

Communication, Decision Making, and Cancer: What African Americans Want Physicians to Know

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Abstract

Purpose: To explore and identify communication and decision making with health care providers for African Americans living with cancer and for their families.

Methods: We used focus group interviews to identify and explore cultural perceptions, expectations, and desires as they relate to quality of life domains.

Participants: Of the 42 African American participants, 33 were women. Half of the participants ($n = 21$) were caregivers of a family member with cancer; the others were cancer survivors and some of them had also cared for a loved one with cancer.

Results: Participants focused on effective communication and decision making as fundamental to overall quality of life. Furthermore, physicians were viewed as having the responsibility to establish and monitor effective communication with patients and families. Within the domain of effective communication, participants stressed that health care providers needed to know the person and family and to tailor communication with them based on that knowledge. Within the domain of decision making, participants emphasized having a sense of control over treatment choices. They also expressed concerns for populations made vulnerable by advanced age, poverty, or low levels of formal education.

Discussion: Our participants indicated that relationship-centered care, in which one's sense of personhood is sought, acknowledged, and worked with, is foundational for effective communication and decision making.

Introduction

WHEN ADULTS HAVE a serious or life-threatening illness such as cancer, the individual and family may face a staggering amount of medical information, clinical encounters, and decisions that need to be made. Effective communication between these seriously ill adults, their families, and health care providers is critical for effective pain management, discussions of death and dying, improved symptom management, emotional adjustment, and greater patient and family satisfaction with care.¹⁻⁵ In fact, effective communication is fundamental for mutual understanding, informed decision making, and effective delivery of health care, including effective cancer care for patients and families.^{2,5-8}

Cancer remains the second-leading cause of death in the United States. For most cancers African Americans have the highest mortality and shortest survival of any racial and ethnic group.⁹⁻¹¹ African Americans and other racial and ethnic minorities receive less effective cancer pain management and report less informed decision making, more unmet communication needs, and poorer satisfaction with health care compared to majority groups.¹²⁻¹⁵ These and other cancer-related disparities are associated with lower overall quality of life for both African Americans and their family members.¹⁶⁻¹⁸

Quality of life (QOL) is a multidimensional construct that includes physical, functional, psychological, spiritual, financial, and social domains.¹⁹⁻²¹ When a person and his/her family are living with a life-threatening illness, the relative

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importance or content of these domains may change, and be reshaped based on relationships with health care providers or a sense of life completion.²² In addition to being multidimensional, the determinants of QOL are racially and/or culturally influenced and therefore it is important to examine the construct of QOL from a racial and/or cultural level as well as an individual level.^{23–25}

Effective communication with physicians and other health care providers is a crucial component of QOL with serious illness. Unfortunately, evidence consistently documents poorer communication and less satisfaction with decision making for African Americans and their families.^{8,16,18,26} Furthermore, limited empirical evidence exists to guide health care providers regarding communication and shared decision making and potential racial and/or cultural influences.^{27–29} Therefore, the purpose of this study was to explore and identify what African Americans living with cancer and their families want physicians and other health care providers to know about the impact of communication and decision making in the context of improving QOL.

Methods

As part of a larger study to test the feasibility of engaging lay health advisors in improving access to care for pain and suffering related to cancer among African Americans, we conducted focus group interviews to identify and explore cultural perceptions, expectations, and desires as they relate to QOL. The primary aims of the focus groups were to explore the acceptability and comprehensiveness of the domains of health-related quality of life as represented by a previously published quality of life instrument. The Institutional Review Board from the University of North Carolina at Chapel Hill approved the procedures used in this study.

Study participants

Participants were recruited between September 2005 and January 2006 using mailings to African Americans with previously expressed interest in research participation, and flyer distributions at local churches, support groups, and hospitals in three central North Carolina counties. Eligible individuals were those who self-identified as African American and had experienced serious illness with cancer or provided family care for someone with cancer. Refreshments, a \$20 incentive, and transportation were provided for the participants.

Data collection

Six focus groups were conducted. Interviews lasted approximately 2 hours and were tape recorded and transcribed. Informed consent was orally obtained and recorded prior to starting the focus group.

