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Challenges of using nationally representative, population-based surveys to assess rural cancer disparities

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Abstract

Population-based surveys provide important information about cancer-related health behaviors across the cancer care continuum, from prevention to survivorship, to inform cancer control efforts. These surveys can illuminate cancer disparities among specific populations, including rural communities. However, due to small rural sample sizes, varying sampling methods, and/or other study design or analytical concerns, there are challenges in using population-based surveys for rural cancer control research and practice. Our objective is three-fold. First, we examined the characterization of “rural” in four, population-based surveys commonly referenced in the literature: 1) Health Information National Trends Survey (HINTS); 2) National Health Interview Survey (NHIS); 3) Behavioral Risk Factor Surveillance System (BRFSS); and 4) Medical Expenditures Panel Survey (MEPS). Second, we identified and described the challenges of using these surveys in rural cancer studies. Third, we proposed solutions to address these challenges. We

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Appendix A. Supplementary data

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found that these surveys varied in use of rural-urban classifications, sampling methodology, and available cancer-related variables. Further, we found that accessibility of these data to non-federal researchers has changed over time. Survey data have become restricted based on small numbers (i.e., BRFSS) and have made rural-urban measures only available for analysis at Research Data Centers (i.e., NHIS and MEPS). Additionally, studies that used these surveys reported varying proportions of rural participants with noted limitations in sufficient representation of rural minorities and/or cancer survivors. In order to mitigate these challenges, we propose two solutions: 1) make rural-urban measures more accessible to non-federal researchers and 2) implement sampling approaches to oversample rural populations.

Keywords

Health care survey; Rural health; Cancer; Health status disparities

1. Introduction

Population-based surveys can provide important information about cancer-related health behaviors across the cancer care continuum, including preventive behaviors, screening utilization, treatment, and survivorship, to inform cancer prevention and control efforts in the United States (U.S.). Specifically, the National Health Interview Survey (NHIS) is used to help monitor progress toward the *Healthy People 2020 (HP2020)* cancer screening objectives (Office of Disease Prevention and Health Promotion, n.d.). The Centers for Disease Control and Prevention (CDC) recommends that Comprehensive Cancer Control Programs use Behavioral Risk Factor Surveillance System (BRFSS) data to develop benchmarks for monitoring cancer prevention and early detection activities (National Comprehensive Cancer Control Program, 2019). In keeping with its mission, the National Cancer Institute (NCI) uses data from the Medical Expenditures Panel Survey (MEPS) Experiences with Cancer Survivorship Supplement to examine the long-term physical, social, and economic effects of cancer diagnosis and treatment (NCI Healthcare Delivery Research Program, n.d.). Similarly, NCI's Health Information National Trends Survey (HINTS) data are used to monitor health communication behaviors and risk perception related to cancer and several HP2020 objectives (National Cancer Institute, n.d.).

Surveillance data have the potential to be valuable for illuminating cancer disparities among specific populations, including rural communities (Kennedy et al., 2018). Use of existing surveillance data has been recommended to examine rural-urban disparities (Kennedy et al., 2018; Srinivasan et al., 2015; Zahnd et al., 2019b). Rural populations are more likely to be engaged in negative health behaviors such as smoking that can increase cancer risk, often have lower cancer screening rates, have higher overall and late-stage incidence rates for many cancers, and have higher cancer mortality rates than their urban counterparts (Bennett et al., 2011; Doogan et al., 2017; Henley et al., 2017). These disparities are exacerbated by the fact that rural populations are often characterized by lower socioeconomic status, less likely to have health insurance, and have greater travel distances to health care services, including cancer care, compared to those in urban areas (Charlton et al., 2015; Foutz et al., 2017; United States Department of Agriculture (USDA), 2019a). However, there are several

challenges to using such data to examine cancer disparities among smaller populations such as those found in rural areas. For example, data sources such as NCI's Surveillance Epidemiology and End Results (SEER) Program database have been shown to underrepresent rural populations (Zahnd et al., 2018). Based upon 2009–2013 American Community Survey data and the USDA's Rural-Urban Continuum Codes (RUCC), only 10.6% of the geography covered in SEER is rural, while 14.8% of the U.S. population (more than 46 million people) are rural (Blake et al., 2017). Depending on the definition of "rural" used, the rural population can include as much as 19% of the population (59 million) (United States Census Bureau, 2018b; U. S. Census Bureau n.d.). Similarly, previous commentaries have warned about the hindrances of small sample sizes in rural cancer research (Srinivasan et al., 2015; Wheeler and Davis, 2017).

