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Rural and Community-Based Cancer Cluster Research

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ABSTRACT

Background: Researchers worked with a community to identify the key questions and methods, gather and analyze data, and disseminate findings regarding childhood and adolescent leukemia and osteosarcoma in the Fruithurst Elementary School. We explore the potential of community-based participatory research to inform a mixed-methods and interdisciplinary approach to rural community cancer cluster concerns.

Methods: Between 2017 and 2021, public meetings and outreach directed the research process. Structured interviews and archival research informed soil and water sampling in 2017. A school district-wide survey of 515 households gathered data on cancer types and exposures, and then informed 2018 and 2019 sampling. Samples at 26 sites were analyzed for heavy metals; semivolatile and volatile organic compounds; and/or radon.

Results: Archival research uncovered missing stormwater discharge reports for local industry and that the former town well system was shut down after failing to meet state water quality standards. Structured interviews with leukemia and lymphoma households identified well-water consumption and/or *in vitro* exposure and extended or immediate family occupational exposure to rubber. Some soil and water samples had elevated levels of contaminants, including carcinogenic bis(2-ethylhexyl) phthalate. Complete prevalence cancer rates in the survey were above the national rate for 16 cancers and indicated possible associations to well water and pesticide exposures.

Discussion: For communities to achieve action through cancer cluster research, our project suggests integrating collaboration with verification; emphasizing more interaction and less control; utilizing flexible boundaries rather than imposed census ones; and approaching experience as significant. Limitations include comparative data and accurate geocoding in rural locations.

Keywords: cancer clusters, Appalachia, community-based research, environmental exposure, well water, pesticides

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INTRODUCTION

Community driven cancer-cluster research has sometimes been a pariah among public health experts, called ''anecdotal'' and ''public clamor.''[1] State

[1]Brian W. Simpson, Patti Truant, and Beth A. Resnick. ''Stop and Listen to the People: An Enhanced Approach to Cancer Cluster Investigations.'' *American Journal of Public Health* 104 (2014): 1204–1208.

departments of public health determine the legitimacy of a community's cancer concern using incidence rates based on census and cancer registry data.[2,3] The infrequent investigations that move forward typically do so when elevated rates are identified. Then begins the search for a pointed cause, such as individual health behaviors, environmental exposure, and genetic predisposition.[4]

In other areas of public health, community identification and involvement in public health research is increasingly recognized by scholars and required by funders. Participants help identify the research questions, inform the methodology, analyze results, and then utilize findings as part of community-based research.[5,6] Community-based research is especially valuable for addressing children's environmental health exposures as well as underserved rural communities, where the need for connecting research to intervention is acute.[7,8,9] U.S. childhood cancer rates have risen for the last few decades and cancer is the second leading cause of death in children ages 1–14.[10] Compounding this, mortality rates for cancer are higher in rural areas than urban ones, especially in Appalachian Kentucky, West Virginia, and Alabama, where disparities in adjusted cancer mortality even exceed their rural, non-Appalachian counterparts.[11,12]

Some community-based participatory research (CBPR) has made its way into cancer research through tools like advisory boards and network programs,[13] but with less emphasis on active participation in each phase of the research.[14,15,16] Prevailing methods for studying cancer incidence and mortality rates make deep participation difficult, as computing rates often rely on preexisting data analyzed via preexisting boundaries.[17] Such an approach can preclude the subpopulation group studies necessary[18] to take on environmental injustices, which are particularly pronounced in rural spaces.[19]

The aim of this research was to contribute to the development of an action-oriented CBPR approach to rural cancer cluster research. We achieved this aim by developing a multimethodological and interdisciplinary process that was action-oriented and included participation in each research phase. We draw our findings from a project with the communities of Fruithurst and Muscadine, Alabama, in the Fruithurst Elementary School.

BACKGROUND

Our CBPR project took place between 2017 and 2021. The project received Institutional Review Board (IRB) for Research Involving Human Subjects from 2017 to 2020 (No. 17-228). In fall 2016, a former student in Ashwood's Community Organization course reached

[2]Michael Goodman, Judy S. LaKind, Jerald A. Fagliano, Timothy L. Lash, Joseph L. Wiemels, Deborah M. Winn, Chirag Patel, Juliet Van Eenwyk, Betsy A. Kohler, Enrique F. Schisterman, Paul Albert, and Donald R. Mattison. ''Cancer Cluster Investigations: Review of the Past and Proposals for the Future.'' *International Journal of Environmental Research and Public Health* 11 (2014): 1479–1499.

[3]Jessica A. Timms, Caroline L. Relton, Judith Rankin, Gordon Strathdee, and Jill A. McKay. ''DNA Methylation as a Potential Mediator of Environmental Risks in the Development of Childhood Acute Lymphoblastic Leukemia.'' *Epigenomics* 8 (2016): 519–536.

[4]Carol S. Rubin, Adrianne K. Holmes, Martin G. Belson, Robert L. Jones, W. Dana Flanders, Stephanie M. Kieszak, John Osterloh, George E. Luber, Benjamin C. Blount, Dana B. Barr, Karen K. Steinberg, Glen A. Satten, Michael A. McGeehin, and Randall L. Todd. ''Investigating Childhood Leukemia in Churchill County, Nevada.'' *Environmental Health Perspectives* 115 (2007): 151–157.

[5]Randy Stoecker. ''Are We Talking the Walk of Community-Based Research?'' *Action Research* 7 (2009): 385–404.

[6]Nicholas Freudenberg and Emma Tsui. ''Evidence, Power, and Policy Change in Community-Based Participatory Research.'' *American Journal of Public Health* 104 (2014): 11–14.

[7]Barbara A. Israel, Chris M. Coombe, Rebecca R. Cheezum, Amy J. Schulz, Robert J. McGranaghan, Richard Lichtenstein, Angela G. Reyes, Jaye Clement, and Akosua Burris. ''Community-Based Participatory Research: A Capacity-Building Approach for Policy Advocacy Aimed at Eliminating Health Disparities.'' *American Journal of Public Health* 100 (2010): 2094–2102.

[8]Jonathon Leider and Carrie Henning-Smith. ''Resourcing Public Health to Meet the Needs of Rural America.'' *American Journal of Public Health* 110 (2020): 1291–1292.

[9]Nicole L. Novak, Barbara Baquero, Natoshia M. Askelson, Lynelle Diers, Brian Dunn, Heidi Haines, Rima Afifi, and Edith A. Parker. ''Health Equity in Midsize Rural Communities: Challenges and Opportunities in a Changing Rural America.'' *American Journal of Public Health* 110 (2020): 1342.

[10]Pamela Hallquist Viale. ''The American Cancer Society's Facts & Figures: 2020 Edition.'' *Journal of the Advanced Practitioner in Oncology* 11 (2020): 135.

[11]CDC (Center for Disease Control). Preventing and Treating Cancer in Rural America, 2018. <https://www.cdc.gov/ruralhealth/cancer/policybrief.html>. (Last accessed on July 28, 2021).

[12]Nengliang Yao, Héctor E. Alcalá, Roger Anderson, and Rajesh Balkrishnan. ''Cancer Disparities in Rural Appalachia: Incidence, Early Detection, and Survivorship.'' *The Journal of Rural Health* 33 (2017): 375–381.

