

Original Article

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Rural disparities in head and neck cancer from 2017 to 2021: a single institution analysis

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Abstract

Introduction: This study aims to look at the trends in our head and neck cancer patient population over the past 5 years with an emphasis on the past 2 years to evaluate how the coronavirus disease 2019 (COVID-19) pandemic has impacted our disparities and availability of care for patients, especially those living in rural areas. An additional aim is to identify existing disparities at our institution in the treatment of head and neck patients and determine solutions to improve patient care.

Materials and Methods: A retrospective chart review was performed to identify patients who were consulted and subsequently treated with at least one fraction of radiation therapy at our institution with palliative or curative intent. Patient demographic information was collected including hometown, distance from the cancer centre based on zip-codes and insurance information and type of appointment (in-person or telehealth). Rural–urban continuum codes were used to determine rurality.

Results: A total of 490 head and neck cancer patients ($n = 490$) were treated from 2017 to 2021. When broken down by year, there were no significant trends in patient population regarding travel distance or rurality. Roughly 20–30% of our patients live in rural areas and about 30% have a commute > 50 miles for radiation treatment. A majority of our patients rely on public insurance (68%) with a small percentage of those uninsured (4%). Telehealth visits were rare prior to 2019 and rose to 5 and 2 visits in 2020 and 2021, respectively.

Conclusions: Head and neck cancer patients, despite rurality or distance from a cancer centre, may present with alarmingly enough symptoms despite limitations and difficulties with seeking medical attention even during the COVID-19 pandemic in 2020. However, providers must be aware of these potential disparities that exist in the rural population and seek to address these.

Introduction

Rural cancer patients face a unique set of barriers to care. The coronavirus disease 2019 (COVID-19) pandemic has exacerbated existing problems related to access to screening, diagnosis, treatment and surveillance for oncology patients. Roughly 60 million or 1 in 5 Americans live in rural areas according to the United States Census Bureau.¹ From anecdotal experience, disparities occur across many aspects of cancer care, including those related to prevention, screening, access to providers and specialty care, travel distance, treatment, financial burden and outcomes. Smaller hospital facilities, physician shortages and recruitment difficulties are more common in non-metropolitan areas.

Compared to rural areas, metropolitan cities have about 1.6 times the oncologist density.² Roughly 20% of Americans live more than 60 miles from the closest oncologist, making travel time, cost of travel and time away from work substantial barriers to oncologic care for patients living in rural communities.² Despite decreasing cancer mortality rates overall, the death rate for all cancer sites in rural communities is decreasing at a slower rate than that for non-rural communities, -1.0% per year versus -1.6% per year, respectively.²

Disparities in care for rural patients have been reported in several different cancer sub-sites. One group reported more advanced stage at diagnosis, less adequate/effective oncologic surgeries and less use of adjuvant chemotherapy for rural patients versus non-rural patients with colon cancer in California.³ Similarly, rural living has been associated with an increase in lung cancer mortality.⁴ Most rural areas had twice as much smoking and lung cancer incidence; additionally, these patients were statistically less likely to receive surgical resection for early stage disease and had a significantly shorter median survival when compared to patients residing in metropolitan areas.⁴

Cancer of the head and neck is a common and often highly curable disease. The National Cancer Institute, Surveillance, Epidemiology, and End Results (SEER) program estimates 53,260

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new cases of oral cavity and pharynx cancers and 12,370 new cases of laryngeal cancers in 2020, constituting roughly 3.5% of all new cancer diagnoses.⁵

Due to COVID-19, medical clinics have put more emphasis on telehealth and providing care to patients remotely. Smartphones and the improvement of cellular networks have granted users real-time access to an array of health-related data. Recent data from the Pew Research Center show that 85% of Americans own a smartphone with that percentage dropping as age increases and income decreases. Only 61% of people over the age of 65 and 76% of people with income of less than \$30,000 own a smartphone.⁶ A study performed by New Mexico State University looked at patients undergoing breast mammography in the rural counties of Otero and Lincoln, New Mexico, and revealed that although 87.2% out of 156 participants used a cell phone on a regular basis, only 73 participants (46%) used text messaging as a means of communication. Out of that cohort, only 26 participants (35.6%) would prefer to have a text to remind them of cancer prevention methods. Although the technology is already available to most patients, some may be reluctant to adopt it for various reasons, such as difficulty of use, limited use of cell phone, lack of interest and lack of access to cell phone coverage.⁷ Specifically, in radiation oncology, telehealth could provide ease and convenience for initial consult especially in patients who are undecided about radiation therapy. Telehealth could also grant access to other family or close friends who are unable to attend in-person appointments due to sickness/quarantine or distance. These initial consults with family and close friends could aid in patients' decisions regarding the utilisation of radiation therapy in their treatment plan. Using this technology could save the patient's time that would otherwise be spent driving, while also granting flexibility.