As part of the Cancer Prevention and Control Research Network's (CPCRN's) rural cancer work group, we have used qualitative and quantitative approaches to understand financial toxicity among rural cancer survivors in the most recent fiscal year's work. The CPCRN is a network of academic, public health, and community partners collaborating to reduce cancer burden particularly among underserved populations through implementation of evidence-based strategies and interventions (CPCRN, 2019). In addition to performing interviews with hospital staff serving rural cancer patients across seven states, the rural cancer workgroup has analyzed HINTS and MEPS data to help elucidate the burden of financial toxicity among rural cancer survivors at the national level (Odahowski et al., 2019a). These analyses have revealed analytic limitations due to the small sample of rural cancer survivors in these datasets. Therefore, we sought to comprehensively examine the challenges of using population-based surveys, including HINTS, MEPS, BRFSS, and NHIS in rural cancer research. Our objective was three-fold. First, we explored the characterization of "rural" in these population-based surveys. Second, we identified and described the challenges of using these surveys in rural cancer control studies. Third, we proposed solutions to address these identified problems.

2. Methods

2.1. Review of population-based survey methodology and studies

We reviewed methodology reports, codebooks, and other documentation files for each survey to extract information on available rural-urban measures, accessibility of rural data, years of data available, mechanisms for accessing data for analysis, survey modality, sampling method, and available cancer-related variables.

To examine the representation of "rural" in population-based surveys and to determine the challenges of using such data to study rural cancer disparities, our team performed a review of published articles that used these surveys as the key data source. We performed a search on February 27, 2019 for each survey in PubMed using the following search strategy: "non-metropolitan" OR "rural" OR "Appalachia" OR "Delta Region" OR "Deep South" AND [survey name] AND "cancer". We included "Appalachia", "Delta Region", and "Deep South" in our search because these are primarily rural regions of the country that experience notable cancer disparities (Zahnd et al., 2017; Blackley et al., 2012; Coughlin et al., 2002). This initial search yielded a total of 95 articles: 47 articles for BRFSS, 18 articles for MEPS,

17 articles for NHIS, and 13 articles for HINTS. We excluded articles that used questions from the respective surveys in primary data collection efforts but did not use the national survey itself. We also excluded articles for which “cancer” or “rural” was part of an author affiliation or were noted in the abstract but were not specifically examined in the study. In total, we examined 32 BRFSS, 9 MEPS, 15 NHIS, and 12 HINTS studies (68 articles total: See Appendix 1 for list of reviewed articles). From each article, we extracted information on the metric used to define “rural,” the way that metric was used to categorize “rural”, sample size, the percent of the sample that was “rural”, year(s) of data used, study outcome(s) of interest, whether the author affiliations were federal or non-federal (e.g., academic, non-profit), limitations noted by study authors, and additional limitations or relevant information identified by the investigative team.

3. Results

We report our findings for each survey separately: BRFSS, NHIS, MEPS, and HINTS. For each survey, we first summarize the methodology and both cancer-and rural-relevant content from our review of the survey documentation materials. Second, we present the study details from our review of peer-reviewed publications that examined rural populations and cancer-related outcomes using these surveys.

3.1. Behavioral Risk Factors Surveillance System

The BRFSS is a phone-based CDC survey that has been conducted annually since 1984, includes more than 400,000 participants each year, and is administered at the state level (Table 1) (Centers for Disease Control and Prevention, 2014). Although states are required to ask a core set of questions, there are optional modules on a variety of topics that states may include in their annual survey. Thus, nationwide BRFSS data are publicly available from the CDC, but may also be obtainable from each state’s public health department. The survey covers a range of health behaviors, chronic diseases, and utilization of preventive health services. Most relevant to the study of cancer, in even numbered years, the BRFSS currently includes questions on screening for colorectal, cervical, breast, and prostate cancer. These questions are also offered as an optional module in some odd numbered years. Optional modules offered in recent years include modules focused on cancer survivorship, human papillomavirus (HPV) vaccination, and lung cancer screening. CDC has provided access to geographically specific data through its Selected Metropolitan/Micropolitan Area Risk Trends since 2013 (Centers for Disease Control and Prevention, 2018b). However, these datasets only include areas with at least 500 survey participants, which would likely not include rural areas. In 2008, the BRFSS began piloting a cell phone survey, and beginning in 2011, both landline and cell phone participants were included in the publicly available dataset. Landlines are sampled using a disproportionate stratified sample and cell phones using a random sample. In 2011, the BRFSS began to employ a new raking weighting methodology that considers more than age, race/ethnicity, and gender in weighting, but also considers educational status, marital status, property ownership, and telephone ownership. This approach ensures that weights are appropriate for each state based upon key demographics; reducing biases, and improving representativeness (CDC, 2012). Metropolitan statistical area (MSA) status of a survey respondent is an available