An experienced African American facilitator used a focus group discussion guide with key questions and probes to guide the discussion (Appendix A). The discussion guide was based on the QUAL-E, a validated measure of QOL at the end of life.³⁰ First, the facilitator asked participants to discuss what, for African Americans, affects QOL when living with a serious illness like advanced cancer. She then asked them to explore how physical symptoms, participation in one's own health care, concerns about the future, and rela-

tionships and completion of life tasks can affect QOL with serious illness. All discussions were observed by a second investigator who took notes on the focus group process and monitored audiotaping.

Analytic strategy

All discussions were audiotaped and transcribed verbatim. Interview transcripts were analyzed using the principles of grounded theory³¹ and the content analysis techniques of theme identification. Glaser's method of constant comparative analysis required the data to be reviewed in light of an initial conceptual formulation and coded repeatedly.³¹ Codes were initially based on domains of the QUAL-E and expanded inductively using an iterative process. Seven members of the analysis team reviewed transcripts for emerging themes; extant codes were revisited, and the coding scheme refined. A subset of the team developed written definitions for each code and examples and directions of when and when not to use the code were detailed in a formal codebook. We then applied codes to each transcript using Atlas Ti software.

Three coauthors (S.W.W., C.B., G.C.S.) independently reviewed the coded data to identify major themes and met to establish thematic categories based on consensus. For the few instances consensus was not reached, we engaged the larger team to reach consensus. Furthermore, we asked 15 conference attendees who had similar experiences with cancer to give feedback on the themes identified in the focus groups, and where necessary additional insights were included in our coding strategy and analysis. While this analysis focused specifically on the codes related to communication and decision making, other codes included denial/acceptance of death, faith, family, health care systems, hospice, multidimensionality of struggle, physical symptoms, resources, and bearing burdens.

Results

Focus groups ranged in size from 4 to 13 participants. Of the 42 African American participants, 33 were women. Half of the participants ($n = 21$) were caregivers of a family member with cancer; the others were cancer survivors and some of them had also cared for a loved one with cancer. Although the focus group script did not ask about physician-patient communication directly, throughout each focus group interview and in all QOL domains, participants described the importance of communication with their physicians to QOL. The themes of sense of personhood and tailoring communication were identified within the domain of effective communication and the themes of sense of control and concern for vulnerable populations were identified within the domain of decision making. These two domains and their component themes are discussed below.

Effective Communication

Participants stressed that fundamental to effective communication was the establishment of a relationship within which the physician and other health care providers sought to know and understand the patient and family as individuals. Participants described this "knowing" of the patient and family as providing the foundation for tailored communication and decision making.

Need to know person/sense of personhood

Participants were clear that physicians should seek to know the person and his/her family as individuals and communicate with them based on that knowledge. One participant indicated, "I think that the doctor should look at me in human terms . . . my thoughts, my feelings, what I'm thinking, as opposed to medical terms; look at me as a human being with my thoughts, my feelings, my judgments." In addition, participants viewed the physician as responsible for initiating and monitoring the effectiveness of communication within the relationship. They indicated that sometimes "you need that push" and they expected the physician to be the one to provide the "push." For example, another participant commented, "It's going to come back to their knowledge as to what the person is dealing with. Because you get the mindset of a person based on what they say. So they just need to kind of dig into the person and ask them, what do you see? How do you see this treatment . . . what do you want to come out of this?"

Tailoring communication

Participants indicated that relationships in which the physician seeks to know the patient and family can help the physician tailor communication with the patient and his/her family. Such tailoring would include (1) appropriate language to use, with attention to education and literacy levels and (2) a determination of the amount and timing of information based on the patient and stage of acceptance/denial of disease as well as other complexities of care.

Participants expressed that when physicians understand the patient and family, it increases the likelihood that the physician will also understand and acknowledge relevant experiences and educational attainment of the patient and family. Such awareness would allow the physician to use language that the patient and family understands and accepts. As one participant noted, "Do they show their human side, or, is it all just, you know, in medical terms; can they come down and relate as if it were, a family member?" Another participant noted the following in the care of her father, "You had to say end of life, talk about comfort, talk about signing over what kind of care you want. Did you want to resuscitate? He didn't know what that was. I told the doctor, speak plainly so he understands what you're talking about."