[13]Thomas W. Valente, Kayo Fujimoto, Paula Palmer, Sora Park Tanjasiri. ''A Network Assessment of Community-Based Participatory Research: Linking Communities and Universities to Reduce Cancer Disparities.'' *American Journal of Public Health* 100 (2010): 1319–1325.

[14]Leona F. Davis and Mónica D. Ramírez-Andreotta. ''Participatory Research for Environmental Justice: A Critical Interpretive Synthesis.'' *Environmental Health Perspectives* 129 (2021): 026001.

[15]Peggy M. Shepard. ''Advancing Environmental Justice Through Community-Based Participatory Research.'' *Environmental Health Perspectives* 110 (2002): 139–139.

[16]Alison Klebanoff Cohen, Andrea Lopez, Nile Malloy, and Rachel Morello-Frosch. ''Surveying for Environmental Health Justice: Community Organizing Applications of Community-Based Participatory Research.'' *Environmental Justice* 9 (2016): 129–136.

[17]ACS (American Cancer Society). Alabama: Cancer Facts & Figures 2018–2019. No. 041407 (2019).

[18]Shobha Srinivasan, Richard P. Moser, Gordon Willis, William Riley, Mark Alexander, David Berrigan, and Sarah Kobrin. ''Small Is Essential: Importance of Subpopulation Research in Cancer Control.'' *American Journal of Public Health* 105 (2015): S371–S373.

[19]David N. Pellow. ''Environmental Justice and Rural Studies: A Critical Conversation and Invitation to Collaboration.'' *Journal of Rural Studies* 47 (2016): 381–386.

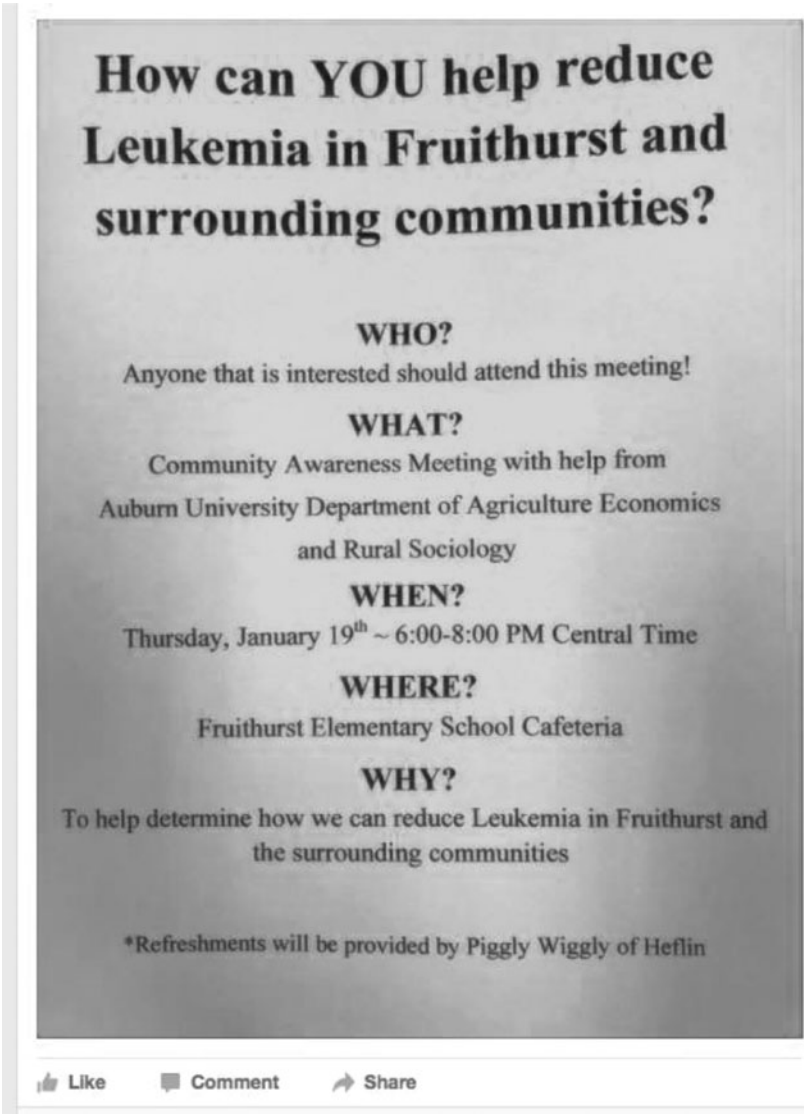

FIG. 1. Community-based participatory research flier distributed at and around Fruithurst Elementary School as well as on social media.

out for assistance investigating childhood cancer proximate to the student's home. The student connected Ashwood to Hiett, the Principal of Fruithurst Elementary School, who was leading local organizing efforts. Between 2014 and 2017, one child was diagnosed with osteosarcoma, one teenager with chronic myeloid leukemia, two children with acute lymphoblastic leukemia, and one infant with acute myeloid leukemia. Affected children lived within the Fruithurst Elementary School district area, which includes 792 households or ~2027 people. The area is part of Piedmont Upland and the Appalachian Regional Commission.[20] The Fruithurst County Subdivision, the closest census approximation to our study area, is 94% white. In that subdivision, 19.3% of the population lives in poverty,[21] and 10% have a bachelor's degree or higher, versus 31% nationally.[22]

Ashwood worked with Hiett, teachers at the school, and other interested community members to utilize the Green Action plan's CBPR research principles to identify a research question that incorporated an action, benefit, and

[20]D.N. Bearce. ''Geology of the Talladega Metamorphic Belt in Cleburne and Calhoun Counties, Alabama.'' *American Journal of Science* 273 (1973): 742–754.

[21]The U.S. Census thresholds for poverty include $13,011 for a single-person household; $16,520 for a two-person household; and $31,021 for a five-person household. When considering 149% of such poverty thresholds, 28.3% of the population lives in poverty.

For more details, see U.S. Census (United States Census Bureau). 2019. ACS 5-Year Estimates Subject Table ID S0601. Selected Characteristics of the Total and Native Populations in the United States. <https://data.census.gov/cedsci/table?q=Fruithurst,%20Alabama&tid=ACSST5Y2019.S0601>. (Last accessed on May 6, 2021).

[22]Ibid.