geographic metric in publicly available BRFSS data. MSAs are urbanized areas with 50,000+ residents (United States Census Bureau, 2018b). However, in the most recently available 2017 BRFSS data, the codebook indicates that only those who participated by landline had a known MSA status. Data from BRFSS codebooks show that unknown MSA status (i.e., data were previously indicated as “Blank” in the codebook) in the publicly available data has consistently increased over time since the inclusion of cell phones; from 15.3% unknown in 2011 to 57.4% unknown in 2017 (BRFSS, 2013; CDC, 2018a, 2018b). In 2010, the year prior to the inclusion of cell phone participants in the publicly available BRFSS data, the proportion of survey participants unknown on MSA status was only 1.4% (BRFSS, 2011). Further, BRFSS questionnaires ask respondents to provide their ZIP code and county, but neither these data, ZIP code level nor county-level rural-urban measures, are publicly available (Centers for Disease Control and Prevention, 2019c).

Seventeen of the 32 BRFSS articles (Table 2 and Appendix 1) that we reviewed were nationally focused; seven articles were focused on a single state; and seven were regionally focused (e.g., Appalachia, Delta Region). One article used data from all states that included an optional module (i.e., HPV vaccination) (Monnat et al., 2016). USDA-based Rural-Urban Continuum Codes (RUCC), Urban Influence Codes (UIC), or Rural-Urban Commuting Area (RUCA) codes were the most commonly used metrics, but these studies were performed by federal researchers who may have had more access to county information to enable linkage or were performed on single state data that may be more readily accessible from the respective state (Table 3) (Berkowitz et al., 2019; Coughlin and Thompson, 2004; Henry et al., 2014). RUCCs and UICs are both county-based measures of rural-urban status developed by the USDA to categorize counties based on population size and adjacency to metropolitan areas (USDA, 2019b, 2019c). RUCA codes are USDA-developed codes that categorize census tracts based on population density, urbanization, and commuting patterns (USDA, 2019d). Most studies did not note the proportion of the study sample that lived in a rural area, but studies that did report the proportion indicated between 12.7% and 49.4% of the study sample lived in rural areas (Henry et al., 2014; Nuno et al., 2012). Overall sample sizes ranged from 1437 in a single state to 316,763 in a study that used national data (Moss et al., 2012; Bennett et al., 2012). Most studies used BRFSS data at the individual level, but a few state or regionally focused studies that employed an ecological design used county-level estimates of health risk factors or screening alongside rural-urban or regional designations (Christian et al., 2011; Sadowski et al., 2016). Studies primarily focused on breast, cervical, and colorectal screening while a few studies focused on cancer-relevant health behaviors and outcomes (e.g., smoking, alcohol use, obesity). Despite the considerable amount of missingness on MSA status, most studies did not note this as a limitation. One study by Bennett noted that, beginning in 2006, the BRFSS stopped publicly releasing data for counties under 10,000 residents, which led to an underrepresentation of rural respondents in BRFSS data, but this was only noted in three subsequent studies (Bennett et al., 2012; Bennett et al., 2011; Bennett, 2013). One study did note that no data from Alaska were released, a largely rural state (Doescher and Jackson, 2009).

3.2. National Health Interview Survey

NHIS is a CDC-sponsored nationally representative survey conducted since 1957 that covers a range of health topics (CDC, n.d.). Specific to cancer, NHIS includes questions on cancer screening, cancer-relevant health behaviors, genetic testing, family history, cancer risk, and cancer survivorship. This survey is administered in person through a computer-assisted personal interview approach (Table 1). More than 87,000 persons are sampled from 35,000 households using an area probability sampling approach that does not currently oversample racial/ethnic groups. Rural-urban variables are not available in the publicly accessible dataset but can be accessed through a research data center (RDC). RDCs are centers, such as the CDC's National Center for Health Statistics (NCHS), RDC located in Hyattsville, MD or 29 Federal Statistical RDCs across the country, that provide researchers with access to restricted-use data while protecting the confidentiality of survey participants (Centers for Disease Control and Prevention, 2019; US Census Bureau, 2019). These data are only accessible onsite at one of these RDCs. In order to use data from RDCs, researchers must submit a proposal to the respective agency or center and gain approval prior to using the data. The cost of data access is typically estimated at \$3000; this does not include any costs associated with travel or accommodations while performing analysis at an RDC (Centers for Disease Control and Prevention, 2019c).

