Decoding the Role of Companions in Supporting the Health Communication of Older African-American Men With Cancer

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Abstract

The objective of this study was to systematically characterize the content and patterning of companion's communicative behavior during oncology consultations for older African-American male patients. Companions and family members often play an important role in patient-centered communication for patients with cancer. Despite their disproportionate cancer burden, little is known about how companions facilitate patient-provider communication for older African-American men with cancer. This study represents a secondary qualitative analysis of 14 video-recorded doctor patient-companion medical visits for African-American male patients with cancer. Videos were captured with consent and institutional review board approval at a Midwest comprehensive cancer center between 2002 and 2006. These medical visits were transcribed, deidentified, and analyzed for the content, frequency, co-occurrence, and thematic clustering of companions' active participation behaviors during the interaction. Results were well aligned with existing studies on accompanied oncology visits. Patients were on average, 60.14 years old and all but one of the 16 companions was a woman. A total 782 companion behaviors were coded across 14 medical interactions. While companions communicated directly with providers (eg, asking questions, providing medical history) and directly with patients (eg, clarifying information, giving advice), there was a lack of triadic communication. This study clarifies the role of mainly spousal companions as important intermediaries in the patient-provider communication dynamic for older African-American men with cancer.

Keywords

cancer, caregiving, communication, clinician-patient relationship

Introduction

On average, more than a third of all medical visits for adults in the United States include patients' spouses, adult children, friends, and other companions. Accompanied medical encounters play an increasingly salient role in patient care processes and outcomes (1-3). Studies report that patients who are less educated and those with more seriously compromised health are most likely to bring a companion with them to a medical visit, and those companions tend to be women (2). While companions' degree of engagement during medical visits varies widely, companions accompanying patients with cancer often provide invaluable instrumental support such aiding heavily in information recall with an emphasis on recollecting symptoms and filling in specific facts and dates related to past treatments, and emotional support such as reassurance (4,5). Companions play a particularly important role in health-care communication processes when the diagnosis is life-threatening. For example, Jansen and colleagues (40) reported that among 100 older patients with cancer and their 71 companions, companions aided patients in understanding and recalling important medical information and instructions regarding chemotherapy treatment. The same study reported that the

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unaccompanied patients with cancer measured significantly lower on the ability to recall information than those with companions (4).

In a separate study, researchers analyzed 28 videorecorded outpatient oncology medical visits at 2 comprehensive cancer centers to examine the questions patients and their companions asked. This study also included global ratings of the oncologists' behavior and the medical visit dynamics as captured by trained observers (5). Findings indicated that companions posed significantly more questions about all topics than the patients they were accompanying, with an emphasis on questions related to treatment, diagnostic testing, and prognosis. Furthermore, patients in this study who were older and less educated asked fewer questions, which is consistent with extant literature on physician-patient-companion interactional dynamics during medical visits (1,5–8).

A majority of research on communication dynamics between patients with cancer, their companions and healthcare professionals has not included sufficient numbers of minority patients and companions to elicit key differences in their health care and communication experiences. For example, the availability of research focused specifically on how African-American patients with cancer and their companions communicate during medical visits is limited. This gap in knowledge is significant because African-Americans broadly, and African-American men in particular, are disproportionately burdened by steep disparities in cancer diagnosis, treatment, survival, and quality of life (9,10). Studies that have investigated African-Americans' communication processes during oncology medical visits have documented patterns whereby some African-American patients with cancer do not receive the level of content or quality of information exchange standard for such interactions, particularly when compared to white patients (11,12).

Poor patient-provider communication contributes to health disparities, and these disparities are intensified when, for any number of reasons, African-American patients do not have the support of a companion during oncology medical visits. For example, an empirical analysis of 109 doctorpatient-companion interactions at 2 US National Cancer Institute-designated, comprehensive cancer centers (NCI-CCCs) revealed that African-American patients asked fewer overall and direct questions during medical visits than their white counterparts, and only 40% of African-American patients were accompanied by a companion compared to 86% of white patients (13). In the same study, medical visits where a companion was present resulted in more than twice as many questions asked by or on behalf of the African-American patients as those on unaccompanied visits. Further, the active presence of a companion has been linked to the length of the oncology medical visit among racially diverse patients and companions at multiple US comprehensive cancer centers (5,13).

