

NIH Public Access

Author Manuscript

Patient Educ Couns. Author manuscript; available in PMC 2012 November 1.

Published in final edited form as:

Patient Educ Couns. 2011 November ; 85(2): e69-e74. doi:10.1016/j.pec.2011.01.036.

Rural-Urban Differences in Discussions of Cancer Treatment Clinical Trials

Robin C. Vanderpool, DrPH¹, Julie Kornfeld, PhD, MPH², Laurel Mills, MPH¹, and Margaret M. Byrne, PhD²

¹ Department of Health Behavior, University of Kentucky College of Public Health, Lexington, KY, USA

² Department of Epidemiology and Public Health, University of Miami Miller School of Medicine, Miami, FL, USA

Abstract

Objective—Compare the characteristics of rural and urban callers to NCI's Cancer Information Service (CIS), and explore the association of geographic location and discussion of cancer clinical trials.

Methods—Using CIS call data from 2006–2008, we assigned a rural or urban designation to caller ZIP codes using Rural-Urban Commuting Area Codes. Calls which discussed clinical trials were analyzed using univariate and multivariate analyses.

Results—The CIS received 227,579 calls from 2006–2008 where geographic location could be determined. Overall, 10.3% of calls included a discussion of clinical trials; there were significantly more discussions among urban dwellers than rural individuals (10.5% vs. 9.4%, respectively). Multivariate regression analyses supported the univariate findings. In addition, compared to other callers, patients (OR 5.58 [95% CI: 4.88,6.39]) and family and friends (6.26 [5.48,71.5]) were significantly more likely to discuss clinical trials.

Conclusion—Urban callers were more likely than their rural counterparts to discuss cancer treatment trials, placing individuals living in rural areas at a disadvantage in learning about and communicating with their providers about possible participation in clinical trials.

Practice implications—Through its multiple access points, the CIS can serve as an important source of clinical trials information for rural cancer patients, family members, and providers.

Keywords

Rural; Cancer; Clinical Trials; Patient Education

^{© 2011} Elsevier Ireland Ltd. All rights reserved.

Corresponding author at: Robin C. Vanderpool, DrPH, University of Kentucky College of Public Health, Department of Health Behavior, 121 Washington Avenue, Suite 111C, Lexington, KY, USA 40536-0003, Robin@kcr.uky.edu, Phone: 859-2190-0773 ext. 270, Fax: 859-219-0557.

Declaration

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

1. Introduction

Cancer treatment clinical trials are vital for the advancement of cancer care and moving science from bench to bedside. However, less than 5% of adult cancer patients participate in clinical trials, well below the 75%–90% of children with cancer who participate in pediatric treatment trials.[1–3] Overall low adult participation rates are further exacerbated by participation disparities among ethnic and racial minorities, older populations, women, individuals of lower socioeconomic status, and residents of rural communities.[2, 4, 5] Notably, rural individuals carry an undue burden of cancer due to lower rates of cancer screening, higher rates of at-risk health behaviors such as smoking and poor diet, and later stage cancer diagnoses.[6-8] Many rural residents live in communities characterized by lower socioeconomic status, increased numbers of older residents, higher rates of unemployment, higher rates of health illiteracy, increased concentrations of ethnic and racial minorities and poor Whites, and geographic isolation.[9-12] Related to healthcare, many of these rural communities are identified as partial or whole health professional shortage areas, have higher under- or uninsured rates, lack primary care and specialty physicians as well as National Cancer Institute (NCI)-designated cancer centers or American College of Surgeonapproved hospital cancer programs, and residents may have to travel long distances to receive cancer treatment.[2, 9, 12-14]

While the literature has identified a general lack of clinical trial awareness and misinformation as significant barriers to trial participation [15, 16], particularly among minorities and lower income and less educated populations [17, 18], few studies have focused on rural individuals' awareness and understanding of cancer clinical trials. Analysis of the 2008 NCI Health Information National Trends Survey (HINTS), which is representative of the U.S. population, reveals a significant difference in awareness of clinical trials between urban (n=4,336, 67.0%) and rural (n=929, 60.7%) respondents (P<0.003) (LF Rutten, personal communication). Coyne and colleagues' in-depth, qualitative interviews with Appalachian West Virginia cancer patients revealed only eight of 17 participants knew what clinical trials were, and three of these eight individuals worked in the medical profession.[19] Similar to other studies with underserved populations, some of this rural sample held misperceptions about clinical trials, including the belief that clinical trials are a treatment of last resort. Other patient concerns included cost and insurance coverage, distance and transportation, side effects and negative treatment outcomes, and whether their family members and physician would support a decision to join a trial.[19] Randall-David and colleagues conducted four focus groups in three rural and one urban community in North Carolina with members of the general public; only 57% of the participants had heard of the term "clinical trial". [20] This study sample held many of the same misperceptions about clinical trials as the Appalachian West Virginia participants. In 1996, rural primary care physicians in North Carolina and South Carolina stated patients' lack of clinical trials knowledge and travel as significant factors influencing cancer clinical trial enrollment.[21] In summary, the sociodemographic and healthcare-related characteristics of rural communities noted earlier, along with a general lack of awareness of clinical trials, place rural cancer patients at a distinct disadvantage in participating in cancer treatment trials.