Data from the Centers for Disease Control and Prevention collected from 1999 to 2014 have demonstrated that some rural areas have seen little progress or even a worsening in cancer outcomes. American Indians/Alaskan Natives (AI/AN) are one of the population groups who have been affected by this technological divide.⁸ The AI/AN population has the highest poverty rate with many of them living on reservation land in the poorest counties in the USA⁹ Indian Health Services are also underfunded with per capita funding in 2019 quoted at \$4,078 as compared to \$9,726 for the general public in the USA.¹⁰

In this project, we aim to outline disparities including those related to rurality, demographics, race and access to care including telehealth in our Oklahoma head and neck cancer patients with an emphasis on the past two years to examine the impact of the COVID-19 pandemic on our patient population. We hypothesise that that our patient population from rural areas and living > 50 miles away trended downwards within the past 2 years due to decreased access to care secondary to the pandemic. An additional goal of this analysis is to identify existing disparities within our head and neck cancer patient population in order to propose solutions to improve patient care at our institution.

Materials and Methods

We performed a chart review across Oncochart, our radiation oncology electronic medical record (EMR) system, through a system wide search on patients who were consulted and received at least one fraction of radiation therapy for a head and neck primary cancer. There was a total of 490 patients ($n = 490$) treated with radiation therapy for a head and neck primary cancer from 2017 to 2021 including patients receiving definitive or palliative

treatment. Calendar years were used for the ease of comparison. Patients were sorted by treatment years based on date of initial fraction for the first course of radiation therapy. Data were evaluated in September 2021, so there is no analysis available for the last three months of 2021. We recorded information on patient hometown, insurance status, travel distance from Stephenson Cancer Center (SCC) and number of telemedicine visits in the year. Medicaid, Medicare, Indian Health, correctional centre and Veteran's centre-based insurances were classified as being funded by the public. Patients' mailing ZIP codes were used to calculate distance from SCC based on Google Maps distances. Rurality was determined based on Rural-Urban Continuum Codes (RUCC) from the United States Department of Agriculture with RUCC codes 1–3 classified as urban and RUCC codes 4–9 as rural.¹¹

Results

Demographics

Table 1 displays patient characteristics. Mean patient age was 63 with males making up 73% of our patients. Racial background was not routinely collected at the time of consult. Based on insurance coverage, 6 patients (1.2%) were of Native American background and qualified for Indian Health benefits.

Distance

From 2017 to 2021, patients travelled a mean distance of 45 miles (range 0.9–292 miles) for radiation therapy. A majority of patients (62%) lived 11 to 20 miles from SCC. Breakdown of percentage of patients and the mileage that they travel for treatment are displayed in Figure 1. Of our 490 patients, 338 (69%) lived ≤ 50 miles from the cancer centre and 152 (31%) lived > 50 miles away (Figure 2). When broken down by year that treatment was started, a majority of patients who came for treatment still lived 11 to 20 miles away from the cancer centre (Figure 3). Patients travelling from 50 miles or more from 2017 to 2021 ranged from 22 to 39 patients making up roughly a quarter of each year's patient population (Figure 4).

Insurance coverage

From 2017 to 2021, 333 patients (68%) had public insurance, 139 patients (28.3%) had private insurance and 18 patients (3.7%) had no insurance (Figure 5).

