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A National Survey of State Comprehensive Cancer Control Managers: Implications of Geographic Information Systems

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Abstract The growth of geographic information systems (GIS) for comprehensive cancer control (CCC) planning activities has been documented. We examined concerns about use and derived principles for practice. A national survey of US CCC program managers ($n=49$) was conducted. Results include statements and frequency of barriers to use GIS mapping for CCC. Uses of GIS for CCC activities have benefits, but must be considered within organizational frameworks designed to safeguard confidentiality of health information and community relationships. Education to guide understanding of and input into the decisions linked to GIS mapping can limit possible harms while advancing CCC aims.

Keywords GIS · Cancer · Mapping · Communication

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Introduction

Geographic information systems (GIS) are a computer-based technology tool with unique capacity to enrich understanding of disease models via representations in maps [1]. In comprehensive cancer control (CCC) planning activities from the Centers for Disease Control and Prevention (CDC), for example, data obtained from cancer registries may be coded into local, state, or zip code level [2]. When combined with information from mortality data, census data, and/or lifestyle data, maps can spatially and temporally depict multivariate relationships between cancer incidence and other variables. These include transportation routes to health-care sites, environmental exposures, and demographic information [2, 3]. As a result, the advantages associated with use of GIS technologies relate to visually communicating the meaning of data in ways that translate to identifying at-risk populations, service gaps, and access issues [4]. For some, this is more advantageous than using tables when communicating to various audiences (e.g., policy makers, reporters, community members).

While GIS maps may suggest novel directions for policy and research, they also convey more than just statistical relationships. These maps represent narratives about communities and those who live in them, including possible insights about environmental exposures or lifestyles. Thus, while CCC program managers in the USA may recognize the benefits of GIS mapping when managing large data sets in cancer control planning efforts [2], they may also have concerns about use as well. CCC program managers' experiences and perceived barriers may thus inform education efforts about the use of GIS technology in CCC activities.

The GIS Mapping Experience

GIS mapping across various industries has revealed a number of challenges that may lessen the perceived and actual value and validity of the tool for CCC activities. Perhaps foremost is the sense that maps imply surveillance. This is aptly illustrated by criticism surrounding Google's "Street View" maps, for example, and the ability to visually depict people and sites worldwide without individual awareness or consent [5]. Maps as surveillance tools may arouse concerns about loss of employment, insurance, school choice, or community standing via linking "place" to health harms or habits [6–8].

Beyond the broadest level of surveillance concerns linked to GIS mapping, studies of managers across marketing, banking, and even mental health industries reflect that individuals may be linked to information, thus threatening confidentiality [9–11]. GIS mapping has the potential to visually represent personally identifiable health information particularly in communities where cancer incidence is low, generating a "small numbers" problem which may lead to violations of confidentiality [12]. Further impacting privacy concerns are that data storage for GIS is contingent upon program needs and requirements to guide choices, as well as limited data and resources to interpret [13]. In efforts to address such small numbers barriers and limited data to mapping, data may be aggregated spatially to county or larger geographic units, and temporally across multiple years [14]. For example, CCC program managers in states with many rural areas may map at the county level rather than the zip code level. This limits the likelihood that any one person will be identifiable, but can also limit interpretability for researchers and policymakers by rendering a less valid picture of patterns [15]. For instance, depictions at the county level, not zip code level, could lead viewers to conclude that a cancer cluster exists when it does not, failing to provide meaningful insights or solutions for cancer control [15].

The promise associated with GIS mapping is the ability to reveal more complex models of disease. The reality, however, is that data is often not available, so mapping may reveal incomplete and possibly inaccurate insights about cancer. An important viewpoint regarding GIS use in cancer control resides with CCC program managers in the USA, who may convey similar but also unique perspectives related to this tool's utility in meeting programmatic needs. To assess this reality, we examined the following research question:

What concerns associated with GIS mapping use emerge in interviews from the managers of state CCC efforts in the USA?

Methods

A national survey of individual in-depth interviews with state CCC program managers was conducted to answer the

research question. The interview included questions to address perceptions about the potential barriers associated with GIS and CCC in their states, as part of a larger project assessing the adoption of GIS technology for CCC activities [16]. Each phone interview occurred at a mutually agreeable time between 14 July 2005 and 27 January 2006. All procedures were approved by the Institutional Review Board.