Companions' question asking during medical visits is a form of active participation, a set of communicative behaviors that results in more positive patient outcomes and improved patient-centered care from health providers (14-17). Current knowledge about the relationship between a companion's active participation during oncology medical visits and specific communication outcomes (ie, information exchange) for African-Americans suggests that African-American patients in general, may be at a distinct informational disadvantage when they both ask fewer questions and do not have a companion present to support them in the communication exchange during oncology medical visits (5,13). Based upon the above discussion, a major aim of this study is to elucidate how companions contribute to medical visit communication dynamics for African-American male patients with cancer, with a specific focus on attaining a better understanding of the content and context of companions' communicative patterns. This is necessary to ultimately develop interventions to better equip African-American men with cancer to optimize medical visit communication, and to reduce communication-related medical errors, misunderstandings, and mistrust that contribute to disparate cancer outcomes.

Methods

Study Setting and Participants

Data for this study came from an existing archive of doctorpatient-companion video-recorded medical visits captured between April 2002 and March 2006. These medical interactions were recorded at the outpatient clinics of 2 NCI-CCCs as a part of a larger study on how patients, their physicians, and companions (if present) discuss and make decisions about cancer clinical trial participation after a new or recurring cancer diagnosis. Patients (and their companions if present) were eligible to participate in the original study if they were age 18 years or older, could speak and read English, and if the physician they were visiting also consented to participate in the study. The institutional review board at the affiliated university and the protocol review and monitoring committee at each participating cancer center approved this study. Patients, companions (if present), and all participating medical personnel provided consent for the study and a waiver of the Health Insurance Portability and Accountability Act (HIPAA).

The entire medical interaction for each patient participant was video-recorded using 2 remote-controlled high-resolution digital video cameras that were managed by a research assistant from a separate, private, and secure location in the hospital. A more detailed description of the participants, institutional approvals, and procedures of the original study have been published elsewhere (5,13,18). Data for the current study represent a subset of medical visits from the archive inclusive of all patients (n = 14) who self-identified as over 18 years old, African-American, and male,

and who were accompanied by at least one companion. Few demographic details were captured for the 16 companions other than race (100% African-American), gender (93.7% female) and relationship to the patient (71.4% wives or partners, 12.5% friends, 12.5% adult daughters, 6.2% adult brothers, and 6.2% professional caregivers). African-American male patients were on average 60.14 years old, 71.4% married, and 57.1% had at least some college education. These patients had either a diagnosis of colorectal cancer (n = 3), liver cancer (n = 3), multiple myeloma (n = 3), lung cancer (n = 2), prostate cancer (n = 1), leukemia (n = 1) and unknown (n = 1).

Analysis

The goal of this analysis was to capture and characterize the content and patterning of companion communication during African-American men's oncology visits. Each medical visit video was transcribed verbatim without any identifying information for each participant in the medical consultation. The 14 transcripts were then uploaded to Dedoose version 4.12, a secure web-based computer assisted qualitative data analysis platform that aids in organizing, integrating, collaborating across, and presenting qualitative and mixedmethods data. Author 1 and 2 graduate student research assistants (T.W. and E.M.) comprised the qualitative analysis team. The analytic process began by having all coders independently read the same 2 transcripts and code all identifiable words, phrases, and sentences spoken by companions. Coders did not establish a priori codes but were trained to establish new codes and "subordinate codes" (ie, nuanced variations on existing codes) in the text that capture key concepts and thoughts. After each coder had fully reviewed the 2 transcripts, the coding team met to share their initial coding categories, achieve consensus on a set of codes to move forward with across all transcripts, and develop brief anchoring definitions to establish uniformity in how communicative behaviors were being identified and coded. The team met to examine any segment of text where consensus about an initial code was not reached and resolved any disagreement through deliberation. During the next level of coding, content analysis (19) was undertaken to sort frequently occurring codes into categories that more accurately captured the type, function, and context of companions' communication. Finally, the coding team utilized complementary analytic tools available in DeDoose, such as 3-D code clouds, interactive descriptor graphs, and code count tables to examine how different codes were related and linked. Again, the research team met to resolve by discussion, any discrepancies on code categorization, cooccurrence, or application.

