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“Cutting” on cancer: Attitudes about cancer spread and surgery among primary care patients in the USA

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Abstract

Many underserved groups in the United States experience disparities in cancer survival. Part of the disparity may be due to differences in treatment or treatment uptake. Previous studies uncovered patient beliefs that surgery could cause cancer to spread and have suggested that this belief may affect uptake of cancer treatment. We explored patients' explanations about surgical treatment of cancer and cancer spread, as well as the perceived impact on decision-making among primary care patients from an underserved area. Focus groups and interviews were conducted with patients ($n = 42$) at a primary care federally qualified health center in 2006 and 2007. Focus groups/interviews were semi-structured and were audio-taped and transcribed. An inductive text analysis with multiple coders was used to analyze the data and extract themes. We found that nearly all respondents had heard that surgery (“cutting”) and exposing cancer to the air would hasten cancer spread and result in worse outcomes. Most participants expressed agreement with this belief. Many participants said this concern would influence their decision about whether to have surgery and/or reported that a family member had refused surgery for this reason. A smaller group of respondents disagreed with this belief and offered experiential evidence to the contrary or hypotheses about its origination. The idea that “cutting” and “air” during surgery can cause cancer to spread may be more prevalent among patients than suspected, based on this sample of predominantly African American patients. While we were unable to disentangle the ideas about “cutting” from those about “exposure to air”, this set of beliefs, when held strongly, can negatively influence patients' or family members' decisions to seek surgical care and, if it is more prevalent in underserved groups, may contribute to cancer disparities.

Keywords

United States; Colorectal cancer; Health disparities; Cultural beliefs; Community health centers

Mortality rates for many cancers have been declining, in part due to advances in treatment. Despite these advances, there remain significant cancer mortality disparities in the United States. Racial and ethnic minority, low-income, uninsured, and other underserved groups have not universally experienced the improvements in screening, early detection, and survivorship that are evident in the overall population (Ayanian, 2010; Laiyemo et al., 2010; Lannin et al., 1998). Receipt of timely and state-of-the-art healthcare account for some of the recent improvements in cancer survival and there is evidence of disparities in receipt of surgery for colorectal (Demissie et al., 2004; Dimou, Syrigos, & Saif, 2009; Morris,

Billingsley, Baxter, & Baldwin, 2004), lung (Hardy et al., 2009a, 2009b; Shugarman et al., 2009; Yang et al., 2010), and breast (Yang et al., 2009) cancers. In particular, one study of 1988–1997 Surveillance, Epidemiology, and End Results (SEER) program data found that while most patients received standard treatment for colon cancer, non-receipt of surgical treatment for early stage cancer was twice as likely among black patients, compared to white patients (Demissie et al., 2004). Another study found that under-use of surgical intervention was more common in black compared to white patients, for both colon and rectal cancers, differences that remained even when controlling for socioeconomic and tumor characteristics (Esnaola et al., 2008). Similar trends are evident by income and health insurance status. Thus, across several studies it has been shown that lower-income, uninsured, and racial or ethnic minority individuals are less likely to receive surgical intervention. Such inequalities are likely the product of individual, clinical, provider, and system level factors as well as tumor characteristics and may contribute to disparities in survival.

The reasons for disparities in surgery are multi-factorial. However, one reason for disparate uptake is that some patients hold lay beliefs or explanatory models (Kleinman, 1978; Kleinman, Eisenberg, & Good, 1978) of disease that may be inconsistent with the biomedical model and recommended surgical practice. Lay explanatory models help patients make sense of disease and health within the context of the patient's culture and experience by offering explanations for causes and courses of illness. Understanding such lay beliefs is important for public health and medicine (Prior, 2003) and for developing approaches to promote informed decisions about cancer surgery.

