Published in final edited form as:

J Cancer Educ. 2018 August ; 33(4): 749–756. doi:10.1007/s13187-017-1196-5.

Rural women's perceptions about cancer disparities and contributing factors: A call to communication

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Abstract

Rural cancer disparities are increasingly documented in the United States. Research has identified and begun to address rural residents' cancer knowledge and behaviors, especially among women. Little, however, is known about rural female residents' awareness of cancer inequities and perceived contributing factors affecting them and their families. The purpose of this study was to address these gaps in the literature via a secondary analysis of qualitative needs assessment in Illinois' rural southernmost seven counties, a geographic region with relatively high rates of cancer incidence, morbidity, and mortality. A convenience sample of 202 rural adult female residents was recruited and participated in 26 focus groups, with 3–13 women per group. Inductive content analysis, guided by the principle of constant comparison, was used to analyze the qualitative data. Most respondents indicated their awareness of disproportionate cancer burden in their communities. Individual-level behaviors and environmental toxins were identified as contributing factors. Interestingly, however, environmental toxins were more often discussed as factors contributing to geographic differences, whereas individual-level behaviors were noted as important for overall cancer prevention and control. This study provides important insight into female rural residents' perspectives and offers novel venues for educational programs and research in the context of communication to eliminate disparities.

Keywords

rural; cancer disparities; incidence; environmental toxins; cancer behaviors

Introduction

The burden of cancer is unequal across population groups.[1] Research suggests greater incidence of different types of cancers in some rural communities in the US.[2–7] For example, Singh[6] found that rural women have a 15% higher cervical cancer incidence rate compared to women living in metropolitan areas. Between 2001 and 2004, Hausauer and colleagues [3] documented a greater decline in invasive breast cancer incidence in urban areas (14%) relative to rural areas (8%). Between 2006 and 2010, the incidence rate of all invasive cancers in southern rural communities in Illinois (496.3 per 100,000; 95% CI=489.3–503.1) was significantly greater than the state’s as a whole (490.1 per 100,000; 95 % CI=488.4–491.3).[2] Simultaneously, rural individuals diagnosed with cancer are more likely to have late stage diagnoses, worse quality of life, and worse health behaviors relative to urban counterparts.[6, 5, 8–14, 7] It is thus not surprising that improving cancer prevention and control in rural settings is a public health priority.[1]

Multiple factors contribute to higher cancer incidence rates within some rural communities, including concentrated poverty, exposure to environmental toxins (e.g., coal mines), and health behaviors (e.g., smoking).[2, 15–17] Important work has characterized rural residents’ knowledge about cancer (e.g., symptoms, commonness) and related individual-level behaviors (e.g., smoking, screenings).[18–24] Nonetheless, little is known about rural populations’ awareness of cancer *disparities* and perceptions of contributing factors (e.g., individual knowledge and behaviors; access, environment).

Characterizing patient perspectives on disparities is a “necessary first step toward changing behavior and compelling action”.[25] For example, obtaining these perspectives can enable researchers to identify misconceptions populations may have about population health due to reliance on less reliable sources of information or personal anecdotes.[26, 27] Such data are also necessary to develop educational programs that are responsive to populations’ perceived health needs and therefore represent appealing, useful solutions.[28–30] For example, members of the targeted populations may perceive individual behaviors to be the primary contributing factors in the disproportionate burden of cancer they and their families experience. In this case, traditional cancer education programs may be optimally effective, as they can be used to motivate the necessary behavior change (e.g., improved diet, guideline-concordant screening) to reduce cancer risk, morbidity, and mortality.[31, 32] On the other hand, members of the targeted populations may perceive contextual factors as primary contributing factors to disparities. In this case, educational programs pertaining to community mobilization and grassroots advocacy strategies may be most appealing to the target population for eliminating cancer disparities through viable policy and community-level solutions.[33, 30, 34]

Toward the long-term goal of calls to communication and educational action about rural cancer disparities, we conducted a secondary analysis of a qualitative assessment originally focused on general community needs and experiences with rural women in rural Southern Illinois. Given our objective concerns residents’ perspectives, we leveraged the strengths of a qualitative, inductive approach to capture comprehensively women’s viewpoints through their own words.[35] Southern Illinois is well-suited for such a study, given it is an area with

disproportionately poor cancer outcomes.[2, 7] Rural women's perspectives about cancer disparities are important for a number of reasons. First, rural women in this region are at high risk for sustained and increasing cancer disparities; the regional female age-adjusted cancer mortality rate (169.1 per 100,000) women increased by 0.9% from 1990 to 2010, and now nearly matches that of heart disease.[7] Conversely, cancer mortality for females in Illinois decreased by nearly 16% during this same time frame.[7] Second, women are likely to be caretakers and support systems for their families and friends with cancer,[36–39] and thus may have a vested emotional stake in cancer disparities, due to increased household responsibilities, schedule disruption, financial challenges, and unmet psychological needs related to anxiety, stress and coping, and lack of support.[40]