Of the 15 studies we reviewed which used NHIS data (Tables 2–3 and Appendix 1), six used an MSA/non-MSA measure to assess rural-urban status (Calle et al., 1993; Duelberg, 1992; Fischer et al., 1998; James et al., 2006; Kleinman and Kopstein, 1981; Leach and Schoenberg, 2007; Makuc et al., 2007), four studies used RUCC (Palmer et al., 2013; Singh et al., 2017; Weaver et al., 2013a, 2013b), two used a census tract measure based on population size (Carlson et al., 2018; Whitfield et al., 2018), and the other studies did not report how rural-urban was categorized. Among the 10 studies that reported adequate details on the samples, sample populations in these studies ranged from 18.8% to 43.2% rural (Fischer et al., 1998; Whitfield et al., 2018), though one study that simultaneously explored rural-urban and racial disparities indicated the rural samples ranged from 5%–65% depending on the racial/ethnic group (Singh et al., 2017). The most commonly studied outcomes were cancer screening and cancer survivorship-related concerns.

3.3. Medical Expenditure Panel Survey

MEPS is a nationally representative survey conducted by the Agency of Health Research and Quality (AHRQ) since 1996. The “Experiences with Cancer” supplement was included in 2011 and 2016 (Table 1) (NCI Healthcare Delivery Research Program, n.d.). MEPS includes survey questions on cancer-related behaviors, screening, and cost of care. The “Experiences with Cancer” supplement is administered to individuals reporting a previous or current cancer diagnosis as an adult and includes questions on financial burden related to cancer, access to care, employment, and use of health care services and prescription drugs. The MEPS draws its sample from households that participated in the previous year's NHIS. As a panel survey, participants are interviewed five times over a two-and-a-half-year period. In the most recently available MEPS iteration (2016), more than 33,000 individuals were surveyed from among 13,587 families. MSA and non-MSA indicators were available publicly until 2013, but are currently only available at either AHRQ's RDC in Rockville,

MD or a federal statistical RDCs (Agency for Healthcare Research and Quality, 2019a; US Census Bureau, n.d.). Like the NHIS protocol, such analyses must be performed at an RDC for an associated cost. At RDCs, researchers can link MEPS data to state and county-level variables such as the Area Health Resource File (AHRQ, 2019a, 2019b, 2019c).

Six of the nine articles that we reviewed (Tables 2–3 and Appendix 1) used an MSA/non-MSA designation to define rural (Han et al., 2015; Horner-Johnson et al., 2014, 2015; Litzelman et al., 2017, 2018; Whitney et al., 2016). The remaining articles used a USDA definition (i.e., RUCC, UIC, RUCA) (Caldwell et al., 2016; Dobalian et al., 2003; Larson and Correa-de-Araujo, 2006). Rural populations ranged from 14.9% to 26% depending on the outcome of interest, although two studies did not provide information on the proportion of the population living in rural areas (Dobalian et al., 2003; Han et al., 2015). Studies utilizing MEPS primarily focused on financial or caregiver challenges surrounding a cancer diagnosis or cancer screening. Of these studies, only two of them used the Experiences with Cancer Supplement.

3.4. Health Information National Trends Survey

HINTS is another population-based survey that is administered by the NCI and focuses primarily on cancer communications, caregiving, screening, risk perception, and cancer-related health behaviors (Table 1) (National Cancer Institute, n.d). The publicly available data includes the RUCC for participants' county of residence. Five iterations of HINTS have been administered since 2003 with data from 2011 to 2018 (the most recent data available) collected in cycles over multiple years. In the early years of data collection, HINTS utilized both random digit dialing and/or an address sampling frame (i.e., mailed survey) but since 2011 have only used the mailed survey approach. As part of its sampling approach, HINTS has identified and created high- and low-minority strata (i.e., areas with high or low proportions of minority populations) and oversampled high-minority strata to facilitate better estimates for minority populations. RUCA codes are also available upon request from the NCI. Additional geographic coverage categorizations include Census Region and Division along with the recent inclusion of Appalachia-specific categories (NCI, 2018). State-level data may be available upon request, but sample sizes may be too small to present stable findings without sufficient aggregations across survey years (National Cancer Institute, n.d).

