagnosis as well as help with working on symptoms and helping them be comfortable.

Both providers also felt that it was important for patients and families to know that patients who receive palliative care can continue to get their usual care, and in some instances, palliative care can be provided in the inpatient and outpatient setting.

The Benefits of Hospice

All respondents said hospice was beneficial to patients who are terminally ill. Providers who had their own experiences with hospice described those experiences. A minister and interviewee reported that, "Hospice is a wonderful service, and for me a wonderful ministry for patients who are facing the end of life. For the patient and for the family—the care that patients and families received from hospice staff is just priceless. It really is." A current hospice patient also described her hospice experience when she said, "Well there is some very sweet people that comes around, is helpful, want to be helpful ... I told them I could do it, but they still here to help me, and I love that. I love the company, the nurses that come by ... they keep me comfortable at home."

Perceived Barriers to Hospice Enrollment Among African Americans

Participants identified several different barriers to hospice enrollment, including cultural differences, conflicts with spirituality and religious preferences, overall lack of knowledge about what hospice entails, and mistrust in the medical system. A hospice provider explained perceived barriers to hospice enrollment among African Americans in this way.

I would say that there are many reasons. There are very strong cultural factors ... African Americans can be very spiritual and really place a lot of importance on spiritual and religious issues. And so, you will find African Americans worried about hospice, meaning that they're giving up on hope or giving up on faith or believing in God ... Another situation that I've encountered is just not having enough information about what hospice really is ... You know, sometimes people think that there's some kind of hospice location where their loved one won't get personal care. Another issue that I've encountered, which has been widely described in the medical literature, is mistrust of the medical care system. I've seen

it over and over again, where some African American patients feel that because of their knowledge of things that have happened in history that they may be getting less than adequate care, and that's why they're referred to hospice.

Strategies to Overcome Perceived Barriers

When asked how they would discuss hospice with members of the African American community, several approaches were mentioned. For instance, to counteract the belief that hospice means giving up on faith, caregivers who had experience with hospice mentioned the power of prayer even after enrolling in hospice. One caregiver suggested that patients and families “go and pray with the Lord about the journey they are about to take.” A minister mentioned that healing can still occur for patients on hospice, just not healing in the traditional sense.

I think that God heals us all, but God doesn't always cure us. To me, to be healed is to live as fully as you can in the present with whatever capabilities you have. That person who is living a life as fully as they can with whatever capacities they have, to me, is a healed person. God is with us and God is able to bring good out of whatever limitations we have as human beings.

Another minister and focus group participant mentioned that hospice agencies must provide education about the purpose of hospice.

They must communicate what they're all about and attempt to debunk the preconceived notions that are out there about hospice care and effectively communicate what the objective of hospice care is ... I think for me, too long hospice care has been kind of kept in a box. We take a person through all these processes, treatments and all types of rehabilitation—all types of other treatment and then when we come to what appears to be the edge, we get hospice.

Participants also mentioned that patients and families can and should continue to seek comfort from their pastor and church members and that hospice chaplains can offer much-needed additional support. They felt that if patients had this continued link with their spiritual community, and their community was also included in the process, patients and families may be more accepting of hospice care.

Respondents indicated that medical mistrust plays a role in completion of advance directives and hospice enrollment. They commented that for patients and families, EOL decision making requires time and the establishment of trust between patients, families, and providers. It also requires providers to “respect where people are” in the decision-making process and speak to them in a language that they can understand. The respondents also realized that though culture and shared experiences certainly play a role in disparities in care, learning about each individual patient is equally as important. They suggested that providers integrate religious and cultural beliefs into the care plan while maintaining that each patient has his or her own individual preferences.

Discussion

Overall, the participants expressed the belief that advance care planning is important, can help to limit conflicts among family members, and alleviate pressures to make “the right” decision for care at the end of life. Palliative care providers indicated the importance of consultation with palliative care team members as valuable opportunities to help patients understand differences between curative treatment and symptom relief with respect to their specific course of the disease. They were aware that there is a lack of knowledge about palliative care among patients and families and felt that increased education about all spectrums of care for the chronically and terminally ill should be enhanced. This was confirmed by our focus group participants. They expressed a keen interest in learning more about palliative care and what it entails. All participants believed that hospice was helpful but understood why there are barriers to enrollment among members of the African American community.

The barriers to completion of advance directives and hospice enrollment identified among those interviewed are commonly cited in the literature as significant barriers to these services among members of the African American community.^{2,3,7,11,12,17} They include medical mistrust, conflict with spirituality, and lack of knowledge. Both providers and recipients of EOL care mentioned possible ways to overcome barriers in this population. Respondents felt that it was extremely important to establish and build trust with patients and their families, avoid use of medical jargon, and allow them time to make informed decisions about their care. They recommended continued prayer, inclusion of the patient’s spiritual community throughout the process, and establishment of connections with faith-based communities so that education can be provided about these important care options. Finally, they noted that whatever decision patients and family members make about EOL care should be accepted and respected.