Methods

Setting

Our study was conducted within southernmost 7 (S7) counties in Illinois, which spans roughly 2,003 square miles and has approximately 67,363 residents.[41] The S7 is located within the geographic bounds of the Delta Regional Authority. The Delta Regional Authority is a federally designated area of 252 counties across 8 states along the Mississippi River and aims to improve the socioeconomic conditions of this historically impoverished region.[42] In addition to sustained poverty, residents of this region have poorer health behaviors and outcomes and higher all cause and cancer mortality rates than the rest of the country.[43, 44] S7 specifically experiences high rates of cancer. In 2010, cancer was the leading cause of death among S7 residents and four of these counties were among the 'top twenty' with regard to cancer mortality among Illinois counties.[41] In the context of incidence, each S7 county exhibited higher incidence rates for between 4 and 10 cancer sites relative to Illinois State as a whole between 2008 and 2013.[45] All S7 counties had higher incidence rates for lung cancer. Three of the seven had higher overall incidence rates relative to Illinois. Figure 1 depicts other particularly high incidence rates per county. The S7 Health Department has largely focused on individual behaviors as factors contributing to disparities, including particularly high rates of smoking, low fruit and vegetable intake, and low screenings for colorectal, breast, colorectal, and prostate cancer.[41, 2]

The current study was a secondary analysis of a larger needs assessment.(BLINDED) The needs assessment resulted from a collaboration in the S7, which included the health department, an academic partner, and multiple community partners that was focused on women's health. Given this, female perspectives were collected and are used for the current study. Fourteen focus groups were conducted during the planning phase of this partnership as part of a community health assessment (Phase I, February–March 2011). The second set of 12 focus groups was conducted prior to the implementation of a cardiovascular health education intervention at various churches (Phase II, July 2012–August 2014).

Eligibility Criteria and Recruitment

For the needs assessment, focus groups were separated by gender (female, male), residence (Alexander; Johnson; Massac; Pope/Hardin; Pulaski; Union), and 4 age groups (18–30; 31–50; 51–70; >70). Thus, eligibility criteria for inclusion in the current study were as follows:

age of 18 years or older (both Phase I and II); residence in one of the S7 counties (both Phase I and II); and, identification as female (Phase I). The 87 males who participated in Phase II were not included in the analysis for the current study.

Focus group participants were recruited using flyers, announcements in church and community newsletters, and newspaper advertisements across 2-month periods. Our wide reach for these needs assessments and subsequent interventions has been estimated at reaching over 600 women (BLINDED). Interested women contacted the S7 Health Department, who kept track of sign-up sheets and notified the study team when approximately 4–6 individuals had signed up. During those calls, S7 Health Department staff screened and signed women up for focus groups, based on their age, area of residence, and availability. Women who were 18–30 and 31–50 years old were less likely to sign up for focus groups relative to those aged 51–70 and >70 years old, as evidenced by two groups being canceled and over five groups being rescheduled due to low sign-up. In addition to women who contacted the S7 Health Department, some participants showed up to the focus groups (e.g., due to coming with a friend), were screened, consented, and then participated in the focus groups. Unfortunately, there was no tracking of women who were screened by phone and women who arrived without prior screening. As well, no tracking was done with regard to the number of women who were interested and screened, but did not ultimately show up to participate.

Data collection

Focus groups ranged in time from 44 to 83 minutes, and included 3 to 13 participants. Focus groups were conducted at public locations, such as clinics, churches, libraries, and senior-living facilities within their communities. Facilitators were trained in qualitative data collection, identified as non-Latino White, were 30–59 years old, and lived in or near the S7 region. The facilitators used a semi-structured guide to lead discussions on participants' perceptions about the health needs of their communities, as well as health needs specific to women. The scripted questions were open-ended and inquired both about perceptions of community health problems and how participants felt those issues may be addressed. Notably, these questions did not focus or directly prompt community members to consider disparities. Example questions included: “What do you think are the most significant health needs or health problems in your community?”; “What do you think are the causes of the health problems that you mentioned?”; and, “The Southern Seven Health Department recently identified heart disease, obesity, diabetes and cancer as health conditions that need to be addressed in your region...What do you think can be done to prevent these health conditions, and/or to help individuals who are affected by these health conditions?.”