Table 1. Strategies Identified by the Community at the First Public Meeting

Strategy	*Content*
General testing	• Test what is coming out *at the end* of the water pipes and then work our way back to the problem. Potential problems: ○ Coating or grease within the water tanks ○ Look for chemicals used to install piping ○ Geiger counter for testing ○ Uranium: is it in the water/soil? ○ Arsenic in poultry litter ○ Families involved in testing • Air testing ○ Families test air from homes ○ Benzene • Soil ○ Testing around ProBlend Plant and other factories ○ Landfill ■ Old Fruithurst Landfill ■ Carroll County Landfill
Timber production	• What is being sprayed on the timber? • Aerial spraying ○ Where and when does it happen? ○ Monitor and compile information about when spraying happens as a community • Air, water, soil • Waste disposal • Question: Do you have the right to tell people not to spray over your property?
Get more information	• Compare the ratio of cancers here and Anniston/Calhoun County • Does Calhoun County have the most cancer cases in Alabama? • Cell Phone Towers/Radio Waves/Cancer Risk • Families—More information from or about families—occupations (what they bring home from work on their clothing) ■ Are families on well or county water? ○ Safety data sheets of waste products from mechanical shops and timber ■ Businesses • What type of tests are done at poultry facilities and why? • Where is poultry litter applied? What happens to poultry waste? • Illegal dump sites in Cleburne County—Along I-20 • What role does diet play in cancer? • How often is the public water tested? • End of pipe testing
Create more community awareness	• Inform garages about safe disposal of wastes • Examine safety data sheets for chemicals that contribute to leukemia/cancer • Give public notice not to burn hazardous materials • Do not allow people to dump illegally • Inform people about the benzene in cigarette smoke; no public smoking • Methamphetamine production and use need to stop
Explore radon contribution	• Soil types on the southside of the mountain range • Find out more about what happened to city wells • At home radon testing • Use of Geiger counter

general theme.[23] They together identified the community-based question: ''How can you help reduce leukemia in Fruithurst and surrounding communities?'' Outreach for the first public meeting in January 2017 included sending fliers home with children, posting fliers, and social media (Fig. 1). The meeting was hosted at the school's gymnasium. About 80 people, including children, attended the first meeting during a severe thunderstorm. Participants were divided into groups of five to eight to answer the organizing question on easel pads, before later coming back together to consolidate strategies as a larger group. Confidential voting resulted in five top strategies for the CBPR research (Table 1).

[23]Loka Ashwood, Noelle Harden, Michael M. Bell, and William B. Bland 2011. Real problems, real answers: The green action plan. University of Wisconsin-Madison and Illinois Institute for Rural Affairs. <www.value-added.org/wp-content/uploads/2014/04/Real_Problems_Real_Answers_The_Green_Action_Plan.pdf>. (Last accessed on April 5, 2022).

METHODS

These strategies informed the research design: (1) archival and historical research; (2) structured interviews with leukemia and lymphoma households in 2018[24]; (3) water and soil sampling design based on archival and interview findings; (4) a 2018 broader community survey; and (5) survey informed soil and water sampling in 2018 and 2019.

Archival research

Researchers worked with community members to acquire documents from the Alabama Department of Environmental Management (ADEM) to find water monitoring information for the local Problend rubber plant and the county landfill. Researchers uncovered Problend's stormwater discharge documents for the local chemical rubber plant—Problend's Preferred Compounding Corp Site—through ADEM's online portal. Community participants uncovered hard copies of documents pertaining to the county landfill and the former town well system stored locally by the City of Fruithurst.

Structured interviews

These archival findings as well as the request to include impacted families, researching the role of diet, and smoking, called for structured interviews specific to case families with a member diagnosed with leukemia or lymphoma. Five-page interview scripts designed separately for children and adults included background, diagnosis and patient medical history, occupational exposure, environmental and *in vitro* exposure, and other (Supplementary Data S1 and S2). Ashwood designed the interview questions first and they were later refined through meetings with the community. Ashwood then interviewed eight adults diagnosed with leukemia or lymphoma or mothers of children with leukemia proximate to the Fruithurst Elementary School. Participants were recruited from public meetings and identified by community members as impacted households. The interviews were recorded. Participants signed an informed consent form approved by the IRB. The interviews were transcribed and analyzed to create a timeline of exposures and diagnosis, differences, and commonalities.

Water and soil sampling

At Auburn University, Lee hosted a citizen-science training where community members learned how to gather water and soil samples. The interview and archival findings then informed the sampling strategy. Samples were collected by geoscientists, trained community members, and graduate students. The 2017 sampling design drew from interview findings and archival research that identified well-water consumption and extended or immediate family occupational exposure to rubber as commonalities. We used Environmental Protection Agency (EPA) Maximum Contaminant Level (MCL) standards for drinking water to help the community interpret the well-water results. Although private well water is unregulated by the EPA, these comparative standards helped rural people understand the potential health impacts of the contaminants found in their drinking water. Test America Laboratory provided analytical reports for semivolatile, volatile, and organic compounds for well-water and soil tests. Lee's lab at Auburn University lab provided some heavy metal analytics alongside Test America. Radon tests were completed by Dimova at University of Alabama lab or the R.A. Data lab, a free Alabama Department of Public Health service. Soil samples taken in 2017 were proximate to dumping sites, the Problend facility, a nearby railroad, and one leukemia patient's residence. The 2018 sampling remained proximate to leukemia and lymphoma patients, but those identified through survey research rather than initial interviews. The final 2019 water sampling was generally informed by cancer hot spots, regardless of type.

Cancer survey

Preliminary findings from 2017 interdisciplinary research were shared with the community at a meeting in 2018 attended by about 250 people. At this time, the community requested a broader cancer survey to expand the research from its leukemia and lymphoma focus. The community-directed survey (response rate of 65%, or 515/792 households) was designed by community members Dr. Allen Furr, and Ashwood based on preliminary findings and earlier public meetings. Questions in the survey included key environmental exposures of interest: well-water consumption (water source at most recent residence); occupational exposure to rubber (''Did you ever work at a rubber plant?''); and proximity to pesticide spray (''Have you ever lived on a property near aerial or boom spraying of pesticides?''). The survey also included questions about social and behavioral factors such as education level (''What is the highest level of school you have completed?''), smoking status (collapsed into those who have a history of smoking more than ''a handful of times'' vs. those who do not), and self-reported health status (''In general, compared to the other people your age, would you say your health is… Excellent/Very good/Good/Fair/Poor''). Survey respondents were asked to provide information on individual, household, and extended family cancer diagnoses.

Furr and Ashwood tested the survey with local teachers and then refined it before dissemination to ensure that the questions were culturally appropriate and applicable. The boundary for the research sample was the Fruithurst Elementary School district area, at the community's request. There was no census-based list of households specific to this geographical boundary available to

[24]M.S. Linet, L.M. Brown, S.M. Mbulaiteye, D. Check, E. Ostroumova, A. Landgren, and S.S. Devesa. ''International Long-Term Trends and Recent Patterns in the Incidence of Leukemias and Lymphomas Among Children and Adolescents Ages 0–19 Years.'' *International Journal of Cancer* 138 (2016): 1862–1874.

distribute the survey or determine the population count. Community members instead acquired an Emergency Management Services Excel file with residential addresses. Residences within the Fruithurst Elementary School district boundary were then geocoded. This initial list included a substantial number of P.O. Boxes, and to overcome this data limitation a postal worker and 20 community volunteers helped correct it. Volunteers were offered financial compensation for their time.