One avenue for increasing awareness of clinical trials as a treatment option among rural cancer patients is the introduction and discussion of clinical trials through the NCI's Cancer Information Service (CIS). For over 30 years, the CIS has provided evidence-based cancer information, in both English and Spanish, to members of the general public, cancer patients and their families, and healthcare providers through a toll-free telephone service (1-800-4-CANCER), email, and an instant messaging online chat service (LiveHelp).[22] CIS Information Specialists (IS) are trained to provide individualized responses across the cancer continuum, including prevention, screening, treatment, survivorship, and end of life care.

Additionally, IS are trained and prepared to reactively and proactively discuss cancer clinical trials with callers, provide tailored clinical trials searches, send clinical trials educational materials, and assist with translating complex scientific information – all of which can be further shared and discussed with callers' healthcare providers. Due to the fact the CIS receives a large number of calls through its telephone service (N=283,094 from 2006–2008), this service has the potential to educate thousands of individuals, including rural residents, about cancer clinical trials. Previous research suggests over 80% of CIS callers who inquire about cancer treatment or clinical trials information indicated that the information they received made them more knowledgeable about their treatment options and almost 50% discussed the information with their physician.[23] This paper will focus on cancer treatment trials due to the large percentage of calls including a discussion of clinical trials that focus on treatment (96.1%) as compared to prevention/screening trials (3.8%).[24]

Therefore, the purpose of this research is to describe overall demographic differences between rural and urban callers to the CIS; compare characteristics of rural and urban callers who discuss cancer clinical trials; and explore the association of geographic location (i.e., rural versus urban) and discussion of cancer clinical trials. This study included an analysis of three years of CIS call data, 2006–2008, and received Institutional Review Board approval from the University of Miami.

2. Methods

As part of usual service, the CIS collects detailed, standardized information about client interactions via the CIS Electronic Contact Record Form (ECRF). This data includes information on type of caller (e.g., patient, friend/family member), type of cancer, stage in the cancer care continuum (e.g., in treatment, recurrence) and subject of interaction (e.g., clinical trials, referral to medical services). The CIS has approval from the Federal Office of Management and Budget (OMB) (Approval No. 0925-0208) to actively collect from every caller how they heard about the CIS, if they have contacted the CIS before and their home ZIP code. Rural-urban designation was determined using the ZIP code Rural-Urban Commuting Area Codes (RUCA) approximation files developed by the Washington, Wyoming, Alaska, Montana, and Idaho Rural Health Research Center. [25] After matching the available CIS caller ZIP codes to the 2004 ZIP codes and their respective RUCA codes (Version 2.0), we aggregated corresponding CIS caller ZIP codes into two categories, rural or urban (Categorization C).[26] For this study, ECRF records were used for all calls received through the CIS toll-free number from 2006–2008 (N=283,094). 55,515 records had missing or invalid ZIP codes, and thus could not be assigned a RUCA code. These records were removed from the dataset, leaving 227,579 total calls. Remaining call records were subsequently flagged as including a discussion of clinical trials if coded with the Subject of Interaction code: "Cancer Clinical Treatment Trials" or Response to Caller code: "Clinical Trials" in the ECRF.

The OMB approval also allows for the collection of demographic information on a random sample of up to 25% contacts (i.e., callers not in a crisis/emergency situation and who are cancer patients, family members/friends, and members of the general public) on all CIS access channels. During this study time, demographic information was collected for 24.1% of telephone contacts with a valid ZIP code.

2.1 Statistical Analysis

We first calculated descriptive statistics for caller characteristics (including caller identity, type of cancer, language of call, and all demographics), year of call, and if the caller was a repeat caller. We then calculated these descriptive statistics by rural versus urban status and conducted chi-square tests to assess differences between those callers classified as living in a

rural versus urban geographic location. *P*-values less than.05 were considered statistically significant.

Next, we calculated the percentage of all calls that included a discussion of cancer treatment trials. We calculated this separately first for all caller characteristics for all calls, and then for all characteristics separately for those callers living in rural locations and in urban locations.