Nine of the twelve HINTS articles (Table 2 and Appendix 1) that we reviewed examined rural-urban differences at the national level (Befort et al., 2013; Goldner et al., 2013; Greenberg et al., 2018; Hong and Cho, 2017; Jiang et al., 2017; Mohammed et al., 2018; Robertson et al., 2018; Zahnd et al., 2010), while the remaining two examined Appalachian/non-Appalachian disparities and rural-urban disparities within Appalachia (Rice et al., 2018; Vanderpool et al., 2007; Vanderpool and Huang, 2010). Most of the nationally focused studies used a dichotomous rural-urban measure with the rural populations comprising 5.6% to 22.1% of the study population (Jiang et al., 2017; Zahnd et al., 2010). Overall sample sizes ranged from 542 (cancer survivors only from one year of data) to 33,749 (all survey participants across multiple years: 2003 to 2014). Study outcomes of interest included: behavioral determinants of obesity, physical activity level, HPV vaccination knowledge, use

of technology for cancer self-management, use of health information technology and other cancer information seeking behavior, fatalistic beliefs about cancer, and sunscreen use.

4. Discussion

4.1. Identified challenges

Our examination of survey documentation and review of articles that used BRFSS, NHIS, MEPS, and HINTS to examine rural cancer disparities identified three key problems: 1) limited accessibility of rural-urban variables; 2) variability in defining rural-urban across surveys; and 3) inadequate sample sizes of rural residents.

First, there are difficulties in accessing rural-relevant variables in BRFSS, NHIS, and MEPS. The BRFSS survey has become increasingly challenging to use for rural-urban analysis. BRFSS is phone-based, and the only publicly available variable that indicates any kind of geography other than state is MSA. Since 2011, when the BRFSS began to include both landlines and cell phones, such geographic indicators have become increasingly missing in the publicly available datasets, making rural-urban comparisons impossible to achieve without significantly biased results. For example, a recent BRFSS study that examined lung cancer screening uptake among eligible individuals identified the inability to examine rural-urban differences as a study limitation (Zahnd and Eberth, 2019). The lack of readily accessible rural-urban variables is particularly problematic for the examination of lung cancer screening. Rural populations are disproportionately burdened by lung cancer, and due to the relative recency of this screening recommendation, it is important to take advantage of population-based survey data to monitor its uptake, particularly among disparate rural populations (Odahowski et al., 2019b; Rai et al., 2019). ZIP code and county-level BRFSS data are collected from survey respondents and appear to be more readily available to federal researchers, as researchers employed by the CDC were able to use small area estimation approaches to generate county-level estimates of mammography utilization (Berkowitz et al., 2019; CDC, 2019c). For the most current NHIS or MEPS data, in order to perform rural-urban analyses, researchers must complete and submit a research proposal to CDC or AHRQ, respectively, pay data set-up fees, and subsequently travel to a RDC to complete the analyses. This required process may be cost and time prohibitive for many researchers, especially early stage investigators. HINTS, the final survey we examined, has at least one rural-urban metric (e.g., RUCC) in each year the survey was fielded allowing for rural-urban comparisons. Further, the RUCC variable includes all nine levels, allowing researchers to categorize rural in the most appropriate way for their research question and the data.

Second, limited availability of rural-relevant variables across the four survey types leads to inconsistency in defining rurality. The studies we examined used seven types of rural-urban and regional measures: Office of Management and Budget metrics (i.e., MSA/non-MSA), USDA metrics, Census metrics, NCHS metrics, % urban by state, presence/absence of health care services, and federally designated regional status. However, each survey varied in what variables or geographic identifiers were readily available. While the BRFSS and MEPS have historically included a binary MSA/non-MSA measure, such dichotomization leads to “underbounding” of rural where geographically large counties with rural areas are classified as “urban” (Hart et al., 2005). NHIS data can be available for analysis at the county level

from RDCs, which enables researchers to use county level rural-urban measures of their choosing. HINTS includes RUCC codes in their publicly available dataset. Each of these rural-urban metrics has its own set of strengths and weaknesses (Hart et al., 2005; Zahnd et al., 2019b). However, the lack of readily available geocoded data in which researchers can link these measures prevent them from examining those strengths and weaknesses in the context of research questions and the population distribution of their sample of interest. For example, studies examining access to cancer care relative to cancer screening may wish to use a metric like RUCAs that consider commuting patterns or RUCCs or UICs. Other studies may prefer a county-based measure that may provide a more intuitive context for policies or interventions (e.g., local health departments are often county based).