Initial dissemination of the survey began in 2018 with a community luncheon, where participants filled out the survey and had lunch. Surveys were returned through ballot box at the luncheon. Those who did not attend the luncheon were delivered door-to-door, geocoded surveys by volunteers that corresponded to the address on our master list. The surveys were then mailed back to the university. Return envelopes and postage were provided. For those who did not respond to the survey, we followed-up twice with reminder postcards encouraging them to fill it out. The survey was also promoted by volunteers on social media. We followed-up with direct letters requesting more information or door-to-door visits to verify missing information in returned surveys. Observations were coded as ''dead'' if we were able to confirm death through survey, door-to-door canvassing, or follow-up with neighbors. Respondents were coded as ''alive'' if we were able to confirm the person was still living through survey, door-to-door canvassing, or follow-up with

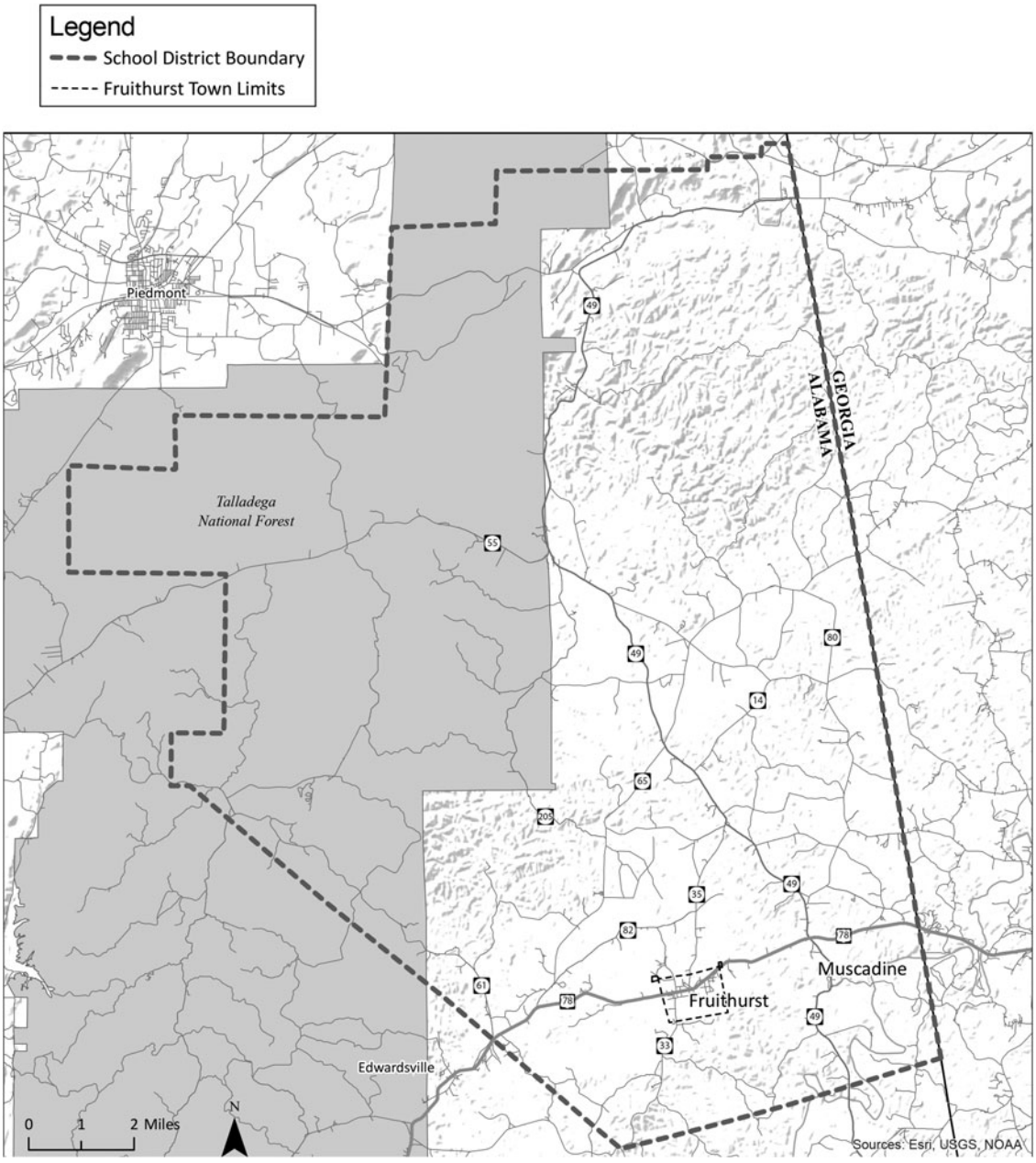

FIG. 2. Map of case study area, Fruithurst Elementary School district area.

neighbors, or, in the case of 30 observations, if we were unable to confirm that the person was alive or dead. We only included in our analysis people listed with a cancer, either the household respondent or in the family tree, that we could geocode. A total of 74 cases of cancer associated with extended family were reported in the survey, but we could not match them with an address that was geocoded. These cases are not included in our prevalence rates. (see Fig. 2 for the map of area).

Survey data were manually entered into Excel and then analyzed by Vick in Stata (Version 15.1). Observations include direct respondents to the survey (447) and family members identified by the direct respondent and confirmed through geocoding to live in the study area (86). Observations representing family members do not include responses for all variables. Respondents also had the option to skip questions.

We computed the Fruithurst Elementary School district complete prevalence rates by dividing the number of respondents or family members alive with specific cancer by the number of household respondents multiplied by the average household size. These rates were compared with the National Cancer Institute's 2017 Surveillance, Epidemiology, and End Results Program (SEER) registry data. National estimates were calculated by dividing the estimated number of U.S. residents living with cancer by the total 2017 U.S. population estimate. Vick performed logistical regression using Stata (Version 15.1) to determine associations between risk exposures of interest and cancer.

A master list of names and addresses was kept separate from the data and was encrypted. Participants received an IRB-approved cover letter explaining the survey, their rights, and the potential to receive a reverse osmosis system based upon analysis of their survey. The IRB protocol also included approval to recontact survey participants.

RESULTS

Archival research

Archival research uncovered that the town's chemical rubber mixing facility, Problend, did not submit half of its required Stormwater Runoff water reports. Of those 24 reports that were submitted since it opened in 1987 and closed in June 2015, the facility was outside the EPA benchmarks for acidity or alkalinity 12 times; total suspended solids 4 times; zinc 22 times; lead (Pb) 3 times; chromium 9 times; and oil and grease twice. Reports included a zinc release at 42,222 times the EPA benchmark and Pb 183 times higher. In 1992, radon in the Fruithurst town wells led the ADEM to warn that ''such levels may be causing a health threat to your customers.''[25] In 1994 and 1995, the Fruithurst Water System did not provide required reports for synthetic organic compounds and semivolatile organic compounds.[26,27] ADEM pressured the town to switch to county water, which it eventually did in the late 1990s.

Structured interviews

Our structured interview analysis in 2017 identified two common exposures for participants: individual, household, or extended family occupational exposure to rubber and well-water consumption. There were cases of pesticide exposure within the house and/or aerial pesticide exposure as well as smoking by mothers or individuals. However, these matters were not common across interviews.

Although the town wells were closed owing to insufficient monitoring and contamination, we learned through interviews that rural residents outside city limits remained largely on private well water. Our interviews found that each adult or child with leukemia or lymphoma either currently, prior, and/or *in vitro* consumed well water. For children, this included consumption of formula mixed with well water and their mothers drinking well water when pregnant or breastfeeding. In terms of the timeline of exposure to well water and disease contraction, the latency periods for lymphomas can range from 2 to 10 years and from 1.5 to 35 years for leukemias. For those <20 years of age, the minimum latency period is 0.4 years.[28] Interviews also uncovered occupational exposure to rubber production by the individual interviewed or in the immediate or extended family.