Finally, we used multivariate logistic regression to explore the association of geographic location and discussion of cancer clinical trials for all callers and then specifically cancer patients alone. For these analyses, we first regressed geographic location only on whether or not the call included a discussion of clinical trials, and then we repeated the regression controlling for caller identity, treatment status (for the regressions with cancer patients only), cancer type, language of call, sex, ethnicity/race, age, education, repeat caller, and year. We did not control for income or presence of insurance because of the very high number of missing values for these variables.

3. Results

Between 2006–2008, the CIS received 283,094 total calls; 227,579 calls could be coded for geographic location. Of these geographically-coded calls, 54,842 (24.1%) were sampled for demographic data (Table 1). A little over a quarter (27.5%) of all CIS callers are cancer patients and approximately a third (34.2%) are family members or friends of a cancer patient. Almost 20% of all CIS callers have used the service previously. The top five cancer sites most commonly discussed include breast (28.1%), colorectal/other gastrointestinal (15.4%), prostate/other urological (12.9%), lung/other respiratory (9.4%), and gynecologic (8.9%), respectively. Most CIS calls are conducted in English as compared to Spanish and the majority of callers are female, non-Hispanic, and white. About 40% of the callers are under age 50; a third of the callers have a high school education or less; close to 50% have a \$40,000 or above annual household income; and 80% of CIS callers have some form of health insurance coverage. Overall, 10.3% of CIS calls discussed cancer treatment clinical trials. There were significant differences in all variables when comparing rural versus urban callers. Notably, rural individuals were more likely to be a family member or friend of a cancer patient, were less ethnically and racially diverse, have lower rates of college or post graduate education, and were less likely to discuss cancer clinical trials, compared to their urban counterparts.

For those calls that specifically discussed cancer clinical trials, family members and friends (15.9%) have a higher frequency of discussion compared to cancer patients (13.2%) (Table 2). Calls focused on melanoma (29.6%), colorectal/other gastrointestinal (16.8%), and lung/ other respiratory (16.6%) cancers discussed clinical trials more frequently than calls focused on other cancer sites. Calls conducted in English were more likely to include a discussion of clinical trials as were calls with non-Hispanics, whites, and males. Individuals with some college education or higher, those with annual household incomes higher than \$40,000, and any health insurance coverage were also more likely to discuss cancer clinical trials.

There were significant differences between rates of discussion of clinical trial between rural and urban callers both overall and when looking at each of the caller characteristics individually. With a few exceptions, discussions about clinical trials were more common for urban callers than for rural callers. However, rural callers ages 71–80, those with a high school education or less, those making \$20,000–\$29,000 annually and \$60,000–\$79,000 annually, and those who had no health insurance coverage were more likely to engage in a discussion related to cancer clinical trials compared to their urban counterparts.

As seen in Tables 1 and 2, the number of discussions of cancer clinical trials declined from 2006 to 2008, which mirrors the overall trend in CIS call volume. Total call volume declined from 83,821 contacts in 2006 to 69,304 in 2008. While call volume has been steadily decreasing, use of other CIS access points, specifically email and LiveHelp, the instant messaging online chat service, has increased by 44.2% from 2006 to 2008. However, the telephone service is still responsible for almost 80% of contacts to the CIS and clinical trials are discussed significantly more often on the phone (10.32%) compared to the two electronic CIS access points combined (6.29%) (P<0.001) (data not shown).

Table 3 presents the results from the logistic regression of all callers and cancer patients to determine the association of geographic location and discussion of cancer clinical trials. Without controlling for any variables, urban callers overall are 13% more likely to discuss cancer clinical trials compared to all rural callers; urban cancer patients are 26% more likely to discuss cancer trials compared to rural cancer patients. Controlling for all other variables strengthened these results, resulting in all urban callers and urban cancer patients being 26% and 33%, respectively, more likely to discuss cancer clinical trials than their rural counterparts. Family members and friends are six times more likely, and patients over five times more likely, to engage in a clinical trials conversation than other callers (e.g., general public, healthcare providers). Cancer patients facing a recurrence are nearly four times more likely to discuss clinical trials. Despite strong univariate results that Spanish language calls were less likely to include discussions of clinical trials, when controlling for other demographic characteristics, Spanish-speaking patients were no less likely to discuss clinical trials than English speaking patients.