Rural-urban continuum codes

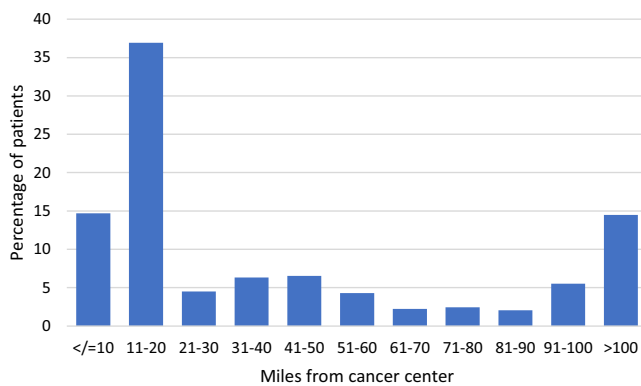
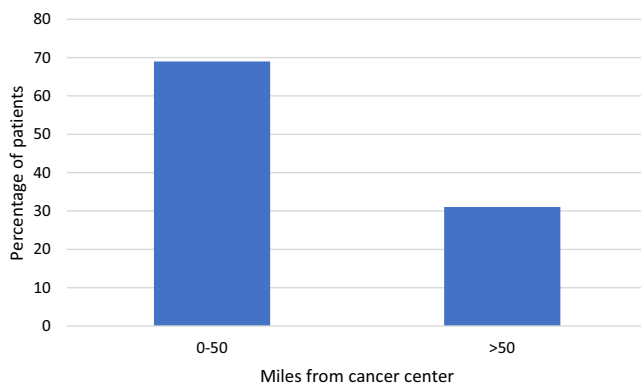
Based on RUCC, 361 patients (73.7%) treated from 2017 to 2021 lived in urban areas and 129 patients (26.3%) lived in rural areas. This was similar year to year: 75 patients (73.5%) urban and 27 patients (26.5%) rural in 2017, 70 patients (77.8%) urban and 20 patients (22.2%) rural in 2018, 80 patients (70.8%) urban and 33 patients (29.2%) rural in 2019, 82 patients (75.2%) urban and 27 patients (24.8%) rural in 2020 and 54 patients (71.1%) urban and 22 patients (28.9%) rural in 2021. This is depicted in Figures 6 and 7.

Telehealth

Telehealth visits were very rare from 2016 to 2019. Telehealth visits rose as a direct response to the COVID pandemic to 5 in 2020 with only 1 visit (20%) with a patient living > 50 miles from our cancer

Table 1. Patient characteristics

| Total | Number of Patients (n) | % |
|-------------|------------------------|------|
| | 490 | |
| Age (Years) | | |
| <= 20 | 5 | 1 |
| 21-30 | 5 | 1 |
| 31-40 | 16 | 3.3 |
| 41-50 | 31 | 6.3 |
| 51-60 | 120 | 24.5 |
| 61-70 | 176 | 35.9 |
| 71-80 | 89 | 18.2 |
| 81-90 | 39 | 8.0 |
| 90+ | 9 | 1.8 |
| Sex | | |
| Men | 360 | 73.5 |
| Women | 130 | 26.5 |

**Figure 1.** Percentage of patients based on distance from our cancer centre from 2017 to 2021.**Figure 2.** Percentage of patients living ≤ 50 miles and > 50 miles from our cancer centre from 2017 to 2021.

centre. The remaining 4 patients lived between 19.5 and 33.7 miles away. In 2021, there were only 2 telehealth consults performed for head and neck cancer patients. Both of these patients lived < 50 miles from our cancer centre.

Discussion

Overall, the patient population that we treat at SCC is one that faces numerous challenges in cancer care. We specifically looked at patients consulted and then subsequently treated at our facility. There is likely a large number of patients who were consulted but did not receive treatment due to barriers in care. Even so, in our treated patient population over the past 5 years, about 30% live over 50 miles from the cancer centre, over 50% rely on publicly funded health insurance, roughly 4% have no insurance and 26% come from towns classified as rural. These numbers are higher than what we expected.

Despite the COVID-19 pandemic starting in early 2020, there were no significant trends in changes to the demographics, rurality or distance to the cancer centre for the SCC head and neck cancer population. Prior to beginning this study, we hypothesised that the proportion of patients that resided in rural ZIP codes and the proportion of patients that lived > 50 miles would have declined over the past two years due to challenges created by the pandemic. However, no such trend was found. As seen in Figures 3 and 7, the makeup of our patient population is roughly the same from year to year. A majority of patients in 2020–2021 still travelled 11 to 20 miles for treatment with no drastic decrease in the number of patients travelling > 50 miles for treatment. The proportion of our patients living in urban versus rural areas of the state based on the RUCC also remained consistent. Despite this, our analysis of our head and neck patient population has given us insight on the disparities that exist at our institution allowing us opportunity to explore solutions to potentially bridge these gaps.

