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Acquisition of Sexual Orientation and Gender Identity (SOGI) Data Among NCI Community Oncology Research Program (NCORP) Practice Groups

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Precis: Only 1 in 5 oncology practice groups routinely collect information on patient gender identity or sexual orientation. Education of healthcare providers and research personnel is needed to improve the cancer care of this understudied minority population.

ABSTRACT

Background:

Sexual and gender minority individuals face numerous cancer-related inequities – many of which appear to be underreported. However, to our knowledge, no one has assessed rates of acquisition of sexual orientation or gender identity (SOGI) data within community oncology settings.

Methods:

Community oncology practices that were part of the NCI Community Oncology Research Program (NCORP) network were asked whether they routinely collect SOGI information and code this information in their electronic medical records. The proportion of practice groups reporting routine collection of SGM information was calculated. Potential associations between collection of sexual orientation and gender identity information and practice group and state level characteristics (from Gallup poll data) are also provided.

Results:

24% of the responding NCORP practice groups reported routine collection of sexual orientation information, and 10% reported collection of gender identity information. Practices located in western regions of the United States, practices in states with higher proportions of sexual and gender minority-identifying individuals, and practices with lower proportions of non-Hispanic patients were more likely to ask patients about sexual orientation and/or gender identity.

Conclusions:

US oncology practices that participate in research do not frequently collect sexual orientation and gender identity information from patients with cancer. Educational initiatives should inform oncology staff and providers about the importance of collecting gender identity and sexual orientation information to improve existent disparities facing sexual and gender minority patients.

Keywords: Sexual and gender minorities, gender identity, sexual orientation, disclosure

INTRODUCTION

Over 10 million adults in the United States identify as sexual and/or gender minorities (SGM) (1). As an umbrella term, SGM encompasses a diverse array of sexual orientations and gender identities, including lesbian, gay, bisexual, and transgender, as well as queer/questioning, intersex, and others. These diverse SGM individuals face cancer-related healthcare disparities, including low rates of cancer screening, high rates of anal cancer, and high rates of cervical cancer (2-9). SGM individuals also potentially face a large number of cancer-related issues that remain understudied (2). Cancer outcomes may be compromised by such inequities, with one study finding that lesbian women with breast cancer have greater disease-specific mortality (10).

Despite such disparities, healthcare providers do not routinely ask about sexual orientation or gender identity (SOGI) (11). Only half of primary care providers and few emergency room physicians inquire about sexual orientation (12-14). As relevant to cancer care, one qualitative study of 39 women with breast cancer observed that healthcare providers rarely or never inquired about their sexual minority status (15). Healthcare providers may not

inquire about sexual orientation and gender identity because of concerns about offending patients (14, 16). Yet, although concerned about discrimination, patients appear to be willing to discuss their gender identity and/or sexual orientation (14). One study of 291 lesbian, gay, bisexual, and transgender individuals found that 79% self-disclosed their identity to a cancer healthcare provider, sometimes as a way to correct heterosexual assumptions (17). In an effort to improve collection of SOGI data, a number of healthcare initiatives have promoted inclusion of SOGI information within medical records, from the 2015 Meaningful Use Stage 3 Rules which require certified electronic medical records to have SOGI fields, to the American Society of Clinical Oncology's recent recommendations for inclusion of sexual and gender minority status on tumor registries (18, 19).

Interestingly, no prior study has reported nationwide rates of routine collection of sexual orientation and gender identity information from among cancer patients. Furthermore, little is known about the oncology practice characteristics associated with routine collection of SOGI information. This study aimed to determine the reported rate at which community oncology clinics and medical centers collect sexual orientation and gender identity information and to report on the factors associated with higher rates of collecting SOGI data.

METHODS

Overview. Data for the current study were drawn from the 2017 NCI Community Oncology Research Program (NCORP) Cancer Care Delivery Research (CCDR) Landscape Assessment. NCORP is an NCI-funded research infrastructure that supports community oncology clinics in recruiting cancer patients and survivors to clinical trials nationwide. The CCDR effort aims to facilitate research and trials that can improve cancer care delivery nationwide. The Landscape Assessment asked administrators and research staff employed at NCORP clinics about issues relevant to healthcare delivery and to the conduct of clinical trials. The current study focused on only a small part of that assessment, namely, the part that queried research practices about whether they routinely asked cancer patients about SOGI data. This study was deemed exempt from IRB review as it relied on a non-patient data base and was therefore not considered human subjects research.