4. Discussion and conclusion

4.1 Discussion

To our knowledge this is the first study to document (1) a comparison of rural versus urban callers to NCI's Cancer Information Service and (2) rural residents' discussion of cancer treatment trials using data from a national cancer information service. We found a larger percentage of rural callers are cancer patients or their family members/friends compared to urban callers. However, significantly fewer of these rural callers engage in a clinical trials conversation. In addition to caller identity, the trend of lower rates of clinical trials discussions holds true for rural callers across all cancer sites, language of call, sex, ethnicity and race, repeat callers, and year of call. Exceptions are noted in one older age category (71-80 years), two lower educational status groupings, one lower and one upper income categories, and those without any health insurance. These exceptions may relate to lower income, uninsured, and/or older callers grasping for a miracle cure or an alternative means to pay for expensive cancer treatments. Further analyses reveal that after controlling for all variables, geographic location is significantly associated with the likelihood of discussing cancer treatment clinical trials. In relation to discussions of cancer clinical trials, during calls to the CIS, urban callers are at a notable advantage compared to their rural counterparts. This finding is consistent with other national findings related to rural residents' limited awareness of and underrepresentation in cancer clinical trials. [2, 4, 5, 19, 20]

Promotion of and education about clinical trials among rural residents presents real challenges considering their limited access to providers and healthcare facilities which participate in cancer treatment trials. In response to this dilemma, increasing rural cancer patients' ability to participle in clinical trials is an NCI priority. To that end, CIS can share this data with program leaders involved in initiatives such as the NCI Community Clinical Oncology Program (CCOP) and Minority-Based CCOPs.[27] These programs help bring clinical trials to community physicians, including those practicing in rural locales, thereby increasing access to rural and minority cancer patients. Another noteworthy NCI program

aimed at increasing participation in clinical trials is the National Community Cancer Centers Program (NCCCP). Thirty community hospitals, many who serve rural residents, are charged with improving patient access to NCI-sponsored trials, maintaining a clinical trials screening accrual log for research analysis, and provision of healthcare professional education related to cancer clinical trials.[28] Interestingly, telemedicine is also being utilized to connect academic cancer centers to affiliated community hospitals giving patients access to the same cancer treatment, including clinical trials, regardless of their geographic location.[29] Additionally, along with Medicare, over 30 states – many with a substantial rural constituency – require health plans to cover routine patient care costs in clinical trials. [30] State comprehensive cancer control programs are also promoting increased participation in clinical trials as part of their state cancer control plans [31] and recently there has been a national call for more community-based participatory research focused on the design, implementation, and dissemination of cancer clinical trials.[32] The CIS data presented here could help to inform targeted outreach and educational activities aimed at reducing disparities in clinical trials awareness between rural and urban populations.

Considering the current focus on increasing access to and enrollment in community-based cancer treatment trials, the novel application of telemedicine to cancer treatment trials, and the existing availability of clinical trials in suburban and urban communities, it is of increasing importance to educate rural residents about clinical trials. Avenues for reaching rural residents with information about cancer clinical trials include primary care providers and family members/friends. Rural primary care providers have been previously identified as a trustworthy, influential source of information and support for patients considering a cancer clinical trial. [19–21] Relatedly, clinical trials education efforts should not dismiss the importance of engaging cancer patients' family members and friends in rural communities [17, 19], considering that 37% of rural CIS contacts were with family members and friends. Rural communities are often reliant on informal social networks and personal testimonies for cancer-related information; these networks and stories can be use to dispel myths and improve perceptions of cancer clinical trials.[19, 20] Lastly, promotion of national cancer information services such as the CIS may help address barriers related to the lack of local cancer information and support resources, the need for travel, financial constraints, patient confidentiality, the "digital divide", and the need for real-time treatment and/or clinical trials information for providers.[33, 34] Specifically, CIS Information Specialists can conduct clinical trial searches for rural callers within a specified number of miles of their ZIP code or family members' locales, share specific strategies and talking points for discussing cancer treatment trials with their local community physician(s), and provide NCI clinical trials education materials tailored to the needs of the caller.

4.2 Limitations

This study has several limitations, most notably, that the study population represents those individuals who proactively contacted NCI's Cancer Information Service by telephone. Many of these callers may be considered active cancer information seekers and reflect affluent, well-educated white females. Thus, the CIS caller population may not be representative of the general population of cancer patients and their family members. It is also noted that approximately 20% of the total telephone sample could not be included in the analysis due to missing ZIP code data. In many instances, callers either disconnect before IS can collect this information or decline to provide their home ZIP code when asked. This is particularly challenging in the LiveHelp and email access channels where, during the study time period, 93% of these contacts had missing or invalid geographic ZIP codes. Online CIS users typically disconnect immediately from their online session upon receiving a response to their inquiry and are no longer available for IS to collect demographic information. Furthermore, we aggregated CIS callers into two major categories – rural or urban. There

are gradations of rural and urban within each of these two primary categories which may have masked additional similarities or differences between rural and urban callers and deserves further analysis.

The data analyzed for this study was collected as part of routine CIS service rather than part of a specified research study. While IS are trained to complete the ECRF record immediately following the call, there may be coding errors and underreported variables. Furthermore, the CIS also does not code which trial phases (e.g., Phase 1, 2, 3, 4) were discussed with the caller. An exploration of trial phases in the discussion would be interesting to assess in light of our findings which suggest callers discussing melanoma, colorectal and lung cancers and those patients facing a recurrence are more likely to discuss clinical trials. Early phase trials are often conducted with patients who are facing advanced disease and/or when standard treatment is no longer effective.