Results

Across all 14 medical interactions, the coding team identified 793 communicative behaviors across the 16

companions. Table one details the frequency, descriptive definitions, and excerpts from the codebook for most types of communicative behavior. The coding categories are not fully mutually exclusive, though the coding team made every effort to minimize overlapping codes. The coding team determined that with few exceptions, these behaviors centered around 2 major thematic clusters: companions communicating directly with providers (physicians) and companions interacting with patients (See Table 1). In addition to the types of communicative behaviors employed by companions, it is important to understand the context in which these companions were active participants in the conversation occurring between African-American male patients and their oncologists. Analytical tools are available in DeDoose that document the cooccurrence of codes and clarify the patterning of certain behaviors. In this study there were 38 instances where 2 behaviors were occurring in the same segment of text across 14 patient-doctor-companion interactions. For example, companions answering the oncologist's questions were coded in the same sentence or series of sentences with the companions aiding in information recall on the patient's behalf. It may be of interest to note that companions often answered questions by the physician that were directed to the patient. There were 21 instances of companions posing their own questions to the oncologist while also making a statement that attempted to further clarified either what the physician or patient were saying. These clarifying statements also co-occurred 16 times when companions were responding to the oncologist's questions (even when directed primarily at the patient). Of note, female spouses or partners (n = 10) were particularly active communicators, such that companions in those encounters overwhelmingly took the lead in question asking and answering, even to the extent of negotiating treatment decisions such as the timing and frequency of chemotherapy and radiation with the oncologist.

Theme One: Companions Communicating Directly With Providers

Our findings demonstrated that companions in this study communicated primarily with doctors, rather than patients during the medical encounter and were more likely to initiate those interactions. This pattern of initiating communication directly with physicians, instead of waiting to be addressed or deferring to the patient's responses, could be related to the fact that the vast majority of companions were wives or partners. While beyond the scope of this study to determine, it is plausible to speculate that spouses or partners may feel both comfortable communicating on behalf of a loved one, and responsible for eliciting as much information as possible in a care giving capacity for their husbands or partners. Companion interactions were characterized by active participation behaviors during the medical visit. Prior studies show that the companions of

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Table 1. Detailed Qualitative Coding of Companions' Communicative Behaviors During Oncology Medical Visits.^a

G	The Number of Times a Behavior was	0/		
Companion Behavior	Coded	%	Behavior Description	Example Excerpt
Answering doctor's questions	275	34.67%	Companion responding to question from doctor, even if not directed at them.	Physician: "Any vomiting, diarrhea, constipation? Companion: Constipation umm he can eat and he will go to the bathroom 10 minutes later, and that's every time"
Clarifying doctor or patient statements	133	16.77%	Companion restating or otherwise attempting to explain statement made by others	Companion: "How do I put this Dr. X is under the impression that with this treatment you will be completely cured."
Directly questioning the doctor	113		Companions posing their own inquiry directed at doctor	Physician: "I just want to make sure that you followed me.
				Companion: I got ya. Okay. The lymph nodes? That's the part that you're not sure of? In other words, it's in question is there another test that you would take that would see if the lymph nodes are involved?"
Offering statements specific to medical history or symptoms	83	10.46%	Companion providing information on medical history, behavior, symptoms, or medication for the patient	Physician: "Now, what have you been told as the reason for your kidney problems? Patient: Nothing
				Companion: Just that he got a kidney problem. He was going to Dr. X and his insurance changed. He started going to these new HMO's and they moved when his insurance changed he was told to keep his blood pressure under control or else it will affect the kidney problem"
Directly questioning the patient	64	8.07%	Companion directing questions toward patient	Companion: "Is that what you are worried about? Patient: Well, sticking myself, I don't like sticking my self"
Companion providing advice to the patient	43	5.42%	Companion offering information/ suggestions to patient	Patient:" I got to take my blood pressure medication Companion: I don't know if you can take that one without food, it might make you sick to your stomach
				Patient: I should have gotten a sandwich or something Companion: Ain't nothing here, you got wait till you go way over town Patient: No I don't
				Companion: You do so"
Companion asking or answering questions of nurse	29	3.65%	Companion interacting directly with nurse	
Companion verbal interaction with another companion	20	2.52%	Companion in discussion only with another companion present	
Inaudible or otherwise categorized communication	33	4.16%	Imperceptible verbal communication or statement categories occurring too infrequently.	

^aA total of 793 companion behaviors coded across 16 companions and 14 medical interactions.

African-American patients are often less likely to actively participate in the medical encounter compared to white patients and their companions (8). However, in the present study, more often than not, African-American companions were actively involved in the medical visit in a variety of ways, such as answering the doctor's questions on behalf of the patient, clarifying doctor and patient statements, and asking questions of doctors. These companion behaviors

have been observed in other studies with non-African-American participants. For example, Jansen and colleagues (4) found that when both companion and patient are able to assist one another in remembering important information during the medical encounter, they are able to provide more information to the health-care provider, medical visits last longer and health-care providers are more likely to provide more information.