While the goal of this study was to examine perspectives on EOL care from the viewpoints of a diverse group of African Americans, the semistructured interviews also serve an additional purpose. These video-recorded interviews have formed the basis of development of an educational intervention that will be tested among African Americans who receive their care at a local safety-net hospital. We have used the rich commentary from the semistructured interviews to design a culturally sensitive intervention that we hope will make seriously ill African American patients and their families aware of their options for advance care planning, management of pain and other symptoms, and EOL care—a research agenda that has been limited in scope thus far. Additionally, we plan to test the feasibility, acceptability, and efficacy of this intervention and if successful, disseminate this program to other sites and settings.

There are certain limitations that should be taken into account with regard to this study. This formative research was limited to a sample of African Americans who have had some experience EOL care in one geographic area. The interviews and focus group responses are not necessarily reflective of all African American patients, caregivers, and providers of palliative care or hospice. Findings noted in this qualitative research, however, are in step with findings from other studies that have examined EOL care for African Americans.

Furthermore, our study examines perceptions of EOL care from a multidisciplinary group of providers, patients, ministers, and caregivers who have had varying degrees of personal and/or professional experiences in EOL care in a variety of care settings.

The participants in these interviews and focus groups gave insight into their lives and practices and shared their personal and professional experiences with EOL care. They further illuminated the importance of advance care planning and the benefits of palliative care and hospice. Ultimately, partnerships should be created among health care, community, and faith-based organizations so that education about these important topic areas can be more widely dispersed. This research takes the important step of moving from identification of racial differences in EOL care to the design and implementation of interventions to reduce those differences so that African American patients and their families can make decisions about their care at the end of life that are truly informed.

Acknowledgments

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The authors would like to thank the faculty and staff of the Stanford University School of Medicine Faculty Development Program in Ethnogeriatrics for their support of this work. This work was conducted with support from AHRQ grant 1R24HS022418 for the University of Texas Southwestern Center for Patient-Centered Outcomes Research. Drs. Halm and Skinner were also supported in part by the UT Southwestern Center for Translational Medicine (1U54AI108323) and the NCI-Designated Harold C. Simmons Cancer Center. The content is solely the responsibility of the authors and does not necessarily represent the official views of UT Southwestern Medical Center and its affiliated academic and health care centers, the National Institutes of Health, or the Agency for Healthcare Research and Quality.

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Table 1.

Selected Themes and Additional Quotes: Perspectives on Advance Care Planning and End-of-Life Care in the African American Community.