Survey Development and Distribution. The NCORP program developed the CCDR Landscape Assessment using an iterative process of question solicitation and review. First, the NCORP Research Bases and community oncology practices were invited to submit questions for inclusion in the Landscape Assessment. Then a working group led by a co-author (KW) and consisting of other co-authors (HN, AK, RC, LG, JU) and the senior author (CK) reviewed the questions for their relevance to cancer care delivery research. The final set of reviewed questions was presented to NCORP Research Bases and community oncology practices, and staff at the practices were trained to collect survey data using a series of webinars. The survey was then distributed to NCORP practice groups electronically.

An NCORP practice group was defined using Cancer Therapy Evaluation Program (CTEP) institution codes; these codes are intended to represent discrete clinical settings in the United States that are available to participate in NCI-sponsored research and to organize clinical trial data submitted to NCI. In some cases several clinical locations in the same geographic region with different CTEP codes shared oncologists, patients, and services (e.g. a main

hospital and satellite clinics). These practices submitted Landscape Data together as a practice group, comprised of multiple CTEP IDs.

Study Goals. The primary goal of the current study was to report the percentage of NCORP community oncology practice groups that reported on collecting information on patient sexual orientation and gender identity. The secondary goal was to report on the characteristics of institutions that collected this information.

Measures: The two survey questions relevant to SOGI information are as follows: “Does your component/subcomponent collect and record information about patients’ sexual orientation in the EHR?” and “Does your component/subcomponent collect and record information in the EHR about patients’ gender identity? This would be distinct from the standard male-female sex field.” Within the LandscapeAssessment, the term “component/subcomponent” refers to the specific NCORP community oncology practice group, and the term “EHR” referred to electronic medical record.

In addition to the above questions, practice group-specific information obtained from the survey and used in our analyses included the following: geographic location of each group; practice group ownership status; reported proportion of patients at the research practice group with insurance coverage from Medicaid, dual Medicare-Medicaid, charity care, and uninsured; total number of new cancer cases each year; percentage of the practice group’s patient population that identified as non-Hispanic; the percentage of group’s patient population that identified as white; and dedicated outreach staff for minority outreach. To benchmark, we used Gallup poll data on rates of SGM individuals living in each state (20). For the multivariate analyses in this report, only the variables mentioned above and Gallup poll data were used.

Statistical Analyses. Initial univariate evaluations of associations between variables were conducted with chi-square and Kruskal Wallis tests (significant p-value < 0.05). A logistic regression model that used backward elimination (p-value < 0.2 used as staying threshold) further evaluated potential associations between reported collection of sexual orientation information (yes/no) and gender identity information (yes/no). The pool of variables that were used during backward selection includes: Practice Group Region (categorical), New Cases per Year, Type of Ownership, Medicaid Insurance Proportion, Medicare Insurance Proportion, Uninsured Insurance Proportion, Dual Medicare-Medicaid Insurance Proportion, Charity Care Insurance Proportion, Percent Non-Hispanic, Percent White, and Statewide Percent LGBT.

RESULTS

Practice Group Characteristics. A total of 943 CTEP institution codes were registered as part of the NCORP network in 2017. Information for 504 of these CTEP institution codes was provided as part of the Landscape Assessment. Survey respondents clustered these 504 codes into 227 distinct practice groups. Respondents indicated these practice groups shared providers, patients, infrastructure, and generally had a common electronic health record; thus, practice-level responses should apply to the practice group as a whole. Based upon the estimate of available data for 504 of the total of 943 CTEP codes, the response rate to the survey as a whole was 53%. Of the sample of 227

practice groups who responded to any part of the survey, 221 practice groups responded to the question on the collection of sexual orientation data, and 222 responded to the question on collection of gender identity information.

Survey Results.