With knowledge of the patient and family's stage of acceptance or denial of the disease as well as the complexities of care, the timing and amount of information can also be tailored to the patient and family's readiness and preferences. Participants noted that some individuals would want as much information as possible, while others may want none and that many individuals would fall someplace in between the two extremes. A participant expressed that the physician needs to have "enough intuition" to know the appropriate level of information. Participants also acknowledged that sometimes there was time-sensitive information that needed to be shared:

I think too, if it's something that's so pressing and they feel the need; that would go back to knowing your patient, and knowing where they are and who they are and them as a person, if that person is strong enough to

take that, then fine, but if that person is weak and at their breaking point, by no means.

Regarding sensitive topics such as the possibility of death, participants indicated that sometimes physicians have to ask indirectly, "Don't say death, just explain maybe you are going to be at a stage where your drugs have taken over and you just can't make a decision; is there anything special that you want done, any special request?"

Decision Making

Participants viewed effective communication based on "knowing" the patient as the foundation for effective decision making. One theme related to decision making was having a sense of control. Participants stressed that a sense of control was related to hope for the patient and his/her family members. A second theme within the decision making domain was concern that not all patients have the capacity to be self-advocates.

Sense of control

Participation in the decision-making process was considered important and equally important was that one's decision be respected by the physician. One person indicated, "You should be able to make a decision whether you want to . . . or don't want to have a procedure done, and you should not be put down because this is why you make that decision." Many others echoed that the physician's role was to clearly outline available options and then to respect the decision making ability and choices of the patient and his/her family. One participant indicated, "I would like for them to look at me as if I'm a member of the team, and that we'll make the decision together." Other comments reflecting the importance of involvement in decision making included, "I mean sometimes they figure, you're too sick to even care or worry about that, but I think that you should always keep them [the patient] involved in every aspect as long as they are able."

An expressed benefit of involvement in decision making was a sense of control for the patient and a connection between the sense of control and hope. One participant indicated that, "Once a person has an opportunity to make decisions, it gives them hope." Another expressed that, "There are forces that are beyond what medicine is all about so I think as long as you have some feeling that you have some control, some direction, when that's taken away from them then they're ready to give up because they no longer have control."

Concern for vulnerable populations

Poignant throughout this discussion was that many of the participants felt as though they could advocate for themselves. However, they expressed concern for populations they believed were unable or uncomfortable advocating and speaking for themselves. Individuals who were older, poorer, and had low levels of formal education were singled out as vulnerable and participants expressed concerns about potential and past clinical treatment of these populations. Our participants felt strongly that vulnerable populations "need to know that they have a choice."

Another thing, I ran into a lot, is that when they have patients, like poor Medicare patients, they would do things to them, order tests, do this, that and the other, that they don't really need, because they figure they don't have a say so in their care.

Several participants indicated that older African Americans "may not have access to resources and that may not be as well read and may not know their options and therefore just trust their doctor." This "just trusting their doctor" was viewed as problematic.

They will come in and say, we need to do this and we need to do that, and, it's all above this person's head and they don't understand. And a lot of black folks, older folks will let them do these things and they don't understand what's going on really, but that goes on a lot.

Discussion

Although the original purpose of the larger study was to examine domains of QOL, we found that participants focused on effective communication in their discussion of all aspects of QOL. Furthermore, physicians were viewed as having a responsibility to establish effective communication and decision making with patients and families.

Participants in our study were clear that effective communication will not happen unless physicians establish a relationship within which they seek to understand the person and family facing cancer. Our findings support that tailored approaches based on understanding patients, families, and relevant health related experiences are necessary.^{27,32-34} The clinical relationship is foundational and relationships in which the patient and/or family feel understood and respected are linked to positive health outcomes.³⁵⁻³⁷ Furthermore, Safran and colleagues³⁸ documented that the patient's perceptions that their physician "knows them as a person" was a leading indicator of adherence, satisfaction with physician, and improved health. Relationship-centered care,^{33,39,40} in which one's sense of personhood is sought, acknowledged, and worked with, is exactly what our participants indicated was important to their QOL.