Theme Two: Companions Interacting With Patients

The second theme revealed that when companions did interact directly with patients, they were questioning the patient or providing advice to the patient. This finding is important because the male patients in this study were older, and older patients consistently ask fewer questions during medical visits (5). It is reasonable to infer that having an involved companion present may result in an increase in the exchange of medical information during medical visits for older men, particularly considering that older adults are likely to be accompanied by the same companion over time to medical visits (2). Prior studies have also shown that the companions of older patients and those in poorer health are more likely to assist the patient in following through with physician recommended health behaviors (20). As a diverse group beset by a range of health disparities, including delayed screening and diagnosis, poorer prognoses, and lower likelihood of survival from several types of cancer, older African-American men would likely benefit from additional attention to the role of active involved companions in their health-care navigation, communication, and decision-making processes. In the subsequent section, we present our interpretation of the aforementioned companion communicative patterns.

Discussion and Conclusion

When present and participatory, companions play an influential and direct role in the health-care communication of family members and important others. This study provides formative data for future investigations on the specific communicative functions of primarily women companions accompanying African-American men with cancer to clinical consultations. The results of this study revealed 2 central themes: (a) companions in this study interacted primarily with physicians and were often driving those conversations; and (b) when companions interacted with patients during the medical encounter they were questioning the patient or providing advice. It is also intriguing to note the marked absence of triadic communication between patients, providers, and companions simultaneously, and the fact that all but one of the companions were women. This notable absence of triadic communication has potentially negative implications for these patients' engagement in care decisionmaking, and the overall quality of their care and clinical communication (21). For example, a meta-analysis of doctor-patient-companion communication (2) revealed that when companions were present, patients provided less psychosocial communication and physicians engaged in less social and more biomedical information exchange. It's conceivable that adult patients could be hesitant to discuss sensitive mental or emotional health concerns with providers in the presence of a spouse, friend, or family member, and that those missed opportunities could have implications for appropriately diagnosing and treating their full range of

health-care needs. When physicians engage in less social conversation during accompanied visits, there are fewer opportunities to build trust, rapport, and better understand the full context of the patient's experiences.

Findings from the current study illuminate the content of female companions' contributions to the informational exchange during oncology medical visits for African-American men, and they are well aligned with existing studies on accompanied oncology visits. For example, Street and Gordon (8) found in a study of 84 patients with cancer with companions, that a high proportion of companions' verbal communication during medical visits were in the form of active participation (eg, question-asking, expressing concern, or stating opinions). Notably, African-American companions in that study were more passive communicators that white companions, yet in the current study, African-American women companions were highly active. As mentioned earlier, active participation includes several communicative behaviors by patients and companions that signals patient and companion agency in driving the direction of health care communication and decision-making. These behaviors have been shown to elicit more positive and attentive care from health providers and subsequent improved health outcomes (14–17,22).

A few limitations should be noted related to these findings. First, we do not seek to make generalizations from our findings on a broader level due to the small nonrepresentative sample, qualitative design, and limited available information on companion demographics. Next, the difference in types of cancer diagnoses represented may contribute to differential patterns in communication, such that some diagnoses may have necessitated more or different types of questions during the medical visit. We were not able to account for these factors. However, the findings in this study serve as a springboard for future research on the ways in which an active and informed companion could shift the trajectory of cancer care for older African-American men. Further, the older age and marital status of participants in the current study may have played an important role in their companions' behaviors. These limitations notwithstanding, this study clarifies the role of mainly spousal companions as important intermediaries in the patient-provider communication dynamic during oncology consultations for older African American men.

Implications for Practice

Future research should investigate the degree and under which circumstances older African-American men welcome their companions' input and active engagement in the patient-provider communication dynamic, how they solicit and respond to such involvement. There is also a need for additional clinical evidence regarding how oncologists respond to this dynamic; important issues that this study was not able to capture. Ideally, practice interventions could be developed and tested that better support the companions of

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older African-American men in advocating for their informational needs, ensuring that patients' questions are asked and answered, and supplying accurate and thorough medical history to supplement the patient's recall during high-stress oncology consultations (and other medical visits).

Authors' Note

Jaclynn Hawkins is now affiliated with School of Social Work, University of Michigan, Ann Arbor. This study has all necessary Institutional Review Board approvals. Patients, companions (if present), and all participating medical personnel provided consent for the study and a waiver of the Health Insurance Portability and Accountability Act (HIPAA). This study was approved by the Wayne State Human Investigation Committee (1006008456) and the Protocol Review and Monitoring Committee at Karmanos Cancer Institute (2013-145).

Declaration of Conflicting Interests

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