Lastly, it should be recognized that a discussion of a cancer clinical trial does not necessarily lead to participation in a clinical trial and there are many barriers to trial participation other than lack of awareness. However, it is our belief that a discussion of clinical trials raises a caller's awareness of trials as an option for their cancer care, and may provide the impetus to engage in an informed discussion of clinical trials with their healthcare provider. Previous research suggests that as a result of contacting the CIS, callers are more informed about their treatment options, including cancer clinical trials, and more likely to discuss CIS-provided information with their providers.[23]

4.3 Conclusion and Practice implications

It is widely recognized that inclusion of individuals from all ethnic/racial groups, sexes, age groups, socioeconomic levels, and geographic locales is crucial for increasing the equity of trial participation and improving generalizability of trial results.[35] This point is particularly salient for the 20% of the US population who reside in rural communities.[19] While government cancer research agencies, cancer centers, government and private insurers, and physicians play an important role in expanding rural individuals' access to and ability to enroll in cancer clinical trials [36], it is also important to raise rural residents' knowledge and awareness of cancer clinical trials. Through its telephone and computer-based access points, access to NCI resources and clinical trials-focused outreach programs, and highly trained staff, the CIS can serve as an important source of clinical trials-related information for rural cancer patients and their family members as well as rural-based healthcare providers.

Acknowledgments

This work was supported by a National Cancer Institute award [N02C051107-12-0-0] and the Florida Bankhead Coley Research Program [07BP-01-12333].

References

- 1. Murthy VH, Krumholz HM, Gross CP. Participation in Cancer Clinical Trials: Race-, Sex-, and Age-Based Disparities. JAMA. 2004; 291:2720–6. [PubMed: 15187053]
- Sateren WB, Trimble EL, Abrams J, Brawley O, Breen N, Ford L, et al. How Sociodemographics, Presence of Oncology Specialists, and Hospital Cancer Programs Affect Accrual to Cancer Treatment Trials. J Clin Oncol. 2002; 20:2109–17. [PubMed: 11956272]
- 3. National Cancer Institute. [Accessed on: June 3, 2010] Building on 50 Years of Cooperative Research. Available at:

http://www.cancer.gov/ncicancerbulletin/NCI_Cancer_Bulletin_031808/page4

- 4. Baylor College of Medicine. [Accessed on: June 8, 2010] The EDICT Project: Policy Recommendations to Eliminate Disparities in Clinical Trials. Available at: http://www.bcm.edu/edict/PDF/EDICT_Project_Booklet.pdf
- 5. Ford, JG.; Howerton, MW.; Bolen, S.; Gary, TL.; Lai, GY.; Tilburt, J.; Gibbons, MC.; Baffi, C.; Wilson, RF.; Feuerstein, CJ.; Tanpitukpongse, P.; Powe, NR.; Bass, EB. Knowledge and Access to Information on Recruitment of Underrepresented Populations to Cancer Clinical Trials. Rockville, MD: Agency for Healthcare Research and Quality; 2005.
- Haynes, MA.; Smedley, BD. The Unequal Burden of Cancer An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved. Washington, D.C: National Academy Press, Institute of Medicine; 1999.
- Gosschalk, A.; Carozza, S. Rural Healthy People 2010: A companion document to Healthy People 2010. College Station: The Texas A&M University System Health Science Center, School of Rural Public Health, Southwest Rural Health Research Center; 2003. Cancer in Rural Areas: A Literature Review.
- Eberhardt MS, Pamuk ER. The Importance of Place of Residence: Examining Health in Rural and Nonrural Areas. Am J Public Health. 2004; 94:1682–6. [PubMed: 15451731]
- 9. Ricketts, TC, III. Rural Health in the United States. New York: Oxford Press; 1999.
- Probst JC, Moore CG, Glover SH, Samuels ME. Person and Place: The Compounding Effects of Race/Ethnicity and Rurality on Health. Am J Public Health. 2004; 94:1695–703. [PubMed: 15451735]
- Phillips CD, McLeroy KR. Health in Rural America: Remembering the Importance of Place. Am J Public Health. 2004; 94:1661–3. [PubMed: 15451725]
- Institute of Medicine. Quality Through Collaboration The Future of Rural Health. Washington, D.C: National Academies Press; 2005.
- The National Advisory Committee on Rural Health and Human Services. [Accessed on: June 8, 2010] The 2008 Report to the Secretary: Rural Health and Human Services. Available at: ftp://ftp.hrsa.gov/ruralhealth/committee/NACreport2008.pdf
- Baldwin L-M, Cai Y, Larson EH, Dobie SA, Wright GE, Goodman DC, et al. Access to Cancer Services for Rural Colorectal Cancer Patients. J Rural Health. 2008; 24:390–9. [PubMed: 19007394]
- 15. Comis, RL.; Aldigé, CR.; Stovall, EL.; Krebs, LU.; Risher, PJ.; Taylor, HJ. [Accessed on: June 8, 2010] A Quantitative Survey of Public Attitudes Towards Cancer Clinical Trials. Available at: Available at: http://www.cancertrialshelp.org/CTHpdf/308-9.pdf
- Ford JG, Howerton MW, Lai GY, Gary TL, Bolen S, Gibbons MC, et al. Barriers to recruiting underrepresented populations to cancer clinical trials: A systematic review. Cancer. 2007; 112:228–42. [PubMed: 18008363]
- Lara PN Jr, Paterniti DA, Chiechi C, Turrell C, Morain C, Horan N, et al. Evaluation of Factors Affecting Awareness of and Willingness to Participate in Cancer Clinical Trials. J Clin Oncol. 2005; 23:9282–9. [PubMed: 16361626]
- Advani AS, Atkeson B, Brown CL, Peterson BL, Fish L, Johnson JL, et al. Barriers to the participation of African-American patients with cancer in clinical trials. Cancer. 2003; 97:1499– 506. [PubMed: 12627515]
- Coyne CA, Demian-Popescu C, Brown P. Rural Cancer Patients' Perspectives on Clinical Trials: A Qualitative Study. J Cancer Ed. 2004; 19:165–9.
- Randall-David B, Stark N, Gierisch J, Torti F. 'What do they know about it?' How the North Carolina public views cancer clinical trials: implications for primary care doctors. N C Med J. 2001; 62:281–5. [PubMed: 11570327]
- 21. Paskett ED, Cooper MR, Stark N, Ricketts TC, Tropman S, Hatzell T, et al. Clinical trial enrollment of rural patients with cancer. Cancer Pract. 2002; 10:28–35. [PubMed: 11866706]
- 22. Bright M. The National Cancer Institute's Cancer Information Service: A premiere cancer information and education resource for the nation. J Cancer Ed. 2007; 22:S2–S7.
- 23. Davis SE, Fleisher L. Treatment and Clinical Trials Decisionmaking: The Impact of the Cancer Information Service. J Health Commun. 1998; 3:71. [PubMed: 10977271]

Vanderpool et al.

- 24. Byrne M, Kornfeld J, Vanderpool R, Belanger M. Discussions of Cancer Clinical Trials with NCI's Cancer Information Service. Journal of Health Communication. In Press.
- 25. WWAMI Rural Health Research Center. [Accessed on: June 8, 2010] ZIP Code RUCA Approximation. Available at: http://depts.washington.edu/uwruca/ruca-approx.php
- 26. WWAMI Rural Health Research Center. [Accessed on: June 8, 2010] Using RUCA Data. Available at: http://depts.washington.edu/uwruca/ruca-uses.php
- National Cancer Institute Division of Cancer Prevention. [Accessed on: June 8, 2010] Community Clinical Oncology Program (CCOP). Available at: http://prevention.cancer.gov/programs-resources/programs/ccop/about/history
- 28. National Cancer Institute Community Cancer Centers Program. [Accessed on: June 8, 2010] About NCCCP. Available at: http://ncccp.cancer.gov/about/index.htm
- 29. University of Maryland Greenebaum Cancer Center. [Accessed on: December 15, 2010] New Telemedicine Program Brings Top-Notch Cancer Care to More Marylanders. Available at: http://www.umgcc.org/news/telemed.htm
- 30. National Cancer Institute. [Accessed on: December 15, 2010] Clinical Trials and Insurance Coverage. Available at: http://www.cancer.gov/clinicaltrials/education/insurance-coverage/page1
- 31. Centers for Disease Control and Prevention. [Accessed on: December 15, 2010] National Comprehensive Cancer Control Program (NCCCP). Available at: http://www.cdc.gov/cancer/ncccp/
- Seifer SD, Michaels M, Collins S. Applying community-based participatory research principles and approaches in clinical trials: forging a new model for cancer clinical research. Prog Community Health Partnersh. 2010; 4:37–46. [PubMed: 20364077]
- Hawkins R, Curtiss C. Patient resources. Cancer resources for providers in the rural community. Cancer Pract. 1997; 5:383–6. [PubMed: 9397707]
- Engelman KK, Perpich DL, Peterson SL, Hall MA, Ellerbeck EF, Stanton AL. Cancer Information Needs in Rural Areas. J Health Commun. 2005; 10:199–208. [PubMed: 16036728]
- 35. Swanson GM, Bailar JC III. Selection and description of cancer clinical trials participants Science or happenstance? Cancer. 2002; 95:950–9. [PubMed: 12209677]
- 36. Institute of Medicine. A National Cancer Clinical Trials System for the 21st Century: Reinvigorating the NCI Cooperative Group Program. Washington, D.C: 2010.