Qualitative data analysis

Verbatim transcripts were checked for accuracy and uploaded into ATLAS.ti version 7 (Berlin, Germany) for subsequent analyses. Two authors (BLINDED) led the primary analysis and interpretation of focus group data; details regarding their comprehensive techniques are provided elsewhere.[46] For the current study, we conducted a secondary analysis of the focus group data with attention to cancer-specific information. Our analysis was based on content analysis techniques and principles of constant comparison.[35] This

was a secondary analysis aimed at understanding disparities from the perspective of the target population. Thus, two domains were selected *a priori* by the study team (the burden of cancer incidence; factors contributing to cancer incidence). We read each transcript and applied in vivo coding concerning these specific domains, in which meaning and themes were identified from this subset of data. The team met, discussed emergent codes, reviewed notes, discussed areas of disagreement to consensus, and adapted the primary codebook accordingly across a series of in-person and e-mail communications. Finally, we underwent analyses to assess which, if any, themes may have differed across periods of data collection, age group, or residential region. Notably, assessment of themes by race/ethnicity and other demographic characteristics (e.g., class, disability status) was not possible, as groups were not stratified by these identities.

Results

Table 1 depicts the demographic characteristics of the study sample. A total of 202 women participated in 26 focus groups, 110 in Phase I and 92 in Phase II. Participants' mean age was 55.0 ± 17.8 years. 23.7% of participants were African American women. A majority of participants were either working full-time (34.5%) or retired (35.7%), and 28.6% had an annual household income equal to or less than \$35,000.

Interestingly, respondents perceived particularly high rates of cancer in rural areas, and in their region in particular. In discussing contributing factors, women did highlight individual-level behaviors in the context of cancer prevention and control. However, most respondents indicated that the disproportionate burden faced by rural communities was largely due to environmental toxins. Cancer-specific information appeared to be discussed more often among older individuals (35+ years old) and discussed at greater length among individuals participating in the first set of focus groups. Nonetheless, the meaning of themes did not vary appreciably by these groups.

Cancer Incidence in Rural Communities

In response to questions about health issues in their community, two respondents from Focus Group #2 emphasized, "There's been an increase in cancer" (R7) and "Cancer is huge" (R1). Women further perceived the burden to be greater in their local communities relative to other geographic areas, as depicted by this Focus Group #3 respondent, "We are a cancer prone community...we have a higher incidence of cancer than most normal populations." Another respondent from Focus Group #11 highlighted, "We have three of the counties [that] are in the top ten in Illinois for cancer rates."

Contributing factors

Individual-level behaviors, specifically unhealthy habits like smoking and poor adherence to recommended health screenings, were discussed in terms of general cancer prevention and control. For example, when asked about factors related to cancer, a respondent from Focus Group #17 noted, "Young people smoking – which if they knew what would lead up to it [cancer], I don't think they would do it." In terms of screening, a respondent from Focus

Group #12 noted, “Health means getting your yearly physical, your yearly mammograms, and so forth.”

Environmental toxins were more often discussed and likely to be considered the major driver of greater cancer incidence in the rural counties in which women’s communities resided. For example, a female respondent from Focus Group #8 noted, “Cancer – they say we have bad soil.” One female respondent from Focus Group #6 stressed, “The water – it’s polluted. You drink it and then you get cancer.” When one respondent emphasized the high amount of cancer in their community (“It’s a lot of cancer”), another respondent from Focus Group #13 remarked, “It’s the environment. We’re breathing it...there’s something in the air that will take paint off your car. That’s metal and you’re breathing that. It can’t be good.”

Respondents were also aware of the interplay between different types of environmental toxins. In response to the prompt “Okay, anything else? Important health issues in your community” the following conversation ensued among the six Focus Group #9 participants:

R1: There’s a lot of cancer.

R2: A lot of cancers [are] in here [the environment] and something has to be attributing to it.

R1: My one daughter-in-law...her thesis was on this area and cancer. There’s a lot more cancer here than there is in other places.

R3: So the area you live in?

R1: The environment.

R4: We’ve got several factories.

R5: Radioactive...and water halogens.