Of the 221 practice groups that responded to both sexual orientation and gender identity questions, fourteen (6.3%) practice groups collected both gender identity and sexual orientation information. Thirty-nine (17.7%) practice groups collected only sexual orientation information. Nine (4.1%) practice groups collected only gender identity information. One hundred fifty-nine (72.0%) practice groups collected neither gender identity nor sexual orientation information.

Fifty-three community oncology practice groups (24% of those that completed the survey) reported that they routinely collect information on sexual orientation. Table 1 shows statistically significant associations between collection of sexual orientation information and practice group characteristics. Of note, while initial univariate analyses showed an association between dedicated staff for minority outreach and routine collection of sexual orientation information (Kruskal-Wallis p-value=0.04), this association was not observed in the multivariate model.

Twenty-three practice groups (10%) reported that they routinely collect information on patient gender identity. Table 2 and Figure 1 show statistically significant associations between collection of gender identity information and practice group characteristics. Based on the multivariate logistic regression analyses, we observed that sites in the Western region of the United States were more likely to collect gender identity information when compared with Southern (p=0.0092) and Midwestern (p=0.0092) regions. Practice groups that identified as a hospital, clinic, or physician practice owned by a large regional/multi-state health system were less likely to report collecting gender identity information when compared to both independently owned sites (p=0.0260) and practice groups within another category of ownership (p=0.0379) based on the multivariate model. Likewise, groups with more than 10% of patients with dual Medicare-Medicaid were less likely to routinely collect gender identity information based on the multivariate model (p=0.0187). Conversely, while the initial univariate analyses showed an association between percentage of state population identifying as SGM and routine collection of gender identity information (Kruskal-Wallis p-value=0.0295), this association was not observed in multivariate analyses.

DISCUSSION

Only about 1 in 5 responding NCORP community oncology practice groups routinely report collecting SOGI data, and site characteristics – including location of practice group, whether the group served a lower proportion of non-Hispanic patients, and whether the group served a higher proportions of LGBT-identifying individuals – were all directly associated with a greater likelihood of querying patients about such information. In keeping with a growing literature on under-reporting (11-15), this study shows that even in a large NCI-funded research network, healthcare

providers and healthcare personnel remain reluctant to ask SOGI information. As data collection on SOGI status does not occur at the majority of cancer institutions, sexual and gender minority patients cannot be identified and may be underserved when cared for at cancer clinics. Physicians who are unaware that they are treating sexual and gender minority patients may be less responsive to these patients' needs, contributing to a lack of patient-centered care.

Not surprisingly, states in the United States with a higher proportion of SGM patients and with non-discrimination legislation appear to have higher rates of asking about gender identity information. For instance, California, Oregon, and Washington have state-wide employment, anti-bullying, and public accommodation legislation, have higher percentages of SGM individuals, and are more likely to collect SOGI information (21). While the association was not evaluated directly in this study, we surmise that SGM individuals who live in regions that harbor SGM-friendly attitudes might explain this favorable association because such states likely have higher numbers of SGM-friendly staff and thereby provide a SGM-welcoming environment (22). Educating oncology staff on cultural sensitivity toward SGM individuals and hiring staff of all sexual orientations and gender identities may enhance collection of SOGI information.

Interestingly, this study also showed that community oncology practice groups with more ethnic diversity (measured by proportions of non-Hispanic patients) were more likely to ask about sexual orientation. While it is not clear why this relationship was observed, SGM individuals are more likely to lack adequate insurance and to report unmet medical needs, sometimes making them recipients of care in underserved areas (23). Potentially, the healthcare providers who work in these underserved clinics are more adept at managing a variety of issues among various minority groups and are hence willing to ask about SOGI information. This may also be a result of the higher proportion of Hispanic patients seen in the Western United States.