Recruitment and Interview Guide

Individuals from a spring 2005 state CCC director contact list were emailed to identify an appropriate contact to interview within each state CCC program about GIS mapping for cancer control efforts. Once interviews were scheduled, the interviewer informed participants that no personally identifiable information would be included in analyses, and interviews would be audio recorded. This report analyzes responses to the open-ended question, "Has the issue of privacy come up during presentations/discussions when using maps to show cancer incidence?" and the probe, "Does privacy present a barrier to the adoption of mapping or has it been addressed by suppressing, aggregating or regionalizing data?"

Coding

All interviews were transcribed verbatim and reviewed by the interviewee for accuracy, resulting in 217 single-spaced pages of data pages (mean=4.43, standard deviation=1.12). Codes used to analyze these data refer to experiences with surveillance, small numbers, limited resources, unavailable data, and aggregate data (see Table 1 for code definitions). Intercoder reliability was established using Cohen's kappa [17] among two pairs of coders. Initial reliability ranged from 0.65 to 0.89, with follow-up leading to refinement of definitions and improved reliability. Remaining differences were discussed to achieve consensus, leading to a single data set for analyses [16].

Data Analysis

Coders compiled responses about perceived barriers to using GIS mapping for CCC planning activities. The compilation of statements was read by two researchers. Illustrations of each code were marked and reread to capture CCC program managers' perceptions and experiences.

Results

Participants

A near census, 49 of 50 (98%), state CCC program managers in the USA were interviewed (Louisiana's

Table 1 Barriers to use of GIS mapping experienced by state CCC program managers in the USA ($n=49$)

Barrier yes, n (%)	Proportion (95% confidence interval)	Definition
Surveillance/privacy violations 25 (51)	0.51 (0.36, 0.66)	Statements about experience with surveillance and privacy issues related to GIS mapping
Small numbers 20 (41)	0.41 (0.27, 0.55)	Statements about experience with small numbers (e.g., small number of residents in the area) and confidentiality issues
Limited resources 12 (25)	0.24 (0.12, 0.39)	Statements about experience with a lack of resources (e.g., financial, time, expertise) to incorporate GIS mapping
Unavailable data 11 (22)	0.22 (0.12, 0.37)	Statements about experience with lacking data or information to use GIS mapping for CCC activities
Aggregate data 5 (10)	0.10 (0.03, 0.22)	Statements that indicate states have a problem with aggregating data to overcome privacy issues

director did not participate due to Hurricane Katrina). Interviews included 39 females and five males, plus five interviews in which two interviewees were on the phone. The majority of CCC program managers (48; 98%) had a college education or higher, with 12 (25%) of participants having a Master's of Public Health degree.

Surveillance Barrier

Twenty-five (51%) of the interviewees stated that they had direct experiences relating to using GIS maps that linked to broad concerns about surveillance and privacy issues. Comments included statements about negative outcomes for citizens. One manager noted that, “it could have other implications such as if they were selling their home if there is a cluster, they wouldn't be able to get money...” Others were often more general in their expressions of concern and experience, with such comments as, “Yes, privacy has come up. That's why we can't show distributions of cancer cases statewide.” A unique perspective revealed in the managers' experiences was their concern about negative outcomes for their organizations linked to use of GIS mapping. Six participants directly mentioned Health Insurance Portability and Accountability Act (HIPAA). One observed, “We would definitely have HIPAA issues if we got down to the county data.” Another concluded that, “For geocoding, I think you have to be extremely careful...some people understand HIPAA...other people have no clue when they breach confidentiality...There's going to have to be a great deal of upfront education on those issues...particularly if your organization is planning on breaking down some of the barriers in technology to put it out there for lots of people to have access to it.”

Small Numbers Barrier

Twenty (41%) of the interviewees expressed concerns about small numbers relating to cancer in their states. For

example, at the individual level, one manager noted that, “when you start to map, and you get down to the lowest common denominator, people will know *who* that person is...there goes privacy.” Another manager explicitly mentioned a concern about cancer being stigmatizing, stating that “The general population would not want to see identifiable information. There is still a stigma around having cancer.” Another said, “If you put maps out there that identify race, sex, age and cancer type in a town, you're not protecting confidentiality.”