An identifiable cause of barrier to care, especially in the context that roughly a third of our patients come from > 50 miles away, is the lack of lodging. Though there are discounted hotels nearby, these run from \$75 to 90 a night. Considering that a course of radiation therapy, especially for head and neck patients, can last up to seven weeks, most patients cannot afford this extra cost. At this time, there is no free lodging for patients or their families (except for paediatric patients at the Ronald McDonald House). There are current plans to build free lodging for cancer patients (American Cancer Society Hope Lodge), but this is unlikely to be available for all patients in need. Most patients commute to and from the SCC each day during active treatment.

Thus, most patients face barriers to treatments including being able to afford petrol money, car breakdowns and lack of transportation. Head and neck cancer patients oftentimes require anti-anxiety medication due to claustrophobic nature of the Aquaplast mask required during radiation treatment, leaving them dependent on friends or family for transportation. This has at times led to unplanned interruptions in treatment when a patient unexpectedly cannot find transportation. There is transportation available for patients with the American Cancer Society and through Medicaid (Sooner-Care in Oklahoma); however, these are often cumbersome and require extensive planning. Also, during head and neck cancer treatment, patients are often unable to complete their work duties that puts additional financial strain on them.

At this time, SCC does not have satellite radiation centres. The logistics of a satellite centre are already difficult and are dependent on availability of space to build vaults for radiation treatment machines, as well as substantial financial resources. Because of this, patients are currently limited to being treated in Oklahoma City or at private centres in Norman, Ada, Ardmore, Shawnee, Enid, Lawton or Tulsa to name a few. The availability of treatment techniques such as stereotactic body radiotherapy (SBRT) or intensity-

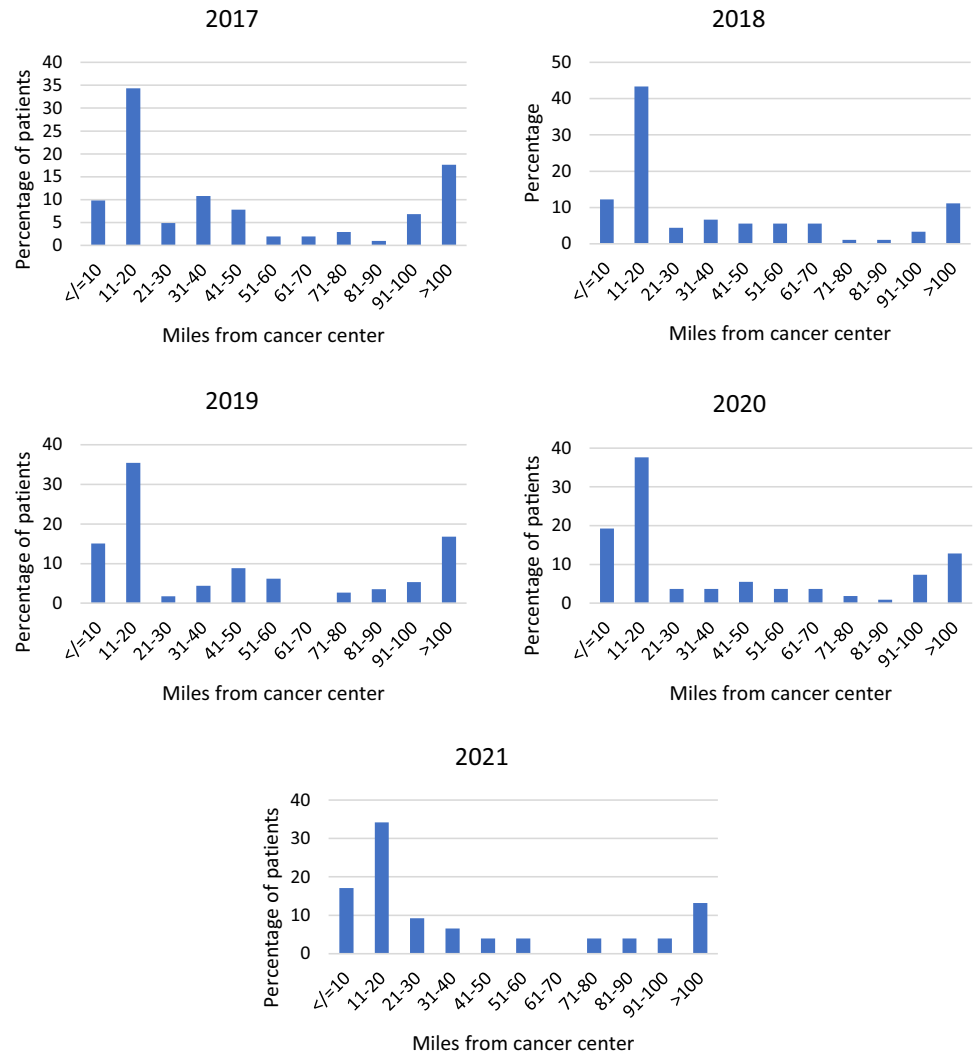


Figure 3. Yearly breakdown of percentage of patients based on distance from our cancer centre.