One lay belief that is relevant to cancer surgery is the idea that “cutting” on cancer (i.e., surgery) and exposing it to “air” causes the cancer to spread, increasing suffering and hastening death (DeLisser, Keirns, Clinton, & Margolis, 2009; Gregg & Curry, 1994; Greiner, Born, Nollen, & Ahluwalia, 2005; Margolis et al., 2003b; Masi & Gehlert, 2008; Soler-Vila, Kasl, & Jones, 2005). This explanatory model for cancer spread has been linked to willingness to accept surgical intervention as well as to screening and stage of diagnosis (George & Margolis, 2010; Lannin et al., 1998; Margolis et al., 2003b). In one study, although women reported nearly all cancer treatments did more harm than good, they expressed some of the strongest negative beliefs about surgery (Gregg & Curry, 1994). Most of the women in that study reported that surgery would expose the cancer to the air and cause it to spread. In a larger, multicenter study on lung surgery, more than one-third of respondents stated that exposing cancer to air would cause it to spread (Margolis et al., 2003a). This belief has been most often reported in African-American and Latino patients (DeLisser et al., 2009; Fernandez et al., 2008; Gregg & Curry, 1994; Greiner et al., 2005; Lannin, Mathews, Mitchell, & Swanson, 2002, 1998; Loehrer et al., 1991; Margolis et al., 2003b; Masi & Gehlert, 2008; McCann et al., 2005; Soler-Vila et al., 2005) but there have not been many direct comparisons between racial and ethnic groups.

Like many explanatory models and lay beliefs, this theory is likely the product of individual, social, cultural, and historical factors (Warnecke et al., 2008). Lay models often emerge from an individual's assessment of observed events (Popay & Williams, 1996) and thus are rooted in personal or collective experiences. It is likely that experiences with predominantly later-stage detection of cancer and poor surgical outcomes perpetuate this theory about surgery, air, and cancer spread among underserved populations (Gregg & Curry, 1994). In the past, it may have been that concerns about the risk of biopsies and inability to correctly assess cancer stage resulted in patients faring poorly after surgery as well as confusing messages for patients and families (DeLisser et al., 2009). Other researchers attribute this belief to the persistence of medical mistrust among disenfranchised groups (Margolis et al., 2003b). It is important to recognize that explanatory models are often formed to help

individuals cope with phenomena (Kleinman, 1978; Kleinman et al., 1978) and can be functional for individuals by helping them make sense of their experience (Keeley, Wright, & Condit, 2009). Understanding how this belief affects patient's thought processes and decisions may be important for addressing surgical uptake among those who initially decline.

To date, little research has explored this belief in-depth or evaluated its impact on decision-making, such as deciding whether to accept surgical intervention. In one study, the belief was linked to patients preferring surgery only for early stage lung cancers (George & Margolis, 2010). Others have linked it to being less willing to undergo lung surgery (Margolis et al., 2003b) and having breast cancers diagnosed at later stages (Lannin et al., 1998). How this belief affects healthcare decisions for other cancers or for preventive behaviors remains unclear.

We encountered statements about “cutting” on cancer during a qualitative study of knowledge and perceptions about colorectal cancer screening among low-income patients of diverse race/ethnicities at an urban federally-qualified primary care health center. Here, we present a sub-analysis of those data, focused on themes specific to the idea that surgery would make cancer spread. In doing so, we attempt to address the gap in the literature related to “cutting”, “air”, and cancer, and the implications for cancer treatment decisions and disparities.

Methods

Study description

This research study used focus groups and semi-structured interviews; data were collected from 2006 to 2007. Our methods and main outcomes are described in detail elsewhere (James, Daley, & Greiner, 2011). In brief, after conducting a series of focus groups, we conducted semi-structured interviews with additional participants so that we could follow-up in-depth on topics that emerged from the groups. We continued conducting interviews until the main themes were saturated. All participants completed a short quantitative survey to collect data on demographic characteristics. Our mixed-method approach provided breadth and depth to the data and allowed participants to use their own words to describe and discuss cancer beliefs. Recruitment and data collection were conducted at a community health center in an urban area of the Midwest United States. Health centers served primarily uninsured and under-insured individuals. No healthcare was provided as part of the study. The University Institutional Review Board and the health center administration approved the study and procedures.

Recruitment and sample

We used convenience and snowball sampling. Recruitment procedures were the same for the focus groups and for interviews. Along with flyers and posters in the clinics and waiting rooms, study staff set up a recruitment table in the main lobby of a primary care health center. Patients who expressed interest in the study were screened for eligibility. Contact information was collected so that participants could be assigned to a focus group/interview slot. Participants were considered eligible if they were age 45 years or older (i.e., approaching the age for colorectal cancer screening). Participants were also encouraged to let others know about the study, but were not asked to actively recruit others. We attempted to recruit a diversity of men and women, and screened/not screened participants. To be eligible for this sub-analysis, transcripts needed to include a mention of “cutting” or “air” (positive, negative, or ambivalent). Altogether, data from five focus groups ($n = 3$ to 5 per group) and 21 interviews were analyzed in this report. Two additional paired interviews

(when two participants appeared at the same time slot) are also included. Two interviews (where cutting was not discussed), one interview where cutting was discussed but the participant was later determined age-ineligible (age < 45), and one focus group where a participant was age-ineligible were excluded from this analysis. The total number of participants involved in this analysis was 42.