Four participants emphasized that community relations could be tarnished if identifiable data were disclosed. One noted, “...it takes us a long time to build trust in those communities and part of doing that is a reassurance that their data will not be shared.” Another said, “People from the community may ask to see maps of their community, but if it is too small, we cannot provide them with maps.”

Limited Resources Barrier

Twelve (25%) interviewees expressed concerns about resources as a multifaceted barrier linked to time, money, training, and policies about using GIS in their states. Such concerns are captured by the participant who stated, “If our staff person that *does* know how to use the mapping tool had more time and if we all had more guidance to give her as to what we would like to have mapped, we would have more maps produced.” One interviewee expressed concern over the expertise of those dealing with mapping, “depending on the level of experience/education/skill of your cancer program director, you can very easily breach confidentiality.” Four respondents expressed concern over enforcement to comply with guidelines when geocoding data for mapping. Statements disclosed concern over the completeness of existing guidelines that ensure confidentiality is protected both at the technology and organizational level. One manager noted, “One of the biggest problems we have here is providing basic sharing files.” Another stated, “I'm not sure

what controls were in place to make sure that data was protected.” And yet another commented, “the bigger question for me is *who* gets the data.”

Unavailable Data Barrier

Eleven (22%) interviewees mentioned that their states had limited or no data available to use for GIS. As one noted, “Some of the things we would like to have mapped, we don’t have sufficient data to map.” One participant revealed how concerns about surveillance sometimes contribute to a lack of data. She stated that, “People don’t want ‘Big Brother’ into their business and government having information about them.”

Aggregate Data Barrier

Five participants (10%) made references to difficulties with using aggregated data to inform policy and practice. One manager observed, “Suppression of data issues may not get a totally accurate portrayal of data. That’s an issue that will have to be addressed.” Another said, “At least in our state, regionalized does *not* provide the information that people want at a local level.” Another conveyed one of the biggest challenges with aggregating data they experienced in her state, “people out in [sic], they thought there was a cancer cluster.”

Discussion

This study highlights potential barriers associated with GIS mapping as a tool to enable CCC activities. The experiences of US CCC program managers suggest possible directions for education and recommendations relating to practices associated with GIS mapping use for CCC activities. Since results are from a national survey of state CCC program managers who are leaders of state cancer programs, they provide valid estimates of concerns among a national representation of individuals leading cancer control activities. Privacy is a key point when using GIS mapping as a tool for CCC activities. Its nuances are tailored by obligations to communities with whom long-term relationships have been built and to policies that govern performance of state organizations committed to cancer control activities. Several recommendations emerge from the managers’ experiences and perceptions.

Recommendations

Concerns related to GIS mapping activities expressed by CCC program managers in the USA revealed the consid-

erations of policy, organizational, and community environments. In considering education designed to enhance the utility of GIS mapping as a tool to facilitate CCC activities, the various audiences and outcomes should be included. This leads to several recommendations for integrating educational efforts into already existing activities.

1. Build collaborations between CCC programs and GIS mapping programmers and designers.

GIS mapping activities at the design and programming level appeared often to be decisions that lacked CCC program managers’ input. This posed limitations on their understanding about how decisions relating to data use had been made. This contributes to a lack of confidence that precautions have been taken to comply with HIPAA, and organizational concern and community concern. To guide these discussions, CCC program representatives should guide a response that moves from a focus on “Can it be done?” to “Should it be done?” GIS mapping designers and programmers may be a unit that serves a state’s overall public health system. The broader the group’s functions, the more likely that many types of data for mapping exist. Thus, the ability to overlay many variables in a map may relate to the scope of GIS services in a state but has to be tempered by the goals of a given program. This includes CCC program managers being involved in the data storing process, as data contingencies are influenced by program needs to guide requirements. Furthermore, CCC programs, as emphasized through these interviews with program managers, depend upon building and sustaining trust with communities. One “wrong” image displaying individually identifiable information in a map can destroy what has taken years to build. It appears critical, therefore, that the professionals and practitioners who want to be able to use maps collaborate with designers and programmers. Together, they can reach agreement about how information about data quality and sources will be portrayed, who will have access to what data, and when different audiences can manipulate or publish the images for their own aims.