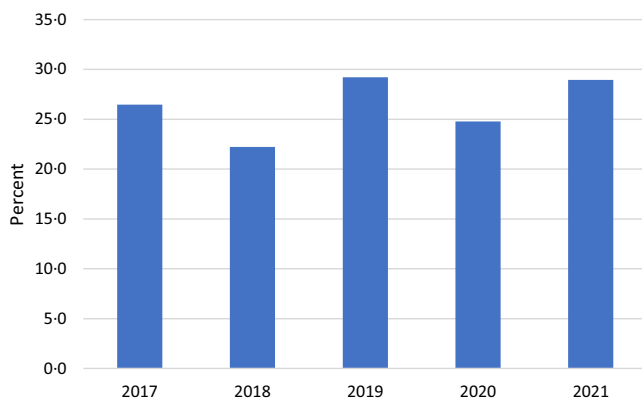


Figure 4. Percentage of patients living > 50 miles from our cancer centre from 2017 to 2021.

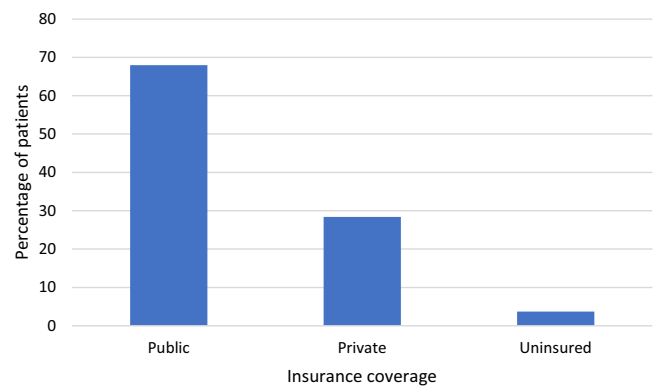


Figure 5. Number of patients with public, private or no insurance from 2017 to 2021.

modulated proton therapy (IMPT) are limited in these private centres. There is also lack of provider comfort in offering re-irradiation, ancillary supportive care services such as speech therapy or palliative care and clinical trial offerings.

Due to COVID-19, there has been a conscious effort to curtail unnecessary in-office visits for evaluation with greater reliance on

telehealth in our clinic. Despite advertising telehealth in the past year and a half as an option for consult and follow-up appointments, only 5 patients in 2020 and 2 patients in 2021 with a head and neck primary cancer utilised it. One patient out of the 7 lived a distance > 50 miles away from the cancer centre. This brings us to wonder if limited resources such as lack of smart phone/webcam or patient preference in visit type also played a part. Our patient's

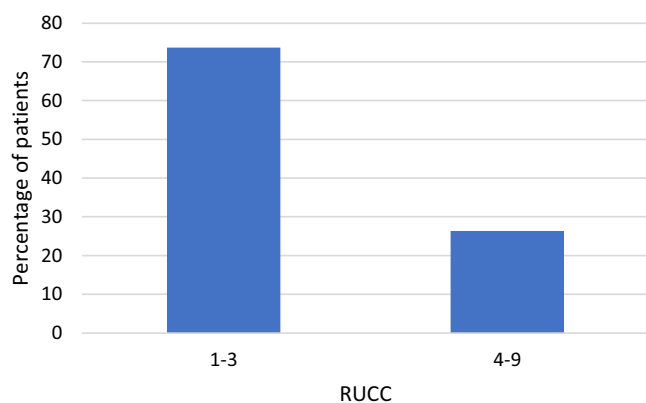


Figure 6. Percentage of patients based on RUCC from 2017 to 2021.

median age is 63 with most being born in the 1960s. The Internet was created in the 1980s when most of these patients were in their 20's which may play into lack of comfort when using our telehealth platform. We currently use the Amwell system for telehealth that requires patients to install a mobile application onto their smartphone, which may also be difficult for older patients to navigate. Despite its convenience especially in the time of a pandemic, telehealth is not without its own limitations including lack of physical exam, specifically a detailed oral/neck exam and laryngoscopy for patients with head and neck cancers. There also may be barriers in telemedicine given the infrastructure of SCC. We typically encourage same day computed tomography (CT) simulation for treatment planning after consultation for head and neck patients. A telehealth visit would not necessarily save them a visit to our clinic if they have already decided on radiation therapy as part of their treatment plan.

