2021 NPCR IDAHO SUCCESS STORY

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Finding Cancer Among Refugees Resettled to Idaho: Leveraging Existing Data to Characterize a Unique Population

National Program of Cancer Registries
SUCCESS STORY

SUMMARY

Idaho welcomes the 2nd highest number of refugees per capita among US states. Idaho public health agencies wanted to characterize cancer burden among refugees, but no population-level data were available for analysis. Thus, the Cancer Data Registry of Idaho (CDRI) collaborated with the Idaho Department of Health and Welfare (IDHW) to link data from the Centers for Disease Control and Prevention's (CDC) Electronic Disease Notification System (EDN) with cancer registry data. To our knowledge, this is the first time EDN and cancer registry data have been linked to characterize cancer among refugees. In doing so, we demonstrated proof-of-concept, and identified areas for enhanced cancer prevention and control efforts among refugees resettled to Idaho.

CHALLENGE

Refugees are persons who are unable or unwilling to return to their country of nationality "because of persecution or a well-founded fear of persecution due to race, religion, nationality, membership in a particular social group, or political opinion (U.S. Immigration and Nationality Act, Sect. 101[a][42])."[1] A median of 816 refugees were resettled to Idaho per year during 2008 through 2019 from a diverse set of home countries, including Afghanistan, the Democratic Republic of Congo, Iraq, Bhutan, and Syria. In 2019, Idaho welcomed 29.3 refugees per 100,000 population – second only to Kentucky among US states in the number of refugees per capita.[2]

Refugees are diverse with disparate cultural backgrounds; yet, also share unique life experiences of trauma and involuntary displacement relative to the general population. Because of this, refugees may have unique health profiles relative to the populations where they are resettled. For example, in Idaho, refugees have been shown to have an elevated prevalence of chronic medical (e.g., diabetes[3]) and psychological (e.g., post-traumatic stress disorder[4]) conditions.

Population-based descriptions of cancer burden among refugees have primarily been conducted in European nations.[5-9] In the United States, our knowledge of the cancer experience among refugees mainly consists of interview data focused on screening behaviors.[10-12] These knowledge, attitudes, and practices data are critical to understanding cancer prevention, but do not provide a picture of potential disparities in cancer incidence and survival.13 In Idaho, refugees are typically resettled to two geographic areas (Boise and Twin Falls) and receive primary medical care at a relatively small number of outpatient clinics. Nevertheless, these clinics provide ample opportunities for community outreach.

In the fall of 2019, due to the potential specific needs and vulnerabilities of this population, Idaho's State Epidemiologist proposed a collaboration between IDHW and CDRI to characterize cancer among Idaho's refugee population. However, there was no existing data set that would answer this question, and key pieces of information such as population denominators for refugees and refugee status among Idaho's cancer patients were missing. Additionally, the question of cancer incidence and burden among

refugees had not been previously addressed at the population level in the United States, thus Idaho needed to come up with a novel solution.

SOLUTION

In response to the challenge of characterizing cancer in the refugee population, CDRI and IDHW collaborated to leverage data available in EDN and identify refugees in CDRI's cancer database. EDN collects health, demographic, and administrative immigration data on legal permanent immigrants, refugees, asylees, and paroleees that enter the United States.[1] IDHW had previously used EDN to characterize mortality in refugees resettled to Idaho; we hoped to successfully adopt this approach for our cancer surveillance data. We knew that this might be challenging, however, as Social Security numbers (SSN) are not included in the EDN system and a large proportion of refugee dates of birth are non-specific, e.g., January 1 of a given year.

IDHW provided CDRI with data on all refugees resettled to Idaho during 2008–2020. CDRI data included NPCR-reportable malignant cases and benign and borderline tumors of the brain and other nervous system diagnosed during January 2008–December 2019. CDRI conducted the linkage using Match*Pro software, commercially available address history tools (e.g., LexisNexis® Accurint®) and supporting information (e.g., dates of immigration and diagnosis) to identify tumors diagnosed in persons who were also refugees resettled to Idaho. To determine if refugees had higher- or lower-than-expected cancer incidence, we needed to calculate the expected number of incident cancer cases in the refugee population. We did so by applying age-, sex-, and time period-specific SEER-18 referent incidence rates[14] to the time from arrival in Idaho through either the date of cancer diagnosis or date of death or end of the study period (December 31, 2019). This number of expected tumors was compared to the number of actual (or observed) diagnosed tumors in CDRI's data. We estimated standardized incidence ratios (SIR; and corresponding 95% confidence intervals) for 43 malignant tumor categories and 3 categories of benign brain and other nervous system tumors using Multiple Primary-Standardized Incidence Ratio (MP-SIR) sessions in SEER*Stat version 8.3.9.1 (Information Management Systems, Inc.).[15]

We worked with IDHW partners to determine which years of refugee data would be most reliable, and which types of information would be most useful to the community. From these preliminary results, we worked with IDHW to identify appropriate partners and providers that might be interested in these data.