Water and soil sampling

Well-water and soil samples uncovered a series of contaminants (Table 2). Of the seven wells tested in 2017 for heavy metals, semivolatile organic compounds and volatile organic compounds, two were above the MCL for carcinogenic bis(2-ethylhexyl) phthalate (DEHP), an endocrine disrupter and plasticizer.[29] In one well, lead (Pb) was at the MCL. In addition, the pesticides

[25]Joe Alan Power. Chief Water Supply Branch. Alabama Department of Environmental Management. Personal Correspondence to Larry Attison re: Fruithurst Water System. (June 2, 1992).

[26]ADEM (Alabama Department of Environmental Management). Compliance Agreement: Fruithurst Water System. Cleburne County. (October 29, 1996).

[27]Thomas S. DeLoach. Personal Correspondence to Larry Attison, Mayor. (December 8, 1995).

[28]J. Howard. ''Minimum Latency & Types or Categories of Cancer.'' Center for Disease Control. World Trade Center Health Program, 2015. <https://www.cdc.gov/wtc/pdfs/policies/WTCHP-Minimum-Cancer-Latency-PP-01062015-508.pdf>. (Last accessed on October 26, 2021).

[29]Patricia A. Thompson, Mahin Khatami, Carolyn J. Baglole, Jun Sun, Shelley A. Harris, Eun-Yi Moon, Fahd Al-Mulla, Rabeah Al-Temaimi, Dustin G. Brown, Annamaria Colacci, Chiara Mondello, Jayadev Raju, Elizabeth P. Ryan, Jordan Woodrick, A. Ivana Scovassi, Neetu Singh, Monica Vaccari, Rabindra Roy, Stefano Forte, Lorenzo Memeo, Hosni K. Salem, Amedeo Amedei, Roslida A. Hamid, Leroy Lowe, Tiziana Guarnieri, and William H. Bisson. ''Environmental Immune Disruptors, Inflammation and Cancer Risk.'' *Carcinogenesis* 36 (2015): S232–S253.

Table 2. List of Selected Contaminants in Well Water and Detected Levels Detected Over a 3-Year Time at Targeted Households

	Data source for each distinct sampling site	*Testing lab*	*As (mg/L)*	*DEHP (mg/L)*	*Pb (mg/L)*	*^{222}Rn (pCi/L)*
2017 Leukemia/ lymphoma	Former Fruithurst Town Water Well	Test America and University Lab	<0.0013	<0.0025	<0.0013	**4077[b]**
	2017 Interview	Test America and University Lab	<0.0013	**0.024[a]**	0.00170	66
	2017 Interview	Test America and University Lab	<0.0013	<0.0025	<0.0013	368
	2017 Interview	Test America and University Lab	<0.0013	<0.0025	<0.0013	842
	2017 Interview	Test America and University Lab	<0.0013	**0.013[a]**	**0.015[a]**	1004
	2017 Interview	Test America and University Lab	**0.003[a]**	<0.0025	<0.0013	1449
	2017 Interview	Test America and RA Data Lab and University Lab	<0.0013	<0.0025	<0.0013	**5391[b] (July) 8449[b] (November)**
	2017 Interview	RA Data Lab (^{222}Rn only)	N/A	N/A	N/A	**6586[b]**
2018 Leukemia/ lymphoma	2018 Household Survey	Test America and University Lab	0.0000	**0.011[a]**	0.00050	2096
	2018 Household Survey	Test America and University Lab	**0.01336[a]**	<0.0025	0.00040	1455
	2018 Household Survey	Test America and University Lab	0.0001	**0.012[a]**	0.00210	658
	2018 Household Survey	Test America and University Lab	0.0004	<0.0025	0.00010	1332
	2018 Household Survey	Test America and University Lab	0.0001	<0.0025	0.00010	922
	2018 Household Survey	Test America and University Lab	0.0000	<0.0025	0.00130	1081
2019 General cancer hotspots	2018 Household Survey	Test America and University Lab	0.0001	<0.011	0.00030	886
	2018 Household Survey	Test America and University Lab	0.0009	<0.011	0.00036	2014
	2018 Household Survey	Test America and University Lab	0.0006	<0.011	0.00055	2942
	2018 Household Survey	Test America and University Lab	0.0004	<0.011	0.00004	2156
	2018 Household Survey	Test America and University Lab	0.0004	**0.022[a]**	0.00016	2433
	2018 Household Survey	Test America and University Lab	0.0013	<0.011	0.00001	2496

[a]Values in bold are at or above the EPA's MCL for drinking water systems; however, private wells used for drinking water are unregulated.

[b]Values in bold are above the EPA's recommended level.

As, arsenic; DEHP, bis(2-ethylhexyl) phthalate; EPA, Environmental Protection Agency; MCL, Maximum Contaminant Level; N/A, not available; Pb, lead; Rn, radon.

naphthalene and caprolactam were detected in one well. Other heavy metals were detected in wells, but not at levels above the MCL. Three wells had radon (^{222}Rn) levels above the EPA's recommended level of 4000 pCi/L, with concetration ranging from 66 to 8499 pCi/L. The five 2017 and early 2018 soil samples found elevated levels of zinc (2600–3000 mg/L). The elevated zinc level may be linked to the release of zinc by Problend Rubber or derived from natural sources of aquifer bedrocks. The semivolatile organic compound DEHP was found in soils near the Fruithurst Problend Rubber plant at levels above the EPA's recommended screening levels.

Our 2018 water sample analysis found DEHP in two of six tested wells (0.011–0.024 mg/L). One well had arsenic (As) at levels above the EPA's MCL of 0.01 mg/L. Of the six wells tested for radon in 2018, none had levels above the EPA's recommended level, with a broad range of 658 to 2096 pCi/L. The seven water samples in 2019 proximate to hotspots of cancer generally, but not specific to leukemia or lymphoma, identified one contaminant above the MCL in one well: DEHP. In effect, the most rapidly responsive sampling and testing proximate in 2017 found the highest levels of contaminants. DEHP, found in 5 of 20 wells tested for volatile and semivolatile organic compounds in our 3 years of sampling, was the most common contaminant found at a level above the MCL of 0.006 mg/L.

Cancer survey

Survey results showed that 218 of 533 observations reported at least one cancer diagnosis. We found that of 21 cancers comparable with estimates based on SEER data, 16 cancers had complete prevalence rates above the

Table 3. Local Versus National Complete Prevalence Based on 2017 Surveillance, Epidemiology, and End Results Program Estimates

Cancer type	*Local complete prevalence*	*National complete prevalence*
Bladder	0.0753	0.2188
Bone	0.0752	0.0173
Brain	0.3010	0.0517
Breast	1.3547	1.0982
Cervical	0.7526	0.0895
Colorectal	1.5804	0.4138
Esophageal	0.0752	0.0146
Gastric	0.0753	Not available
Head or neck	0.3763	Not available
Heart	0.000	0.0471
Leukemia	0.6020	0.1335
Liver and intrahepatic	0.2257	0.0276
Lung	1.5804	0.1713
Lymphoma	1.2041	0.2209
Melanoma or other skin	2.5588	0.3823
Oral and pharyngeal	0.3763	0.1177
Ovarian	0.3763	0.0716
Pancreatic	0.1505	0.0242
Prostate	0.9031	0.9733
Renal	0.3010	Not available
Stomach	0.4515	0.0357
Testicular	0.1505	0.0828
Thyroid	0.1505	0.2640
Other cancer	0.0753	Not available

national 2017 SEER estimate: bone, brain, breast, cervical, colorectal, esophageal, leukemia, liver and intrahepatic, lung, lymphoma, melanoma, oral or pharyngeal, ovarian, pancreatic, stomach, and testicular (Table 3; Fig. 3). These results were disseminated to the community by video through social media owing to the COVID-19 pandemic in January 2021 and shared by Hiett at a summer 2021 county commission meeting.