Procedures

Except for group size, the procedures and questions were the same for focus groups and interviews. Participants were contacted by telephone to schedule a focus group or interview and received a reminder call 1–2 days before their scheduled slot. Participants provided written informed consent immediately prior to participation. Focus groups were led by a trained moderator who had prior experience conducting focus groups with underserved patients; interviews were conducted by trained research assistants who had attended the focus groups. At each session, an assistant was present to take notes, help with the informed consent and survey, and operate the recording equipment. Focus groups lasted approximately 90 min; interviews lasted between 30 and 60 min. Each participant received a \$25 gift card and light meal or snack. A semi-structured format was employed. Sessions were audio-taped and transcribed verbatim.

Measures

Immediately prior to the focus group/interview, participants completed a short quantitative survey that addressed demographics, personal and family history of cancer, and colon cancer screening history. The moderator's guide addressed knowledge, screening experiences, attitudes toward screening, and cancer beliefs.

Analytic strategy

A sub-sample of transcripts was checked for accuracy against the audiotape; very few discrepancies between were detected and all were minor. Data were analyzed using standard inductive text analysis (Bernard, 2006). For this sub-analysis, two trained coders and the Principal Investigator re-read all study transcripts for any mention of “cutting” or “air” in relation to cancer, and then met to develop code categories and the codebook. Although we were looking at only quotes related to this specific topic, codes were inductively derived from the transcripts. The two coders then re-read the transcripts and coded the text according to the definitions in the codebook. Coders worked independently but met regularly to compare and contrast codes. Discrepancies were few, but were resolved by the principal investigator. The research team met to discuss themes and identify exemplar quotes. Transcripts were coded by hand and entered into Atlas-ti to facilitate organizing the data. Only saturated themes are reported.

Results

Data from 42 participants are reported here (5 focus groups; 21 single interviews; 2 paired interviews); in four of those sessions, participants brought up the idea before the moderator asked about it. In remaining interactions, the moderator read a statement about cutting or air causing cancer to spread and asked for the participant's opinion. Of respondents analyzed here, 62% were female. Most (81%) self-identified as African-American. Respondents ranged in age from 46 to 75 years of age (See Table 1 for additional demographic information). Similar themes emerged in the interviews and focus groups, so we analyzed them together. Five themes were identified and are discussed below.

1. *Many participants supported the idea that cutting on cancer or exposing it to air would cause the cancer to spread.* Most participants who said they had heard of this

belief expressed some level of agreement with the idea. For example, one participant said, *“I already know if you’ve got cancer and they cut on it, 9 times out of 10 it spreads even worse”* (Focus group). We did not specifically probe on the mechanism of how cancer would spread, and respondents usually discussed “cutting” and “air” in tandem rather than only addressing one or the other. However, a sub-theme that exposing cancer cells to air (oxygen) would cause spread was evident, as explained by these participants:

“Everybody that I’ve ever known that had cancer, they were fine until they went under the knife.the minute they open them up and that oxygen mix with that cancer, it spreads” (Focus group). *“It’s the air. Once air hits cancer it spread like a wildfire”* (Interview).

One participant explained that surgery would cause cancer to spread, but that the impact could be reduced with certain biomedical techniques: *“...before they cut you, ...I think you need to like burn all those cells around it,...with the radiation.... take a little chemo and then let that...then cut”* (Interview). A common qualifier was that surgery might work in early stage cancers but not for advanced disease: *“When the air hits, you know, that makes it spread; IF it’s too far gone”* (Interview).