This study has both strengths and weaknesses. A strength is that this work was undertaken nationwide, within research settings embedded in community-based oncology settings. Although previous studies on this topic have focused on clinical practice settings, this research perspective is of great importance (13, 17). Understanding that SGM issues are not addressed in a research setting undercuts our abilities to learn how to better screen or detect cancer in potentially high-risk SGM individuals and to learn if malignancies within SGM individuals behave differently and thereby require a modified treatment approach. Thus, at a broad, public health level, these findings point to a need for further education among healthcare providers and clinical research personnel in an effort to collect these data routinely and systematically. In terms of weaknesses, this study did not use a validated questionnaire to assess SOGI data. The fact that our survey was rooted in a quality initiative and the fact that our queries and goals are somewhat unique explains why our project needed to be built from the ground level. In addition response rates were low, increasing the risk for nonresponse bias. For this reason as well, power to detect true associations may have been limited. Similarly, we are unable to report on data from practice groups that did not

provide a response because no comparable data is available for these groups. Despite such limitations, this study provides important information that should prompt efforts to better serve this understudied minority population.

In summary, this study provides an important starting point for investigating integration of SOGI information into cancer clinical trial research. Such efforts will be of value in moving forward research initiatives and better patient care in this group of cancer patients.

Figure legends

Figure 1. Practice Group Characteristics Statistically Significantly Associated with Reporting Gender Identity.

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Table 1: Collection of Sexual Orientation Information.

		Univariate*			Multivariate**		
Variable	Comparison Group	Collection of Sexual Orientation Information Reported to Occur	Collection of Sexual Orientation Information Reported to NOT Occur	P-Value	Odds Ratio	Confidence Interval	P-Value
Percentage of non-Hispanic ethnicity	not available	75.2 ± 36.7	91.5 ± 17.6	0.02	0.78 (per 18.76% increase)	0.58, 1.05	0.09
Percentage of state population identifying as a SGM	not available	3.8 ± 0.6	3.9 ± 0.5	0.14	1.36 (per 0.55% increase)	0.96, 1.91)	0.08
Dedicated staff for minority outreach	yes	15 (34.9)	28 (65.1)	0.04	Not included in multivariate analyses (removed from model based on backward elimination)		
	no	36 (20.5)	140 (79.5)				

*For categorical variables, N (%) and Chi-Squared p-value are reported. For continuous variables, mean value ± standard deviation (SD) and the Kruskal-Wallis p-value are reported.

**19 of 221 practice groups that responded to the sexual orientation question were excluded from multivariate analyses due to missing data.

Table 2. Collection of Gender Identity Information.

	Univariate*	Multivariate**
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Variable	Comparison Group	Collection of Gender Identity Information Reported to Occur	Collection of Gender Identity Information Reported to NOT Occur	P-Value	Odds Ratio	Confidence Interval	P-Value
Practice group region	Midwestern	7 (6.3)	104 (93.7)	0.03	1	(Reference)	0.02
	Western	10 (21.7)	36 (78.3)		3.01	1.31, 6.88	
	Northeastern	2 (14.3)	12 (85.7)		1.23	0.34, 4.49	
	Southern	4 (7.8)	47 (92.2)		0.44	0.16, 1.23	
Practice ownership type	Independently owned	9 (11.4)	70 (88.6)	0.07	1	(Reference)	0.08
	Hospital, clinic, or physician practice owned by a large regional/multi-state health system	9 (7.5)	111 (92.5)		0.45	0.22, 0.91	
	Other	5 (23.8)	16 (76.2)		1.90	0.83, 4.35	
Percentage of non-Hispanic Ethnicity	Not available	80.3 ± 23.9	88.5 ± 24.5	0.05	0.69 (per 24.84% increase)	0.44, 1.07	0.09
Proportion of Dual Medicare-Medicaid Cases	≤10%	20 (13.2)	131 (86.8)	0.10	1	(Reference)	0.02
	>10%	3 (5.3)	54 (94.7)		0.43	0.21, 0.89	
Percentage of State Population Identifying as SGM	Not available	4.1 ± 0.6	3.8 ± 0.5	0.03	Not included in multivariate analyses (removed from model based on backward elimination)		

*For categorical variables, N (%) and Chi-Squared p-value are reported. For continuous variables, mean \pm SD and Kruskal-Wallis p-value are reported.

**22 of the 222 practice groups that responded to the sexual orientation question were excluded from multivariate analyses due to missing data.

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Site Characteristics Statistically Significantly Associated with Reporting Gender Identity