The third challenge of these datasets is inadequate sample sizes for rural research, particularly in the study of subpopulations (e.g., minorities or cancer survivors). Two studies that utilized the MEPS Experiences with Cancer Survivorship Supplement had very wide confidence intervals due in part to small rural sample sizes (Litzelman et al., 2017; Whitney et al., 2016). As another example, in order to examine cancer screening rates using BRFSS data, which had the largest annual sample size of the surveys that we examined, Cole and colleagues combined data from 1998 to 2005 to have sufficient sample size to examine colorectal cancer screening rates in rural minority populations (Cole et al., 2012). In turn, this aggregation of data makes findings difficult to interpret as rates change drastically over time among subpopulations. Additionally, a study using HINTS data noted that there were challenges in assessing rural-urban differences in skin cancer prevention behaviors among cancer survivors or those with a family history of skin cancer because of small sample sizes (Zahnd et al., 2010).

4.2. Potential solutions

In order to mitigate these methodological and analytic challenges, we propose two key solutions. First, we suggest that federal agencies make geocoded data more readily available to outside researchers either publicly through virtual mechanisms (e.g., remote portal) or through clear data request procedures. This will allow researchers to perform analyses at their home institutions with security precautions in place. Additionally, having geocoded data would encourage researchers to use the rural-urban metric most appropriate for their study and not the one prescribed by the dataset. HINTS is a good example of providing multiple rural-urban measures options (i.e., RUCCs and RUCAs as continuous). Cancer registry data (e.g., SEER) and some federal administrative datasets (e.g., datasets maintained by the Healthcare Cost and Utilization Project [HCUP]) both have accessible geocoded data (e.g., county or zip code level) (Agency for Healthcare Research and Quality, 2019b; National Cancer Institute, n.d). These data sources provide an established precedent and set of procedures to ensure that privacy and confidentiality of data are maintained, and that, when necessary, results are required to be suppressed or presented based upon the statistical stability of the estimates. In order to obtain and use SEER data – either through SEER*Stat software or through the receipt of data on hard media – researchers are required to sign a data use agreement (DUA) stating that they will not share data in such a way that individuals can be identified or that individual level data cannot be linked to other datasets (National Cancer Institute, n.d., 2019). Researchers who use HCUP datasets, such as the National

Inpatient Sample, are required to complete a tutorial as part of the DUA process that emphasizes data protection and ensures that researchers understand their responsibility to be good data stewards both in the analysis and presentation of data (Agency for Healthcare Research and Quality, 2019c). Such approaches could be leveraged and utilized by the federal health agencies that maintain these data to enhance the ability of researchers to explore rural cancer disparities.

Our second recommendation is for these surveys to alter their sampling approaches and subsequent weighting methodologies to oversample rural populations. For example, HINTS currently over-samples for racial and ethnic minorities and subsequently weights the data accordingly. HINTS also has obtained a specific sample of the 13state Appalachian population. This provides a precedent for future iterations of HINTS or other surveys meant to be representative of the nation. The BRFSS, although under the umbrella of the CDC, is conducted at the state level, which may preclude standardized approaches to sampling and survey dissemination. Most states disproportionately sample from strata within sub-state regions to help improve sample sizes in geographically defined regions, but this approach is not nationally standardized (CDC, 2017).

4.3. Limitations

Our review of population-based surveys was not without limitations. While we reviewed surveys that have been commonly used to examine rural cancer disparities, we did not examine all CDC, AHRQ, or NCI-sponsored surveys that may be used for disparities research. For example, although not population-based, NCI has linked several surveys to SEER data that may have been used to examine rural-urban cancer disparities such as the Medicare Consumer Assessment of Healthcare Providers and Systems patient surveys and SEER-Medicare Health Outcomes Survey (Mollica et al., 2018; National Cancer Institute, 2019a, 2019b). Additionally, although we performed a comprehensive review of articles using these surveys, we did not perform a systematic review. There may be articles that used these surveys that we did not identify during our search process. However, our review of articles using these surveys was complemented by an evaluation of survey codebooks, methods reports, and other documentation to assess the utility of these surveys for rural cancer disparities research and subsequently make recommendations to improve the accessibility of these surveys for researchers. Our objective was not to identify the universe of all published studies using these surveys, but to identify and define noted challenges.

5. Conclusions

Population-based surveys are helpful for informing cancer prevention and control planning, including the assessment of cancer disparities experienced by rural populations. However, our assessment of studies using these data and survey data documentation identified three issues: 1) rural-urban variables are not always readily accessible for non-federal researchers; 2) there is broad inconsistency in defining rural; 3) frequently, sample sizes are insufficient to examine rural-urban disparities. We propose two solutions to address these findings. First, federal agencies should make geocoded data more accessible to non-federal researchers. Second, surveys should be re-tooled to oversample rural populations in order to enable the

calculation of stable estimates in rural populations. Incorporating these recommendations into data access processes and general survey methodology will improve the study of rural cancer disparities and cancer prevention and control efforts more effectively by acknowledging and responding to the disparity rural Americans face.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Population-based surveys for rural cancer research.