2. *A minority of participants had not heard of this explanation and others expressed disagreement.* Of those who had not heard about this explanation, most expressed disbelief. Disagreement was verbalized in terms of a direct dismissal of the idea, explanation of its roots, or personal experiences that countered the theory. Below is an example of a participant who countered the belief by sharing an example:

“I’ve always heard that once they start cutting on you that only quickens our death, and sometimes they can cut it and then, like, don’t get all of it and then it can go somewhere else, your cancer. So I mentioned about my uncle and who had prostate cancer and he had surgery. He had it removed and he’s doing alright now. Perhaps they got all of it...” (Focus Group).

In terms of direct dismissal, a typical response was *“I don’t know where they get that [belief] from. I really don’t”* (Interview). Others disagreed with the idea but explained its roots with people whose cancer was too advanced at the time of surgery. *“You waited too long when they opened you up there was nothing they could do so they closed you right up”* was one of the more common theories for how the belief developed. As another participant explained,

“That’s an old wives’ tale. It used to be that if someone had cancer and then went to surgery to do an exploratory, and sometimes if the physician opened them if they cancer was too advanced they just close them back up. Well, that was translated as, ‘they opened me up, the air will spread’, so that was just lack of information” (Interview).

3. *Participants knew family members who had declined surgical intervention because they were afraid it would make the cancer worse.* This belief was expressed both in terms of people who clearly stated that the fear that cancer would spread would cause them personally to avoid surgery if they were diagnosed with cancer, and in terms of instances where this idea influenced family member’s healthcare decisions. The experience and expected effects of this belief on behavior varied, because many participants still seemed willing to (hypothetically) consider surgery under the right circumstances: *“I’d have to have some kind of assurance that it wouldn’t immediately spread through the whole body. I’d like to have a little time, you know, to kind of say goodbye”* (Interview).

Others vehemently stated that they would avoid surgery:

“If I had cancer right now, sister, I’m going to die with it. You will never cut me. ‘Cause once the air hits it... it spreads. Now, why, I don’t know... I know that when you have surgery (‘cause I’ve lost several friends that have had surgery with cancer to cut it out), it spreaded. So, um, if I ever get cancer, I don’t care what kind it is, I’m going to die with it.... Because once you open me up, the cancer, to cut it out, it usually spreads. So that’s why a lot of patients are taking chemotherapies now to keep the doctors from cutting them. Because once you open it up, it’s a done deal, you’re dead. That really is a death sentence” (Interview).

“I think if I had cancer don’t do surgery on me, ‘cause I’ve had a girlfriend to die from it. Once they did that, it spread it... And to me I felt like she might have had a better chance if they had not opened her up and the air wouldn’t have hit it” (Interview).

Stories of family members who turned down surgery were fairly common: *“I have a stepmother right now that has cancer as we speak and she refused to do the surgery because she knows if she lets them open her up and that oxygen, that air gets to that cancer...”* (Focus Group). But at times, the belief complicated family discussions about treatment, and caused discord. As one participant said, *“I said they couldn’t cut on my grandpa because he was too old. But they said because they cut on my grandfather – my brother and them – it’s spreading. I don’t believe it”* (Interview).

4. Beliefs about “cutting” and “air” spreading cancer often appeared alongside fatalistic statements about cancer, and individual’s theories about cancer and cancer treatment. Many times, the idea that surgery would worsen cancer was linked to statements that reflected fatalistic beliefs or skepticism about the potential for curative surgery. For example,

“It’s like [doctors say] ‘we got it all out’. How you gonna get all that cancer out [of] that person? Where do you think some of it went to while you were in there digging?” (Interview).

Skepticism about whether the surgeon “got it all” was echoed by several other participants. As one participant said, *“that word they use, remission, I don’t believe in it”* (Interview).

Participants also mentioned strategies that might make them more likely to accept surgical treatment for cancer, or would make surgery more helpful and less harmful. In addition to the above participant who mentioned pre-surgery chemotherapy to reduce the chance of spread, another participant suggested that *“if they could possibly do [surgery] without... you know, they’ve got these little microscope things, if they could do it that way”* (Interview). This idea relates to the previous theme where participants believed that surgery would cause spread, but were willing to try surgery under certain circumstances.

Discussion

We found that many low-income adults in our study believed that surgery worsens cancer, causing it to metastasize and resulting in poor outcomes. The belief was often significant and strongly held, and influenced decisions of participants and of their family members or friends with cancer. Because surgery is often a first-line intervention for many cancers, it is imperative that there be open discussion between physicians and their patients about this

topic, as it seems to be one contributor to non-receipt of surgery. Given that the explanatory model has been reported more often in the same populations who experience surgical disparities (Soler-Vila et al., 2005), this may contribute to differences in receipt of surgery.