To understand the potential influence of social and behavioral confounders against environmental risk factors, three regression models were considered together (Table 4). Social and behavioral variables of interest include education level, having ever smoked, and self-reported health rating. In a logistical regression model containing only these social and behavioral risk factors, education level and smoking status were not statistically significant predictors of having a cancer diagnosis. Positive increases in self-reported health rating were correlated with a lower likelihood of reporting a cancer diagnosis, with lower odds of cancer for ''very good'' as compared with ''good,'' and still lower odds of cancer for ''excellent'' as compared with ''very good'' (Table 5).

Environmental variables of interest include well-water use at most recent residence, occupational exposure to rubber, and residential proximity to spray or boom pesticide application. In a logistical regression model containing only these environmental risk factors, well water use is a statistically significant predictor of having a cancer diagnosis ($p < 0.5$). Those reporting well-water use have 1.65 times higher odds of reporting cancer than

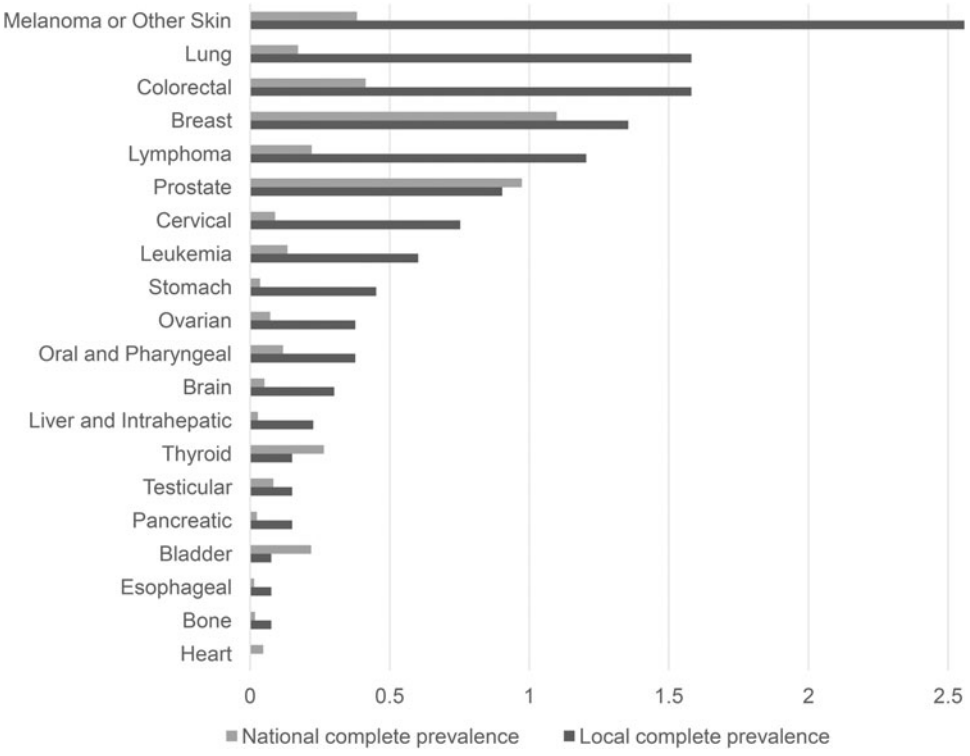

FIG. 3. Fruithurst area versus national complete prevalence rates.

TABLE 4. RESULTS FROM LOGISTICAL REGRESSIONS

	Type of exposure		
	Environmental	*Social/behavioral*	*Full*
Well water	*1.65 ± 0.414		1.51 ± 0.402
Rubber	0.71 ± 0.281		–0.82 ± 0.359
Spray pesticide	*1.91 ± 0.502		*1.77 ± 0.503
Education			
Some high school		–0.60 ± 0.212	*–0.4 ± 0.167
Some college		–0.87 ± 0.261	–0.72 ± 0.252
College graduate		–0.76 ± 0.243	–0.79 ± 0.283
Smoking		–0.96 ± 0.261	1.09 ± 0.343
Self-related health			
Poor		***13.33 ± 10.057	**14.25 ± 12.002
Fair		5.29 ± 3.186	**6.60 ± 4.633
Good		**4.52 ± 2.573	*4.1 ± 2.73
Very good		2.1 ± 1.222	2.33 ± 1.588
Constant	***–0.36 ± 0.075	**–0.19 ± 0.113	**–0.12 ± 0.088
Observations	294	351	287
Pseudo R^2	0.028	0.057	0.087

Constant, Observations, and Pseudo R^2 values are in bold.

Cancer diagnosis (any type) and environmental, social, and behavioral risk factors (p-values levels indicated as: *$p < 0.05$, **$p < 0.01$, ***$p < 0.001$).

those not on well water. Residential proximity to spray or boom pesticide application was also a statistically significant predictor of reporting a cancer diagnosis ($p < 0.05$), with pesticide exposure having 1.9 times higher odds of reporting cancer than those not reporting it. Occupational exposure to rubber was not statistically significant.

In a logistical regression model combining social and behavioral with environmental risk factors, exposure to pesticide spray remains a statistically significant predictor of higher cancer odds ($p < 0.05$), with 1.8 times higher odds of having a cancer diagnosis. Self-reported health rating remains statistically significant with higher self-reported health predicting lower odds of cancer. Smoking status and occupational rubber exposure remain statistically insignificant. Well water is not statistically significant in the full model. We tested for interactions between smoking and pesticide exposure, well-water use, and occupational exposure to rubber, and returned no statistically significant interaction effects.

Participatory action and change

Participants incorporated into the grassroots organization Cleburne Cancer Concerns in 2018, which is run by local residents, specifically Director Christy Hiett and board members Laura Cobb, Pamela Gann, Stephanie Perry, and Mark Truett. Cleburne Cancer Concerns and collaborators at Auburn University initially funded their work through a GoFundMe Campaign. Since then, an Alabama RC&D, a Center for Health and Environmental Justice, and an Auburn University Outreach Grant have funded organizing, surveys, and the purchase and installation of 70 reverse osmosis systems as well as the connection of 67 low-income households to municipal water.

A Congressman has called for benchmarking funds for broad access to municipal water in Fruithurst. Agencies that formerly were unresponsive began to respond, and a 2019 EPA site assessment unfolded as well as an investigation of Problend paired to the wells we tested in 2017. These later assessments found lower levels of contamination than our initial results and led to no formal remediation. Locally, the community cleaned up numerous dump sites. Commissioners were attempting to reopen the Cleburne County Landfill, which was closed in 1994. Chemicals detected in nearby monitoring wells as recent as 2020 include methylene chloride, tetrachloroethane, trichloroethene, and vinyl chloride.[30] All this action pertained to the earlier stages of the project, centered around interview and sampling findings.