Theme	Quote
Conflicts between family members about loved one's end-of-life care	<p>... Even though you're brought up in the same house, in the same church, sitting side by side, as you grow older, people take different paths. Coming back to something in the home setting, they didn't really have a real understanding of the process ... Two of my sisters joked, but I think they were serious. They said, "Oh, don't let old non-compassionate [respondent's name] in my room if I get sick, because she'll unplug you in a minute!" ... I would see her [mother] 24/7 ... There's a difference when you're living there with the one that's being cared for than when you're just coming over on the weekend or sometime in the evening. So, once they came and stayed longer ... I think it resonated with their spirit, that it's just best. (Caregiver/daughter of a hospice patient, semistructured interview participant)</p> <p>... My adult children. One, my son really doesn't want to talk about it. My daughter will do it and the question for me is which one of them is strong enough ... I think my daughter is strong enough to make the decisions because she knows how I think. We've lived together for about eight years, and she knows what Mama wants and don't want—what Mama thinks. My son on the other hand, will challenge her. Now I haven't figured out a way to say to him, you can't challenge her because it is in writing ... (Patient, focus group participant)</p>
The importance of completing an advance directive	<p>My experience with that has been that most people don't have one [an advance directive], and my opinion is that everybody needs one. It doesn't matter your age, because we never know what's going to happen to us. (Minister, semistructured interview participant)</p> <p>Even though you have a terminal illness does not mean that you will pass away tomorrow. Tomorrow is not promised to anybody, so it's important to be prepared. One of our mantras I guess, is we hope for the best but prepare for the worst. (Palliative care provider, semistructured interview participant)</p> <p>African Americans are less likely to participate in advance care planning, and I know that to be true for myself and my family. I know the importance of it, but don't have it in place. I have seen my relatives, and I have been a long-distance caregiver, and still don't have it in place. So you know, it's time. We can't wait any longer. You need to do this. (Patient/caregiver focus group participant)</p> <p>... And I'm actually going through this right now with my father. My father has dementia. My mother is his primary caregiver. My mother suffered a TIA so she was in the hospital, and we found out that she had multiple strokes over the years and she didn't tell us. So now my mother can't take care of my father and my father, because he has dementia, is incapable of telling us anything or giving us any information to take care of him. My father was a deacon in the church. I was brought up in the church. My brother's a minister. My brother-in-law is a pastor and here we are all looking at each other like what are we going to do because these types of preemptive steps weren't taken and a lot of this had to do with, unfortunately, my mother held a block up. She would say, "Oh, let the Lord have His way. Oh, I believe the Lord's gonna heal your father. Oh, just have faith. Oh ... " and it's heart wrenching now because we ... like I said, it's been so difficult to get care for my father and now with my mother going through her challenges, it's like she just did not want to come to grips with the fact that she was getting older and that she could not keep on the way that she's been going. (Minister/caregiver/focus group participant)</p>
Strategies to overcome barriers to advance directive completion	<p>I tell patients, it's not a matter of ... you fill out this paperwork and we're no longer going to do anything for you. We want to do right by you, so I think it's very important for you to address this—not only for yourself but for your family. (Palliative care provider, semistructured interview participant)</p>
The benefits of palliative care	<p><i>The Interdisciplinary Approach.</i> We have chaplains. We have social workers, so we don't only focus on your disease process. We focus on you, your family, your spirituality, your emotional wellbeing ... it's kind of the whole, instead of just, you have this disease and that's all we're going to talk about. (Palliative care provider, semistructured interview participant)</p>
The benefits of hospice	<p><i>Some Relief of Caregiver Burden.</i> My experience with hospice was so wonderful. The people were so nice and compassionate. It's a wonderful program. And you know what? It was for the patient, but it was also for the caregiver, too ... It took the actual day-to-day work off of me—that was their responsibility. They told me it was theirs and I did not try to hold on to it. (Caregiver/daughter of a hospice patient, semistructured interview participant)</p> <p><i>Compassionate Care.</i> I felt something that I didn't expect to feel, and that was just so much admiration and heart for the providers ... for somebody to have the kind of heart to choose to deal every day, all their career with people who are at the end, that takes a special type of person. (CAP member/focus group participant)</p>
Barriers to hospice enrollment	<p><i>A loss of faith in God.</i> I think again, it goes back to the faith thing. That if I go on hospice does that mean I'm losing my faith in God, that I'm saying that God can't heal me, or God won't heal me, because I've gone on hospice? I've given up, and so God is not going to act on my behalf for sure because I'm not trusting God enough to just heal me? Again, God is going to do what God's going to do. (Minister)</p> <p><i>Fear of death/losing a loved one.</i> I have a strong faith because I actually believe that all things are possible. But there are some times when we will talk our faith and not walk our faith. It's not that you're giving up on God, but what I don't think they realize is that when they pray for a healing, death is a healing. ... It's not the healing that you might want, but as sure as we're born we're going to die. And we're healed from the troubles of this world ... So, I think their fear is not so much that they've given up on God, it's that they don't see death as a healing, and that they're loved ones are truly, truly in a better place. (Caregiver/daughter of a hospice patient, semistructured interview participant)</p>

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Theme	Quote
	<p><i>Mistrust in the Medical System.</i> I think enrolling African American patients in hospice is difficult, and the reason why is because I think patients equate hospice with death. And I also think that they feel that once we enroll them in hospice, we've given up, no one cares, and no one is going to check on them, focus on them, and we're just saying, "You know what? You've got this disease process that you may not last long with and we're just done" ... It's important for patients to understand that we still care. (Palliative care provider, semistructured interview participant)</p>
Strategies to overcome perceived barriers to hospice enrollment	<p><i>Continued use of Prayer Throughout the Process.</i> Well I'm a firm believer in prayer, and I believe that anyone who gets bad news, whatever, it may be, to consult God with it. And also pray that He sends the right people in your life. I think a lot of people when they pray forget about that, that God directs the right people in your life to keep you encouraged, to keep you built up, to help you even with your health and everything. We simply prayed on the doctors and nurses and hospice—just everyone big or small that would be around my mom. (Caregiver/ daughter of hospice patient, semistructured interview participant)</p> <p><i>Communicating Effectively with Patients and Families.</i> No, you don't just walk in the room and start spilling all of that doctor stuff. Spewing all of this medical language ... You've got to build as much relationship as you can with that family, and you've got to be compassionate about it ... In the end still respect where they are and that it's going to take them some time to get there. (Minister, semistructured interview participant)</p> <p><i>Recognizing the Importance of the Individual.</i> You can't look at the race as a whole. Everyone in the race is not the same, and so, you'll have people who have different life experiences ... You can get their religious beliefs, their cultural beliefs, who's most important to them, and kind of integrate that. (Palliative care provider, semistructured interview participant)</p>

Abbreviation: CAP; Community Advisory Panel.