Many participants expressed reluctance or concern about surgery to treat cancer, because they believed it would worsen their health. The link between beliefs about surgery and fatalistic statements about the curability of cancer that we found is consistent with what other researchers have reported or speculated about (Greiner et al., 2005). Alongside statements about how surgery would worsen cancer were statements that expressed doubt in the efficacy of any cancer treatment and stories of family members and friends who did not survive. Differentiating lay beliefs about cancer spread from general perceptions about the incurability of cancer and cancer fatalism may be an important avenue for future research and for better understanding both theories about spread and perceptions of the curability of cancer. Not all participants equated the distrust of surgery with incurability of cancer. For example, there was a participant who expressed that laparoscopic options may be less likely to cause spread, indicating that for these persons, less cutting and less exposure to air may mitigate the risk. Other patients suggested that chemotherapy or other treatments may reduce the cancer before surgery, again minimizing the chance of spread and increasing the curative potential. Interestingly, some treatment protocols do recommend pre-surgery chemotherapy, so this suggestion is not inconsistent with medical practice (though the reasoning may be different).

These lay models could certainly result in altered use of care for cancer patients, specifically use of surgery, and may contribute to cancer disparities. Our participants mentioned several instances where family members declined surgery (or where the discussion caused family discord and potential delay) because of fear that it would worsen the patient's health. At least one prior study found that lower rates of surgical intervention in African American patients were due to patients' declining treatment (McCann et al., 2005). While clearly related to treatment decisions, we speculate that this belief may also be associated with screening. Findings that this belief was associated with later stage breast cancer (Lannin et al., 1998) could suggest that patients were less likely to accept screening. Additionally, in our data, concerns about spread sometimes emerged during discussion of screening, where participants expressed concern that screening would show cancer and *"that'd scare me because I know they'd probably want to cut on it"*. The impact on screening could be direct or it may occur in conjunction with beliefs about incurability of cancer, as fatalistic beliefs are associated with lack of screening (Powe, 1995). While most of the discussion in our study was about impact on treatment decisions, further research that elucidates any impact on screening – and ways to mitigate the negative impact – would be useful.

Explanatory models often function to help individuals make sense of disease (Rajaram & Rashidi, 1998), and the idea that surgery causes cancer to spread may serve to help underserved patients make sense of poor survival and observations that loved ones decline rapidly after surgery for later-stage cancers. Indeed, we encountered many personal stories about negative outcomes of surgery. Dialog about cancer processes and surgical intervention may have great importance for practitioners and researchers as prevention and treatment options become more widely available.

Limitations in our study include the small sample size and lack of diversity in the sample (our sample was predominantly African American and all were lower-income), and our inability to quantify response rate or prevalence of the belief. However, given the paucity of data on this topic, this study provides a beginning to understanding this belief and emphasizes the need for further inquiry into this area, especially among low-income African Americans.

Increasing our understanding of this potential barrier to surgical treatment of cancer is crucial today as the associated delay in diagnosis and surgery can impair response to treatment and survival. These explanations about the roots of this belief may prove to be a useful conversation point with patients who are resistant to surgery. Future prospective studies of the impact of this belief should be helpful, and point-of-care interventions to assure optimal outcomes for the underserved will need development and testing. Studies of the belief that “cutting” or exposing “air” to cancer could cause spread to date have been limited and rarely have relied on qualitative data or explored the meaning of this belief to patients. This investigation offers unique insight and a focused look into patients’ explanations of this belief and the mechanisms of how spread may occur. Efforts to enhance trust between low-income patients and healthcare professionals may be needed, practitioners may do well to discuss with patients how they interpret their cancer and cancer processes, in order to help patients make informed decisions about their treatment.

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Table 1Socioeconomic characteristics of the sample ($n = 42$).

	n	%
Health insurance		
Currently has health insurance	21	50.0%
Education		
Completed some high school	7	16.7%
High school degree or GED	12	28.6%
At least some college	23	54.8%
Employment		
Unemployed (looking for work)	18	42.9%
Not employed for other reasons	15	36.6%
Employed full-time or part-time	8	19.5%