RESULTS

During 2008–2019, 9,499 refugees were resettled to Idaho. The refugee population is younger, with a median age at resettlement to the United States of 22.0 years (interquartile range [IQR]: 10.0–34.0; versus a median age of Idaho residents of 36.9 years in 2019). Although refugees resettled to Idaho were born in > 80 countries, nearly 70% of refugees resettled to Idaho were born in 8 countries: Iraq (n = 1,374); Democratic Republic of Congo (n = 1,371); Bhutan (n = 1,094); Myanmar (n = 937); Tanzania (n = 500); Ethiopia (n = 422); Nepal (n = 412); and Afghanistan (n = 400). We identified 69 tumors diagnosed among refugees during 2008–2019, including 60 malignant cancers, 2 in situ, and 7 benign and borderline malignant behavior neoplasms of the brain and other nervous system. Figure 1 shows the birth countries of refugees resettled to Idaho and diagnosed with a cancer during 2008–2019.

Figure 1: Map of birth country of refugees resettled to Idaho and diagnosed with cancer during 2008–2019.
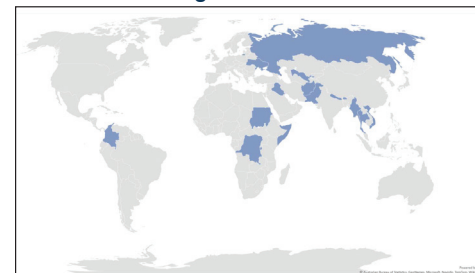
The mean age at time of cancer diagnosis among refugees was 54.3 years for all malignant primary sites and 55.9 years for benign and borderline malignant tumors. The median age of Idaho residents diagnosed with a malignant cancer in 2018 was 67.0 years. A total of 57 malignant tumors and 7 benign and borderline tumors were included in SIR analyses, with a mean time from arrival to the end of the follow-up period of 6.5 years. Approximately 44% (25/57) of tumors diagnosed among refugees were late-stage cancers (distant or regional stage), versus 41.5% of tumors diagnosed at late-stage in 2018 among all Idaho residents; this difference was not statistically significant.[16] For all malignant cancer sites combined, refugees had a lower-than-expected number of cancer diagnoses (57 observed versus 95.6 expected), with an observed-to-expected (O/E) ratio of 0.60 and 95% confidence interval (95% CI) of 0.45, 0.77 (Table 1). Cases of female breast cancer and cancers of the male genital system (driven by a lower-than-expected number of cancers of the prostate) were also statistically significantly lower among refugees than in the SEER-18 referent population. For most other comparisons, the number of cancer diagnoses in refugees was statistically equivalent to the SEER-18 referent population, except for cancers of the esophagus. The number of cancers of the esophagus diagnosed among refugees was statistically significantly higher than expected based on the SEER-18 referent populations (SEER-18 O/E ratio = 6.3; 95% CI = 1.7, 16.0; n = 4). These cancers were all diagnosed among refugees born in Southeast Asian countries. The number of cases of benign and borderline tumors of the brain and other central nervous system diagnosed in Idaho's refugees was like the expected number (Table 1).

With support from IDHW, we were able to identify potential partners at local public health districts and health systems where refugees are commonly resettled. In addition, IDHW and local public health partners intend to connect with the relatively small number of providers in Idaho that treat and screen Idaho refugees.

Table 1: Malignant and benign and borderline malignant tumors diagnosed during 2008–2019 among refugees resettled to Idaho during 2008–2019, as classified by the SEER Site Recode ICD-O-3/WHO 2008 and compared to SEER-18 (Nov 2020 submission) referent rates.

	Observed	Expected	O/E	CI Lower	CI Upper
All Sites	57	95.97	0.59#	0.45	0.77
Digestive System	15	19.92	0.75	0.42	1.24
Esophagus	4	0.64	6.25#	1.7	16
Stomach	4	2.35	1.7	0.46	4.36
Colon and Rectum	5	9.38	0.53	0.17	1.24
Respiratory System	9	9.47	0.95	0.43	1.80
Lung and Bronchus	7	8.73	0.8	0.32	1.65
Male Genital System	4	11.20	0.36#	0.1	0.91
Prostate	4	10.18	0.39	0.11	1.01
Urinary System	7	5.68	1.23	0.5	2.54
Kidney and Renal Pelvis	4	3.40	1.18	0.32	3.01
Endocrine System	9	5.72	1.57	0.72	2.99
Thyroid	9	5.37	1.68	0.77	3.18
Leukemia	4	3.10	1.29	0.35	3.3
Benign Brain and Other Nervous System	7	3.50	2	0.8	4.12

Confidence intervals are 95%.
= P < 0.05
Site category rows with small cell suppression (< 4 cases) are excluded for succinctness.

SUSTAINING SUCCESS

Although this novel linkage presented challenges; we identified primary sites with higher- or lower-than-expected incidence among refugees and refugee sub-populations that might benefit from concentrated clinical and public health efforts. CDRI and IDHW have started to identify local public health agencies, and clinical and social support programs that may use these data to improve cancer-related care for refugees. CDRI and IDHW will continue to conduct this linkage and re-analyze the data annually. Despite the younger age of refugees at resettlement, establishing this refugee cancer cohort and practitioner partnerships now will position Idaho to characterize cancer in refugees as they age, potentially improving our ability to serve this vulnerable population.

REGISTRY CONTACT INFORMATION

208-338-5100
https://www.idcancer.org/

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