Since their public dissemination in January 2021, the survey results have inspired efforts to end herbicide application on roadsides by the Cleburne County Commissioners and advocate for keeping the landfill closed. Despite the efforts of community members and County Commissioner for District 1, Laura Cobb, the majority of County Commissioners voted to continue spraying as of spring 2022—although they voted to end the herbicide spraying in August 2021. The Cleburne County Commission is currently contracting with Integrated Vegetation Management (IVM) Solutions to spray herbicides. IVM Solutions was fined $500 and placed on a 1-year probation for misusing the herbicides in 2021 after videos were taken locally of the company spraying

[30]Southeast Environmental Compliance. ''Corrective Action: Groundwater Monitoring Report September 30, 2020.'' Cleburne County Sanitary Landfill. Permit No. 15-01.'' (December 27, 2020).

TABLE 5. SURVEY DEMOGRAPHICS

	Frequency	*Percent*	*Cumulative Percent*
Observation type			
Respondent or family member			
Respondent	447	83.86	83.86
Family member	86	16.14	100.00
Life status at the time of the survey			
Confirmed or assumed alive	456	85.55	85.55
Confirmed dead	77	14.45	100.00
Cancer diagnosis			
Is a cancer diagnosis reported for this observation?			
Yes	218	40.90	40.90
No	315	59.10	100.00
Sex			
''Are you male or female?''			
Female	239	44.84	44.84
Male	155	29.08	73.92
Not provided	137	25.70	99.62
Other	2	0.38	100.00
Age, years			
''What is your age?'' Recoded into ranges			
10–19	2	0.38	0.38
20–29	33	6.19	6.57
30–39	67	12.57	19.14
40–49	64	12.01	31.14
50–59	63	11.82	42.96
60–69	87	16.32	59.29
70–79	47	8.82	68.11
80–89	26	4.88	72.98
90–99	1	0.19	73.17
Not provided	143	26.83	100.00
Smoking			
''Please mark the circle that best describes your current situation regarding cigarette smoking… I currently smoke (I've smoked for <1 year), I currently smoke (I've smoked for >1 year), I used to smoke (I quit <10 years ago), I used to smoke (I quit over 10 years ago), I have only smoked a handful of times, I have never smoked a single cigarette.'' Recoded to those having smoked ''more than a handful of times'' (yes) and those who have not (no)			
No	92	17.26	17.26
Yes	268	50.28	67.54
Not provided	173	32.46	100.00
Self-rated health			
''In general, compared to other people your age, would you say your health is…''			
Poor	17	3.19	3.19
Fair	63	11.82	15.01
Good	134	25.14	40.15
Very good	113	21.20	61.35
Excellent	30	5.63	66.98
Not provided	176	33.02	100.00
Education level			
''What is the highest level of school you have completed?''			
Some HS	66	12.38	12.38
HS completed	152	28.52	40.90
Some college	94	17.64	58.54
College graduate	83	15.57	74.11
Not provided	138	25.89	100.00

There were 533 total observations.

waterways and near people and personal property.[31] IVM Solutions is spraying monosodium acid methanearsonate (MSMA) Target 6 Plus, which contains arsenic. MSMA weed killers are known as Agent Blue, and are connected to skin and lung cancer risk in occupational and environmental settings.[32]

The complete prevalence rates that are the highest in our case study are melanoma or other skin cancer and lung cancer (Fig. 3). The local complete prevalence rate for melanoma or other skin cancer is 6.7 times the national average; and the local complete prevalence rate for lung cancer is 9.2 times the national average (Table 3).

DISCUSSION

An interdisciplinary and multimethodological approach provides a series of insights for CBPR rural cancer cluster research.

Less verification, more collaboration

In a verification frame, community-identified cancer issues have been accused of confirmation bias, where communities form a hypothesis and then search for subsequent facts without giving alternatives attention.[33] Others, in contrast, have expressed concern that communities have not had the space to bring forward their own evidence, as called for by popular cancer epidemiology.[34] CBPR enables professionals and academics to engage in co-learning and capacity building with communities, an approach distinct from verification.[35] Furthermore, the process of verification is typically slow, tied up in layers of bureaucracy. Slow responses are a barrier to collecting relevant sampling data, as our findings suggest.

Mounting evidence shows that collaboration through a combination of evidence, civic engagement and political participation produces notable changes in health outcomes.[36] Viewed in this light, public interest in cancer clusters becomes less perceived as public clamor,[37] but more a vital point of contact for public health intervention. The movement away from verification decenters evidence from the prevailing apparatus of power and gives space for hybrid knowledge, including politically relevant interventions in rural communities,[38] indigenous and grassroots theories, or community advocacy.[39]

Less imposed, more flexible boundaries

Critics have called community-identified boundaries of environmental exposure to be an ''arbitrary geographical border.''[40] However, borders have a long history of social construction and contestation.[41] The parameters for census data are important and useful, as are those provided by police precincts, city/state planning, and public health agencies. These boundaries, however, do not always correspond to pollution plumes or watersheds or other places where participants think the issues at hand are most pronounced. Communities

[31]See Chloe Vincente. ''Herbicide Spraying to Continue in Cleburne County Despite State Code Violation.'' February 22. <https://www.cbs42.com/your-voice-your-station/herbicide-spraying-to-continue-in-cleburne-county-despite-state-code-violation/?fr=operanews>. (Last accessed on April 5, 2022); Chlow Vincente. ''Dept of Agriculture Finds Violations in Cleburne County Herbicide Spraying Investigation.'' November 19, 2021. <https://www.cbs42.com/your-voice-your-station/dept-of-agriculture-finds-violations-in-cleburne-county-herbicide-spraying-investigation/https://www.cbs42.com/your-voice-your-station/herbicide-spraying-to-continue-in-cleburne-county-despite-state-code-violation/?fr=operanews>. (Last accessed on April 5, 2022); Bill Wilson. ''Cleburne County Commissioners Are Urged to Halt Herbicide Spraying.'' June 2, 2021. <https://www.annistonstar.com/news/cleburne/cleburne-county-commissioners-are-urged-to-halt-herbicide-spraying/article_e206394a-c36a-11eb-95e6-536c050d1244.html/https://www.cbs42.com/your-voice-your-station/herbicide-spraying-to-continue-in-cleburne-county-despite-state-code-violation/?fr=operanews>. (Last accessed April 5, 2022); Bill Wilson. ''Cleburne County Commission Ends Herbicide Contract.'' August 11, 2021. <https://www.cbs42.com/your-voice-your-station/herbicide-spraying-to-continue-in-cleburne-county-despite-state-code-violation/?fr=operanews>. (Last accessed on April 5, 2022); Bill Wilson. ''Cleburne County Commission Hears Arguments Against Herbicide Use.'' May 19, 2021. <https://www.annistonstar.com/news/cleburne/cleburne-county-commission-hears-arguments-against-herbicide-use/article_7fe2c210-b87f-11eb-be14-6327dee7fe1c.html/https://www.cbs42.com/your-voice-your-station/herbicide-spraying-to-continue-in-cleburne-county-despite-state-code-violation/?fr=operanews>. (Last accessed on April 5, 2022).

