



## Short report

## “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.

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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 underuse 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

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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

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