In response to the prompt “Any other causes that you can think of for some of these health problems that we’ve mentioned?”, some of the eight respondents from Focus Group #17 noted:

R1: This area tends to have high incidence of cancer. So, what’s the cause of that? I mean, is it the ground water? Is it—

R2: The power lines.

R1: It’s the power, what is it? And what’s being done about that?

R3: Lots of kidney stones, lots of cancer.

R1: I mean some big brain tumors...It is a small community, and so when we keep hearing, you know, that brain tumor, brain tumor, brain tumor...of the hundred people I know, five of them suddenly have been diagnosed with a brain tumor? Now that’s surprising. That’s a high number.

When the moderator asked, “What do you feel are some causes of the higher rate of cancer?” to the thirteen women involved in Focus Group #16, the following conversation concerning the intersection environmental and individual factors ensued:

R1: No insurance really – they’re not seeking medical attention soon enough.

R2: The environment. The mines. I think it’s [the] environment.

R3: I think it’s the water.

R4: The water that is from the mines.

R5: Sometimes you can go outside and you can smell the chemicals from nearby plants. You’re breathing in that stuff.

R6: Air quality, pollution.

A respondent from Focus Group #15 remarked:

Most of the employers around here are rock dust – mining...my dad passed away from smoking and they flat out told him it was smoking. And he worked in the mines all his life. So, I think he just had it down the lobes. But, I think when you’re smoking so much, that the lung cancer, that’s part of the problem here too.

Discussion

The current study provides important findings regarding rural women’s awareness of disparities and perceptions of contributing factors in their communities. First, women indicated high levels of awareness about cancer disparities within their communities. Second, rural women perceived both individual-level behaviors and environmental toxins as important factors to consider in the context of cancer. Interestingly, however, women were more likely to perceive environmental toxins to be the etiologic factors of disparities in their rural area. Individual-level behaviors, on the other hand, were considered important for overall cancer prevention and control for all communities.

Female respondents overall exhibited high levels of awareness about rural cancer disparities. These results are somewhat surprising. Past research in a non-rural setting suggested that local news coverage of cancer disparities was relatively limited [47] Understanding the source of health disparity information among rural respondents is an important next step, especially in terms of ensuring accurate and up-to-date information is communicated to targeted populations in the future. Greater awareness may be a result of personal experiences, as respondents mostly emphasized the burden of cancer for their own communities and social networks. While important, one concern is that these experiences may not be as accurate due to psychological biases (e.g., confirmation bias; availability heuristic).[26] Alternatively, respondents may have been informed about cancer disparities by their clinicians, public health practitioners, non-profit organizations, and/or policymakers. Along with traditional media sources (e.g., television, newspapers, and print), health professionals, peers, and the internet have been found to be common sources of cancer information.[48–50]

Female respondents’ perceived contributing factors have been increasingly documented within academic research and public health practice. Nonetheless, most research in this geographic area has focused on cancer incidence in relation to individual-level behaviors, especially smoking.[41, 2] Intervention and public health practice has, accordingly, focused

on tobacco cessation, improving dietary habits, increasing physical activity, and increasing cancer screening.[41] Of note, female respondents were aware of these traditional cancer prevention and control efforts. This knowledge of efforts provides an opportunity to translate prevention awareness into improved health behaviors and increased screening adherence.

Our study, however, suggests that these individual-level factors may not address all of the determinants of cancer that worry the women of the target population. Female residents' concerns about environmental toxins align with some recent work concerning the role of environmental factors in cancer incidence within rural Illinois, including proximity to coal mines.[15] Further, it should be noted that recent efforts have sought to examine levels of environmental toxins, including radon.[41] Target populations however may be more generally aware of individual- and interpersonal-level determinants of health and associated interventions than they are of contextual factors and interventions.[51, 52] Rural female residents may not be aware of ongoing, viable strategies to characterize and address environmental toxins. Our work thus suggests that more exposure is warranted to evidence concerning cancer risk factors at multiple levels and local efforts to address them. Relatedly, such informational campaigns may benefit from offering information about the relative effects different risk factors have for cancer incidence (e.g., smoking versus coal mine exposure). Such work might be particularly relevant given perceived and objective risk may not always be concordant (e.g., for environmental risk among rural communities).[53]