2. Add GIS mapping to the agenda for media relations activities of CCC programs.

Public health and media have formal relations linked to safeguarding the public’s health. To address many expressed concerns about confidentiality and the translation of a map’s meaning into a public health message, CCC programs should add a request to preview any map portraying a cancer statistic as part of the news story and to provide a public health interpretation. One goal in these messages is to convey how confidentiality is protected. If the public feels that their personal information may be accessed by other members of the public or used by the

media, citizens may impede support for GIS mapping. This may happen by refusal to participate in surveys linking health habits to health status that might then be used to produce multivariate maps. Or, there may be reticence to seek screenings or treatment if individuals feel that their behaviors will be tracked in public maps. Citizens, in general, need explicit messages about what and how personal health information will be used [4]. Importantly, for cancer patients and survivors, these efforts to communicate must also say “why.” Clearly state what is the direct benefit for those whose information is being used and what are the indirect benefits for others.

3. Include workshops about HIPAA and GIS mapping for CCC activities at conferences for developers and users, and about GIS mapping's scope as a tool at conferences for CCC professionals and practitioners.

GIS mapping software developers and programmers have periodic opportunities related to continuing education and conferences, as do most professionals and practitioners working in cancer control. These disciplines might use these opportunities to convey to their own and each other's members' perspectives and experiences. These settings provide ideal outlets for CCC managers, for example, to convey the CCC experience in ways intended to guide the questions. Developers and programmers might ask when collaborating with CCC professionals and practitioners on the design of maps to communicate about cancer to various audiences. Similarly, GIS developers and programmers might offer insights about best practices for maps to communicate where data has come from, sample sizes, or other criteria to use in judging its quality and meaning. Via introductions through continuing education and conference settings, mutual understanding may lead to more efficacious translations. Both informal guidelines and standard rules guide decisions about the ethical use of GIS mapping to limit perceived and actual harms [18]. These workshops provide a setting in which to convey these realities.

4. Add GIS mapping to the agenda of CCC representative meetings with advocacy groups.

At the broadest level, surveillance of cancer trends guides decisions about allocating resources to cancer prevention and treatment. For CCC program managers, awareness that citizens fear possible abuses of the technology linked to GIS mapping should guide meetings with advocacy organizations to seek their insights about concerns and to educate them about the advantages of using these maps. CCC program managers should make an effort to know the privacy concerns of their community. More resources may become available as advocacy groups promote efforts to understand environmental exposures' role in cancer causation, especially

if multivariate maps make a credible case for such a role. More resources also may be allocated to increase access to cancer care if maps portray underserved areas and a link to higher morbidity and mortality. Such efforts can only benefit the mutual goal of both organizations toward improving cancer care to individuals and communities.

5. CCC programs should participate in the translation of GIS maps to data for different audiences.

Small numbers have been recognized as a limitation to the validity and value of using GIS mapping since its inception. Users should explain the safeguards that have been put in place within the organization to protect patients' confidentiality when information is computerized. For instance, to protect data confidentiality, some systems differentiate between general public users and registered internal users. Public sites might make only aggregated data available and restrict access to more specific information, which is something CCC program managers acknowledge as a potential problem. Aggregating data spatially and temporally is a practice that has been adopted as an informal and sometimes formal guideline to protect privacy [13]. This may not remain the trend as states broaden their use of GIS as a tool for CCC and their desire for more accurate representations of community health data increases. Statistical medical studies have shown inaccuracies reflected in data and decisions based on the aggregating method [13, 19], suggesting that for audiences making decisions linked to resource allocation and the displays of data, aggregating data may be inappropriate.

Limitations and Future Directions

Interviews reflect perceptions of GIS use and potential barriers among 49 of the 50 state CCC program directors for cancer control. Future research should incorporate other stakeholders such as cancer registry informants in order to provide a more comprehensive view of concerns with GIS use and cancer control.

Conclusion

The goal of this article was to understand perceived concerns among CCC program managers in their use of GIS mapping to guide future education programs about the use of this technology for cancer control. Statements indicate CCC program managers find privacy to be a multifaceted issue, and offer new insights into understanding the perception of privacy and how it affects organizations, individuals, and communities.

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