Barriers in care can potentially be improved through several methods. First of all, community initiatives to increase vaccine availability could be undertaken. Educating and then widely vaccinating patients with the human papillomavirus (HPV) vaccine, for example, could decrease cancer incidence. Also, by making the COVID vaccine more available, we could decrease fear in patients who are apprehensive about coming into clinic due to exposure to the virus. We could also work on making telehealth more accessible to patients by offering video tutorials on installation and how the mobile application works. We could also look into expanding our cancer centre's reach with the addition of satellite sites in the future. We would need to determine areas of need and may run into staffing issues and availability of vault space; however, these would be issues that we would need to tackle in the future. Additionally, we could improve our available transportation systems and transportation assistance. Patients could be scheduled for rides for daily treatments weeks in advance to allow for adequate scheduling. For unexpected ride needs, we could partner with short notice ride services such as Uber or Lyft. Finally, we could work to coordinate care between providers so that appointments are on the same day for convenience.

When looking at the geography of Oklahoma, Oklahoma City is centrally located within the middle of the state. The next biggest city in Oklahoma is Tulsa, which is located roughly 1.5 h northeast of Oklahoma City with a population of 401,190. No other major cities exist in Oklahoma, with the next closest urban population being Dallas, Texas, which is 3 h south of Oklahoma City. Tulsa does have several options for radiation therapy including the Saint Francis Health System, Oklahoma Cancer Specialists and

Research Institute and Northeastern Oklahoma Cancer Institute; however, SCC is the only National Cancer Institute designated centre in the state. As a whole, we also do not see many patients from the Tulsa area (only 10 patients (2.0%) were from Tulsa county within the past 5 years) unless they choose to pursue treatment in Oklahoma City.

Per USA (USA) Census Bureau data from 2019, Choctaw County, which includes the towns of Hugo, Boswell, Grant and Fort Towson, is the lowest earning county in Oklahoma.^{12,13} This county is located in the southeast corner of Oklahoma roughly equidistant from Oklahoma City and Dallas. Specifically, median household income in 2019 for Hugo, OK, was \$21,212 and per capita income was \$16,324 with 42.8% of the population living in poverty. The US Census Bureau defines poverty as a total income that is less than a calculated family's threshold based on family size and composition. A high percentage, 28.4%, of people in Hugo, OK, under age 65 also have no health insurance. Looking at these numbers, it is clear as to why patients in this area have difficulty with obtaining cancer care. In contrast, Oklahoma as a whole has a 15.2% rate of persons in poverty with median household income and per capita income of \$52,919 and \$28,422, respectively. As reported in 2019, 16.8% under age 65 did not have health insurance.¹³

AI/AN make up 10% of Oklahoma's population. The city with the highest AI/AN population in Oklahoma is Anadarko with 40.4% of the town's 6,504 population being AI/AN. Anadarko has higher percentage of persons in poverty at 24.2% when compared to Oklahoma as a whole with median household income of \$43,072 and per capita income of \$23,228.¹³ A study by Guadagnolo et al. looked at the cancer care access and outcomes for AI populations in the USA⁹ Overall, there are poorer outcomes, sub-optimal screening and high-risk cancer behaviours in this population of patients in the setting of low and middle income. We would need to perform further analysis on our patient population in order to determine whether race also factors into disparities in cancer care and outcomes at our centre.