Interestingly, factors like socioeconomic conditions, access to care, and utilization of care did not emerge as contributors to cancer disparities for most participants. Empirically, some cancers, such as cervical and liver cancers, have higher incidence rates in impoverished areas.[54] Residents in the Delta Region have a lower density of primary care physicians compared to the rest of the country.[43] Paradoxically, despite a higher proportion of rural residents stating they have a usual source of care, rural residents appear to utilize preventive services and cancer screenings less than their urban counterparts.[55] Regular doctor visits provide physicians with the opportunity to educate patients about cancer prevention and health behaviors. However, focus group participants may have considered the preventive health behaviors (e.g. not smoking, eating fruits and vegetables) specifically, rather than the source of such information (i.e. physicians), as they relate to cancer disparities. Because poverty and lack of access to primary care in the region is persistent and pervasive (i.e. a shared experience among residents), such factors may not be perceived as striking contributors to cancer disparities. The lack of identification of these factors may provide important information regarding the context of health communication and education efforts to mitigate cancer disparities in the region.

The current study had several limitations. First, rural women's perceptions of disparities and contributing factors were not primary objectives for the original studies. Thus, we did not obtain important data, including the sources of information underlying perceptions about disparities and contributing factors as well as awareness of potential solutions for disparities. There is further a need to understand the perceived reference groups among rural women, in order to direct future equity-focused health promotion among local populations. This includes future observational research that is designed to assess perceptions concerning disparities in this group in order to confirm our findings (e.g., a focus group guide centered

on disparities; facilitator-participant matching) and expand our understanding of perceptions (e.g., target populations' perceived reference group). Second, non-probability based methods were used to recruit participants. Given this, generalizability of our findings may be limited. Unfortunately, our study team did not systematically assess recruitment flow. Thus, we are unable to provide estimates nor compare demographic information among individuals who were reached by recruitment efforts, individuals who contacted staff but did not participate, individuals who contacted staff and ultimately participated, and individuals who ultimately participated with previously contacting staff. We focused on the perspectives of rural women; however, rural men and children may have different perspectives. Further, our groups were racially heterogeneous; thus, we were not able to assess differences in perceptions by women of color and non-Latino White women. Prior studies have found racial and gender differences in beliefs about the influence of environmental risks on health[57–59] and in cancer-related information seeking behavior.[60–62] Specifically, women and minorities tend to perceive more risk and engage in more information seeking behavior.[61–62] Such work should expand on our findings, especially in the context of assessing gender and racial/ethnic differences in perceptions about disparities. Third, it should be noted that little empirical research exists to compare the relative effects of individual-level behaviors and environmental toxins on disparities. Fourth, there was discordance between facilitators and some participants in the context of age, area of residence, and racial/ethnic identity. This discordance may have affected participants' willingness to discuss certain challenging topics, including disparities.

Conclusion & Future Directions

Our project offers important evidence concerning rural women's awareness of cancer disparities and contributing factors. First, there is a need for further observational research that is designed to assess perceptions concerning disparities in this group (e.g., a focus group guide centered on disparities; facilitator-participant matching) and expand our understanding of perceptions (e.g., target populations' perceived reference group). Such work should expand on our findings, especially in the context of assessing gender and racial/ethnic differences in perceptions about disparities. Overall, future research is warranted to confirm our findings; assess rural men and children's perspectives; examine factors contributing to residents' perceptions; and, characterize residents' awareness of current and possible solutions to disparities. Second, our findings have important implications for the *type* of cancer equity educational programs that may be most appealing for rural women (e.g., awareness of environmental research; focus on interplay of individual and environmental factors). Finally, our work suggests the benefit of incorporating target populations in multi-sectoral, multi-level cancer equity efforts to address rural disparities.

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Figure 1.

The map depicts cancer sites wherein cancer incidence was greater in the county relative to the state as a whole between 2008 and 2013.

Table 1

Study sample demographics (n = 202)

Characteristic^a	
Data Collection Phase	n
February–March 2011	110
July 2012–August 2014	92
	M (SD)
Number of individuals per group	5 (2)
Age (years)	55.0 (17.8)
	n (%)
Race/ethnicity	
Non-Latino White	147 (75.8)
African American	46 (23.7)
Other	1 (0.5)
Educational Attainment	
High school	11 (13.4)
>High school	71 (86.6)
Marital status	
Married	55 (65.5)
Other	29 (34.5)
Employment status	
Working full-time	29 (34.5)
Working part-time	14 (16.7)
Retired	30 (35.7)
Other	11 (13.1)
Annual household income	
\$35,000	24 (28.6)

^aDemographic (age, education attainment, education status, and annual household income) information representative of 84 participants in July 2012–August 2014 data collection