[32]Vladimir Bencko and Florence Yan Li Foong. ''The History of Organic Arsenical Pesticides and Health Risks Related to the Use of Agent Blue.'' In: L. Simeonov, F. Macaev, and B. Simeonova. (eds). *Environmental Security Assessment and Management of Obsolete Pesticides in Southeast Europe*. NATO Science for Peace and Security Series C: Environmental Security. (Springer, 2013).

[33]Andrea Gurmankin Levy, Neil Weinstein, Erin Kidney, Suzanne Scheld, and Peter Guarnaccia. ''Lay and Expert Interpretations of Cancer Cluster Evidence.'' *Risk Analysis: An International Journal* 28 (2008): 1531–1538.

[34]Craig W. Trumbo. ''Public Requests for Cancer Cluster Investigations: A Survey of State Health Departments.'' *American Journal of Public Health* 90 (2000): 1300.

[35]Barbara A. Israel, Edith A. Parker, Zachary Rowe, Alicia Salvatore, Meredith Minkler, Jesús López, Arlene Butz, Adrian Mosley, Lucretia Coates, George Lambert, Paul A Potito, Barbara Brenner, Maribel Rivera, Harry Romero, Beti Thompson, Gloria Coronado, and Sandy Halstead. ''Community-Based Participatory Research: Lessons Learned from the Centers for Children's Environmental Health and Disease Prevention Research.'' *Environmental Health Perspectives* 113 (2005): 1463–1471.

[36]Lisa Cacari-Stone, Nina Wallerstein, Analilia P. Garcia, and Meredith Minkler. ''The Promise of Community-Based Participatory Research for Health Equity: A Conceptual Model for Bridging Evidence with Policy.'' *American Journal of Public Health* 104 (2014): 1615–1623.

[37]Ibid. Trumbo (2000).

[38]Loka Ashwood. ''Rural Conservatism or Anarchism? The Pro-State, Stateless, and Anti-State Positions.'' *Rural Sociology* 83 (2018): 717–748.

[39]Nina Wallerstein and Bonnie Duran. ''Community-Based Participatory Research Contributions to Intervention Research: The Intersection of Science and Practice to Improve Health Equity.'' *American Journal of Public Health* 100 (2010): S40–S46.

[40]Ibid. Levy *et al.* (2008). 1536.

[41]Benedict Anderson. *Imagined Communities: Reflections on the Origin and Spread of Nationalism.* Revised Edition. (Verso, 1983).

recognize this, as they live within these social-ecological landscapes. Our utilization of a community-identified boundary to compute complete prevalence rates provides an alternative for thinking about how to work with communities to explore cancer clusters. Although the Alabama Department of Public Health found no reason for investigation based on incidence, our research found a complete prevalence of cancer for various cancers higher than national estimates. This suggests the relevancy of designing broader epidemiological studies in accordance with noncensus-based population estimates. It also suggests the importance of context-specific research with smaller populations. Simultaneously, it indicates that marginalized communities with concerns outside the prevailing data collection and analytical apparatus face time and resource-intensive work to gain recognition.

Less control, more interaction

Doing detailed, time-intensive work with communities to research cancer can potentially lead to a better understanding of cancer etiology through a focus on interaction.[42] The mix of occupation, radon, semivolatile, and heavy metal exposure provides a multivariable and interactive understanding of exposure alongside socioeconomic vulnerability. Although interviews with leukemia and lymphoma households found occupational exposure to rubber production and well-water exposure as crucial, survey research found pesticide exposure to be statistically significant across multiple models. These differing results are not a cause for alarm or contestation but rather evidence of potential interaction and the need for multiple methods for cluster-level research. Interaction allows for multiscalar analysis that facilitates community empowerment.[43] For communities, this kind of depth of study and diversity of results is replicable in the sense of process and action through their lived experiences. In the Fruithurst Elementary School district area, the identification of multiple routes of exposure facilitated multiple phases of social action, including cleaning up dump sites, installing reverse osmosis systems and municipal water connections, investigating a local chemical rubber mixing facility, advocating for the end of boom spraying of pesticides on roadways, and keeping the county landfill closed.

More experiential significance

Communities interested in tackling cancer are told not to because ''most reports do not require investigation because they can be explained through education, for example, by describing how common cancers are (people have ''a one in three-lifetime probability'' of receiving a cancer diagnosis)…''[44] Premising intervention and support for communities on prevailing forms of population estimates, which can be ill-suited to environmental exposures, can further disadvantage marginalized groups. Although important in an aggregate sense, these protocols can invalidate death and illness experiences locally and overlook more aggregate trends, for example, increased rates of childhood cancer at large.[45,46] CBPR brings research (interviews, sampling, and surveys) into dialogue with experiential and cumulative evidence through an interdisciplinary and multimethodological approach.

Limitations

Our process provides contextually rich, but time-intensive data collection through the local identification of boundaries. There was no up-to-date list of residents in our study area, which made geocoding time-consuming and we did not include in our prevalence rates those whom we could not geocode. We also do not have state-level comparative data; the Alabama Statewide Cancer Registry determines mortality information with data from the Alabama Department of Vital Statistics, but does not perform active surveillance like that provided by the SEER registries.

Our CBPR research lacked the ''large-scale, costly, and multiagency'' resources of cancer cluster studies that include toxicological work that can establish a causal relationship between contaminant, exposure, and disease outcome.[47] Our capacity to gather water and soil samples was limited owing to funding constraints and specific to a 3-year period. Like many underserved areas—particularly rural ones—there was no existing groundwater monitoring site in Cleburne County. Thus, we do not have a basis for comparing our water sampling findings with historical data. This calls for more sustained groundwater monitoring efforts in underserved and marginalized rural communities.

CONCLUSION

Our project suggests a pathway for cancer cluster research to bring collaboration into verification; interaction into control; flexible boundaries into imposed ones; and experience into significance. Our project did not uncover a single cause of cancer, which is sometimes mistaken to be the goal of communities who request help. Our approach works conjoinedly with local knowledge and experience through an interdisciplinary, quantitative, and qualitative methodology. The community implemented self-directed health interventions, like the cleanup of dump sites and the installation of water filters. In rural communities where interest in addressing cancer is high, we find the CBPR approach to cluster-level research promising.

CBPAR research that is multilogical through different methods and disciplines offers crucial insights for understanding cancer etiology. Interviews streamlined sampling targets for geoscientists that uncovered DEHP

[42]Ibid. Goodman *et al.* (2014).
[43]Ibid. Freudenberg and Tsui (2014).
[44]Ibid. Simpson *et al.* (2014). 1204.
[45]Ibid. Viale (2020).
[46]Ibid. Israel *et al.* (2005).
[47]Ibid. Rubin *et al.* (2007).

and radon in wells used by households with leukemia of lymphoma, among other contaminants. Survey research identified an overall association of all cancers analyzed with pesticide exposures and locally high complete prevalence rates for lung, melanoma, and other skin cancers at higher risk of contraction in line with Agent Blue exposure. Without these different methods and disciplines, these multiple routes for environmental exposure would likely not have been uncovered. Taken together, CBPAR that aims for better outcomes in communities can also make for better outcomes in science.

AUTHOR DISCLOSURE STATEMENT

No competing financial interests exist.

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SUPPLEMENTARY MATERIALS

Supplementary Data S1
Supplementary Data S2

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