Table 1

Demographics of callers to the National Cancer Institute's Cancer Information Service

	% All callers	% Urban	% Rural
<i>Identity of Caller (n=227,579)</i> ***			
Patient	27.48	26.89	30.4
Family member/friend	34.22	33.72	36.71
Other	38.3	39.39	32.89
Cancer Type (n=186,865)***			
Prostate, other urological	12.85	12.76	13.3
Breast	28.21	28.84	25.12
Colorectal, other gastrointestinal	15.37	15.4	15.25
Hematologic	7.24	7.22	7.32
Skin	3.79	3.78	3.83
Gynecologic	8.91	8.95	8.73
Lung, other respiratory	9.35	8.97	11.17
Head and Neck	3.72	3.65	4.09
Melanoma	2.57	2.5	2.92
Other	7.99	7.93	8.26
Language of Call (n=227,569)***	ĸ		
Spanish	5.64	6.38	1.94
English	94.36	93.62	98.06
Sex (n=52,724)***			
Female	75.98	75.64	77.55
Male	24.02	24.36	22.45
Race (n=47,004)***			
White	78.59	77	85.58
Black	14.62	16.1	8.11
Other	6.79	6.9	6.31
<i>Ethnicity (n=51,538)</i> ***			
Hispanic	12.65	14.12	5.77
Non-Hispanic	87.35	85.88	94.23
Age (n=52,126)***			
40 years and younger	21.96	22.47	19.54
41–50	21.82	21.87	21.58
51-60	23.25	22.88	25
61–70	18.51	18.07	20.54
71-80	11.08	11.18	10.56
81 and older	3.39	3.52	2.77
Education (51,657)***			
Less than high school	9.09	8.49	11.89
High school graduate	25.84	24.36	32.76

Vanderpool et al.

	0/ A.B. B.	0/ TT 1	0/ D 1		
	% All callers	% Urban	% Rural		
Some college	29.4	29.05	31.02		
College graduate	22.99	24.27	16.99		
Post graduate schooling	12.68	13.82	7.35		
Household Income (n=22,261)**	*				
< \$20,000	16.36	15.95	17.97		
\$20,000-\$29,000	20.34	19.79	22.49		
\$30,000-\$39,000	17.84	17.61	18.73		
\$40,000-\$59,000	14.45	14.47	14.36		
\$60,000-\$79,000	18.63	19.24	16.27		
\$80,000 and up	12.38	12.94	10.18		
Insurance (n=32,842)**					
No coverage	19.58	19.27	21		
Any coverage	80.42	80.73	79		
Repeat Caller (n=227,579)***					
Yes	18.49	18.81	16.9		
Year (n=227,579)*					
2006	36.83	36.86	36.7		
2007	32.72	32.81	32.26		
2008	30.45	30.33	31.04		
Discussion of Clinical Treatment Trials (n=227,569)***					
Yes	10.32	10.5	9.41		

Test for significant difference between rural and urban for each variable category, chi-square test

* P<.05

** P<.001

*** P<.001

Table 2

Percentages of calls that included a discussion of clinical treatment trials

	% All Calls	% Urban	% Rural
Identity of Caller***			
Patient	13 19	13.66	11 12
Family member/friend	15.19	16 34	14.18
Other	14.73	3.33	2.51
Cancer Type ***			
Prostate, other urological	12.34	12.61	11.07
Breast	5.41	5.56	4.56
Colorectal, other gastrointestinal	16.84	16.99	16.12
Hematologic	12.19	12.65	10
Skin	8.33	8.74	6.36
Gynecologic	10.88	11.26	8.96
Lung, other respiratory	16.56	17.05	14.67
Head and Neck	11.63	12.11	9.56
Melanoma	29.63	30.64	25.45
Other	19	19.53	16.54
Language of Call ^{***}			
English	10.77	11.02	9.56
Spanish	2.82	2.86	2.16
Sex ^{**}			
Female	9.83	15.07	11.71
Male	14.52	10.06	8.76
Race***			
White	12.44	13	10.21
Black	7.06	7.33	4.68
Other	10.37	10.64	9.11
Ethnicity ***			
Non-Hispanic	11.86	12.35	9.77
Hispanic	4.85	4.87	4.6
Age **			
40 years and younger	8.4	8.49	7.92
41–50	10.58	10.98	8.69
51-60	11.87	12.49	9.24
61–70	13.17	13.61	11.35
71–80	11.43	11.37	11.76
81 and older	9.63	10.58	3.94
Education ****			
Less than high school	4.39	4.35	4.53
High school graduate	7.86	7.68	8.48

Vanderpool et al.