Survey (acronym)	Available rural-urban measure(s)	Accessibility of rural data	Years of data availability	Most recent year data available for rural analysis	Geographic coverage	Survey mode	Sampling method	Available cancer-related variables
Behavioral Risk Factor Surveillance System (BRFSS)	MSA/non-MSA	NCHS urban rural-classification scheme for counties MSA/non-MSA	1984–2017	2017	National: Large counties and MSAs (no rural) State: Dependent on state	1984–2011: Telephone (landlines only) 2012–2017: Telephone (landlines and cell phones)	Disproportionate stratified sample (landlines) and random sample (cell phones)	Cancer-related health behaviors, cancer screening, optional cancer survivorship module
National Health Interview Survey-Cancer Control Supplement (NHIS)	Currently, any measure linked at the county level (e.g. Urban Influence Codes)	Research Data Center	1987, 1992, 2000, 2005, 2010, 2015	2015	National	In-person, computer-assisted survey	Area probability design sampling, does not currently oversample by race/ethnicity at the household level	Cancer screening, health behaviors, genetic testing, family history, cancer risk, cancer survivorship
Medical Expenditures Panel Survey (MEPS)	MSA/non-MSA until 2013	Research Data Center (data released after 2013) MSA/non-MSA (data released before 2013)	Household Component: 1996–2016 Cancer Survivorship Supplement: 2011 and 2016	2016	National	In-person paper survey	Nationally representative sample of households sampled in NHIS	Household Component: Cancer-related behaviors, screening, costs of care, Experiences with Cancer Survivorship Supplement: Cancer-related financial burden, access to care, employment, utilization of care, use of prescription drugs
Health Information National Trends Survey (HINTS)	Rural Urban Continuum Codes (RUCC), Rural Urban Commuting Area (RUCA)	Publicly available, free	2003, 2005, 2008, 2011–2015; 2017–2018	2018	National, Census region/division, Appalachian region, state level potential	2003 & 2005: Telephone survey and mailed 2008: Telephone survey 2011–2015, 2017–2018: Mailed survey	2003 and 2005-random digit dialing (RDD); 2007-RDD & address sampling frame with explicit strata with high and low concentrations of minority populations; 2011–2018: address sampling frame with explicit strata with high and low concentrations of minority populations	Cancer communication, caregiving, cancer screening, risk perception, cancer-related health behaviors

Table 2

Summary of reviewed studies by survey type.

Survey	Sample size ranges	% of sample categorized as rural	Sub-populations examined	Outcomes examined	Author affiliations	Rural-relevant data limitations
Behavioral Risk Factor Surveillance System (BRFSS; n = 32)	1437–316,763 in individual-level studies; 102–3142 counties in ecological/small-area estimation studies	5.4% in race-specific analysis-100% in rural specific analysis in individual level studies	<ul style="list-style-type: none"> Rural minorities Adolescent girls and their parents Cancer survivors 	<ul style="list-style-type: none"> Cancer screening Breast Cervical Colorectal Cancer-related lifestyle behaviors Smoking Physical activity Obesity 	<ul style="list-style-type: none"> Academic/non-profit (n = 24) Federal (n = 7) State and academic (n = 1) 	<ul style="list-style-type: none"> Exclusion of counties with fewer than 10,000 residents or fewer than 50 survey respondents Missing on metropolitan statistical area status Declining response rate over time
National Health Interview Survey-Cancer Control Supplement (NHIS; n = 15)	2223–300,910	5% in a racial/ethnic groups specific analysis to 43.2%	<ul style="list-style-type: none"> Racial/ethnic and nativity cohorts Cancer survivors 	<ul style="list-style-type: none"> Cancer screening Cancer-related lifestyle behaviors Response to cancer diagnosis and treatment 	<ul style="list-style-type: none"> Academic/non-profit (n = 9) Federal (n = 5) Federal and academic (n = 1) 	<ul style="list-style-type: none"> Dichotomous rural-urban metrics available
Medical Expenditure Panel Survey (MEPS; n = 9)	225–65,506	14.8%–26% (not reported in 3 studies)	<ul style="list-style-type: none"> Cancer survivors Those with disabilities Cancer caregivers Nursing home residents 	<ul style="list-style-type: none"> Depression in cancer caregivers Financial and work barriers in cancer survivors Cancer screening 	<ul style="list-style-type: none"> Academic/non profit (n = 6) Academic and federal (n = 2) Federal (n = 1) 	<ul style="list-style-type: none"> Inability to control by cancer stage Inability to account for other contextual factors (i.e. all rural is not the same)
Health Information National Trends Survey (HINTS; n = 12)	542–33,749	5.6%–23.8%	<ul style="list-style-type: none"> Cancer survivors 	<ul style="list-style-type: none"> Perceptions of behavioral determinants of cancer-related health behaviors (e.g. obesity) Cancer prevention knowledge Cancer-related information seeking, particularly online 	<ul style="list-style-type: none"> Academic (n = 9) Academic and federal (n = 3) 	<ul style="list-style-type: none"> Oversampling of central Appalachia The need to combine multiple iterations of data for sufficient sample size may mean anachronistic rural-urban metrics are used for consistency