Various summaries outline elements of effective communication for physicians.^{8,41,42} Two such strategies, elimination of medical jargon and tailoring the amount of information, were expressed in this study. Royak-Schaler and colleagues¹⁸ in a study of family caregivers of deceased cancer patients indicated that the use of medical jargon impedes understanding and decision making. A number of studies also reports that patients vary greatly in the amount of desired detail regarding the cancer diagnosis and treatment options.^{18,34,43,44} Consequently, physicians need to understand individualized desires for information and readiness for participation in decision making.^{42,45} We agree with the conclusion by Hagerty et al.⁴⁶ that physicians can provide the right amount of information only after eliciting the patient's goals and values. We extend that conclusion to the patient's family because family inclusion is especially important for African American patients who more often than Whites include family members in the decision making process.^{28,47-49} However, it is critical to acknowledge patient rights, HIPPA

guidelines, and to understand that African Americans also vary in their openness about cancer and the level of involvement they desire from their family.

Although many of the findings from this study have been previously documented, most of those studies included all white samples and/or few African Americans. However, unique within this context of individuals who could be considered vulnerable, was a concern about the treatment and welfare of older, poor, and less educated African Americans. Limitations of this study include a sample of volunteers and similar to other research studies with a nonrandom sample, the views of those who volunteered for this research study may differ from those who did not. Also, the focus groups included individuals with cancer along with family members. While separate groups with all family members or all individuals with cancer may have yielded more detailed information about specific needs and concerns of the individual with cancer versus the family, our findings may reflect a more realistic expression of the family unit instead of separate entities within the family.

A major strength of the study is its focus on African Americans who continue to have unmet communication needs, poorer relationships with physicians, and poor cancer-related outcomes.^{9,12-15,26} Given that poor communication remains systematic and problematic, information provided by this study suggests specific areas to improve communication and decision making with African Americans. However, we along with others, caution that while race and/or culturally specific findings from any group can inform and guide interactions,⁵⁰ they also can be used to apply stereotypes and therefore do harm.^{51,52} We encourage physicians and other health care providers to use race and cultural specific knowledge as a guide and not as truth specific to all members within the racial and/or cultural group.

Overall, findings from this examination of what African American patients and families living with cancer want physicians to know, stressed relationship-building and an individualized and tailored focus on the patient and family to improve QOL. Unfortunately, physicians often spend more time building relationships, asking questions, and seeking understanding with white patients.^{4,16,53} Findings from this study can inform physicians and encourage personal reflection and inclusion of effective relationship building interactions for all patients and families living with cancer, regardless of race and culture.

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APPENDIX A: DISCUSSION GUIDE FOR COMMUNICATION, DECISION MAKING, AND CANCER:
WHAT AFRICAN AMERICANS WANT PHYSICIANS TO KNOW

When you hear the phrase “quality of life,” what images or thoughts come to mind? Probe: What does “quality of life” mean to you?

How is the meaning of “quality of life” different for someone living with a serious illness like cancer versus someone who is not living with a serious illness like cancer?

Some people say that physical symptoms have a strong influence on the quality of life when someone is living with a serious illness like cancer. What do you think? (Physical symptoms include problems with pain, nausea, lack of energy, confusion, or shortness of breath.)

Some people say that being an active participant and decision-maker in his or her health care have a strong influence on the quality of life when someone is living with a serious illness like cancer. What do you think?

Some people say that concerns about what will happen in the future have a strong influence on the quality of life when someone is living with a serious illness like cancer. What do you think?

Some people say that feelings that one life is complete have a strong influence on the quality of life when someone is living with a serious illness like cancer. What do you think?

Think about all the things we talked about so far—physical symptoms, being an active participant and decision maker in his or her own health care, concerns about the future, and feelings that one life is complete. What have we left out that, for African Americans especially, is an important influence on quality of life when facing a serious illness?