	% All Calls	% Urban	% Rural
C	70 An Cans	70 OTDan	
Some college	10.19	10.49	8.86
College graduate	13.67	13.77	13.07
Post graduate	19.05	19.42	15.84
Household Income*			
< \$20,000	5.27	5.48	4.56
\$20,000-\$29,000	6.36	6.1	7.28
\$30,000-\$39,000	7.78	8	6.97
\$40,000-\$59,000	9.08	9.23	8.47
\$60,000-\$79,000	12.03	11.92	12.52
\$80,000 and up	14.56	14.73	13.7
Insurance*			
No coverage	4.63	4.6	4.8
Any coverage	11.44	11.75	10.01
Repeat Caller ***			
Yes	11.51	11.8	9.9
Year			
2006	11.57	11.77	10.59
2007	10.2	10.37	9.38
2008	8.92	9.09	8.05

Test for significant difference between rural and urban for each variable

* P<.05

** P<.01

*** P<.001

Table 3

Logistic regression results exploring the association of geographic location and discussion of a cancer clinical trials

	All Callers	Patients	All Callers	Patients
	n=227,569	n=62,540	n=40,216	n=13,892
Rural urban designation				
Rural	Ref	Ref	Ref	Ref
Urban	1.13 (1.09, 1.17)	1.26 (1.19, 1.35)	1.26 (1.16, 1.37)	1.33 (1.26, 1.65)
Identity of Caller				
Other			Ref	NA
Patient			5.58 (4.88, 6.39)	
Family member/friend			6.26 (5.48, 7.15)	
Treatment Status				
New patient			NA	Ref
In treatment currently				1.67 (1.47, 1.89)
Post-treatment				0.80 (0.67, 0.96)
Recurrence				3.85 (3.26, 4.55)
Cancer Type				
Prostate, other urogenital			Ref	Ref
Breast			0.65 (0.58, 0.74)	0.62 (0.51, 0.75)
Colorectal, other gastrointestinal			1.67 (1.50, 1.86)	1.52 (1.27, 1.82)
Hematologic			0.90 (0.78, 1.04)	0.79 (0.63, 0.99)
Skin			0.67 (0.55, 0.82)	0.56 (0.41, 0.77)
Gynecologic			1.26 (1.10, 1.45)	1.17 (0.93, 1.47)
Lung, other respiratory			1.42 (1.26, 1.61)	1.48 (1.21, 1.82)
Head and Neck			1.09 (0.91, 1.30)	1.11 (0.82, 1.50)
Melanoma			2.55 (2.17, 3.00)	1.54 (1.26, 1.91)
Other			1.68 (1.48, 1.90)	2.15 (1.66, 2.78)
Spanish Language Call				
No			Ref	Ref
Yes			0.55 (0.37, 0.82)	0.54 (0.24, 1.19)
Sex				
Male			Ref	Ref
Female			0.76 (0.71, 0.82)	0.77 (0.68, 0.87)
Race				
White			Ref	Ref
Black			0.60 (0.54, 0.67)	0.62 (0.52, 0.73)
Other			0.87 (0.76, 0.98)	0.84 (0.67, 1.05)
Ethnicity				
Non-Hispanic			Ref	Ref
Hispanic			0.69 (0.57, 0.84)	0.68 (0.49, 0.95)
Age				
40 years and younger			Ref	Ref

	All Callers	Patients	All Callers	Patients
	n=227,569	n=62,540	n=40,216	n=13,892
41–50			1.07 (0.97, 1.19)	1.31 (1.04, 1.87)
51-60			1.15 (1.04, 1.27)	1.40 (1.13, 1.74)
61–70			1.17 (1.06, 1.30)	1.40 (1.13, 1.74)
71-80			0.93 (0.83, 1.05)	1.02 (0.81, 1.29)
81 and older			0.84 (0.69, 1.02)	0.90 (0.67, 1.22)
Education				
Less than high school			Ref	Ref
High school graduate			1.53 (1.29, 1.80)	1.46 (1.14, 1.87)
Some college			1.96 (1.67, 2.31)	2.02 (1.59, 2.57)
College graduate			2.55 (2.17, 3.01)	2.53 (1.98, 3.22)
Post graduate schooling			3.46 (2.93, 4.09)	3.43 (2.68, 4.42)
Repeat Caller				
No			Ref	Ref
Yes			1.10 (1.01, 1.18)	1.01 (0.90, 1.15)
Year				
2006			Ref	Ref
2007			0.86 (0.80, 0.92)	0.79 (0.70, 0.88)
2008			0.69 (0.64, 0.74)	0.62 (0.55, 0.71)