Table 3

Rural-urban and regional measures used in studies analyzing nationally representative survey data.

Rural-urban or regional measure	Defining agency	Definition	Geographic scale	Surveys to which the measure was applied
Metropolitan Statistical Area (MSA)/non-MSA	Office of Management and Budget	An MSA contains an urban cluster of at least 50,000 inhabitants. Non-MSA includes all other areas, including micropolitan areas containing urban clusters between 10,000 and 50,000 residents.	Variable, may represent multiple counties or sub-county areas	BRFSS (n = 9 studies); NHIS (n = 6 studies); MEPS (n = 6 studies)
Rural-Urban Continuum Code (RUCC)	United States Department of Agriculture (USDA)	A nine-point scale distinguishing micropolitan counties (RUCCs 1–3) by population size and non-metropolitan counties (RUCC 4–9) by population size and adjacency to micropolitan counties. Codes are updated every 10 years based upon the U.S. Census population counts.	County	BRFSS (n = 6 studies); NHIS (n = 3 studies); MEPS (n = 1 study); HINTS (n = 9 studies)
Urban Influence Codes (UIC)	USDA	A ten-point scale distinguishing micropolitan counties (UIC = 1–2) by population size and non-metropolitan counties (UIC = 3–12) as micropolitan (UIC = 3,5,8) and non-core (UIC = 4,6,7,9–12) based upon proximity to a micropolitan area and inclusion of a town of 2500+ inhabitants. Codes are updated every 10 years based upon the U.S. Census population counts.	County	BRFSS (n = 6 studies); MEPS (n = 1 study)
Rural-Urban Commuting Area (RUCA)	USDA	Primary RUCA codes (1–10) define census tracts-based population density, urbanization, and commuting patterns and define micropolitan, micropolitan, small towns, and isolated rural areas. Secondary codes (30 total) area based upon secondary commuting patterns. RUCA codes are also approximated to the ZIP code tabulation area.	Census tract; approximated to ZIP code tabulation area	BRFSS (n = 2 studies); MEPS (n = 1 study)
Urban-rural classification for counties	National Center for Health Statistics (NCHS)	A six-point scheme based upon MSA status which categorizes micropolitan counties as large central, large fringe metro, medium metro, small metro, and non-metropolitan counties as micropolitan or non-core.	County	BRFSS (n = 1 study)
Urbanized areas, urban, clusters, rural areas	U.S. Census Bureau	Urbanized areas include 50,000 + people; urbanized clusters contain 2500 to 49,999 people. Rural areas contain all areas.	Variable, may represent multiple counties or sub-county areas	BRFSS (n = 1 study); NHIS (n = 2 studies)
Population density	N/A	Measure of population within a geographic unit relative to the land area.	Variable, county and state	BRFSS (n = 1 study)
Appalachian Regional Commission	N/A	A federal designation established in 1965 to designate impoverished counties in Appalachia for socioeconomic development purposes. Currently, this includes more than 25 million people across 420 counties, many of which are rural, in 13 states.	County	BRFSS (n = 5 studies); NHIS (n = 1 study); HINTS (n = 3 studies)
Delta Regional Authority	N/A	A federal designation established in 2000 to designate impoverished counties along the Mississippi River for socioeconomic development purposes. Currently, this includes more than 10 million people across 252 counties and parishes, many of which are rural, in 8 states.	County	BRFSS (n = 1 study)

Note: 3 studies used either an unstated rural definition or used presence of a mammography center as a “rural” designation. Some studies used multiple rural and regional measures. BRFSS = Behavioral Risk Factor Surveillance System; NHIS = National Health Interview Survey; MEPS = Medical Expenditure Panel Survey; HINTS = Health Information National Trends Survey.