Other institutions have found mixed data regarding rural disparities in head and neck cancer patients prior to COVID-19. Javadi et al. analysed Surveillance, Epidemiology, and End Results Program (SEER) data for oral cavity cancers and HPV-positive oropharynx cancers, stratifying patients based on gender, race, geography and rurality. When separated into subsites, HPV-positive oropharynx cancers had a higher trend in incidence in rural patients when compared to their urban counterparts. The authors hypothesise that this could be secondary to the availability and administration of HPV vaccines.¹⁴ Similarly, Zhang et al., looking retrospectively at over 500 Canadian patients with squamous cell carcinoma of the oral cavity, found those who lived in more rural areas experienced decreased overall survival, with five-year estimates of overall survival of 65% in those living less than 50 km from a cancer centre versus 52% for those living greater than 100 km away. Among other factors, it is hypothesised that post-treatment surveillance adherence could play a part in this discrepancy.¹⁵

Mukherjee et al. looked at rurality, race and age at the time of diagnosis in head and neck cancer patients in the South-Eastern USA and found mixed results. The retrospective study evaluated a total of 4,258 patients in Alabama and found that patients in rural counties were less likely to be diagnosed at a young age (defined as ≤ 45). Cancer stage at the time of diagnosis did not differ based on rurality in this cohort, and outcome differences based on rurality were not reported.¹⁶

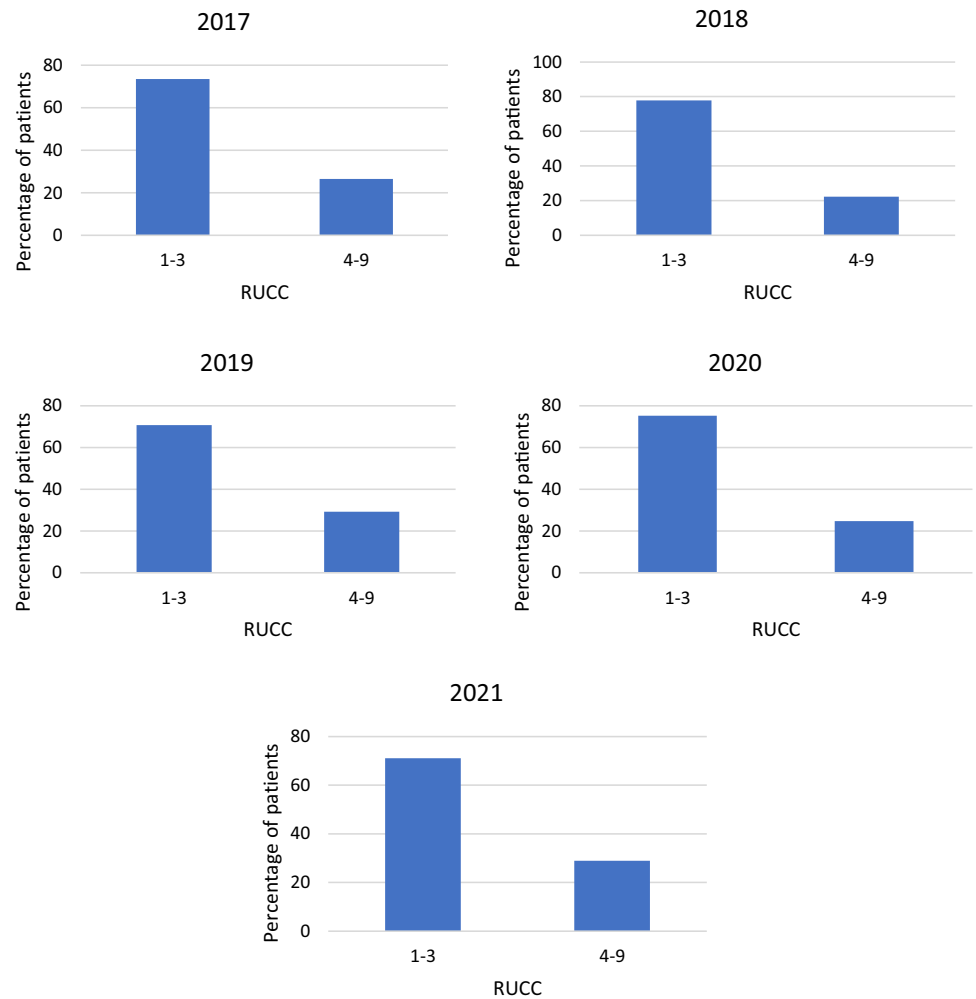


Figure 7. Yearly breakdown of percentage of patients based on RUCC.

Clarke et al. examined the relationship between race and rural-urban context on the basis of survival in head and neck cancers using the National Cancer Database. Unlike our study, they specifically looked at survival which showed that black patients especially those in rural areas have decreased survival when compared to their Caucasian counterparts.¹⁷ We did not specifically look at survival or classify our patients based on race. Instead, we looked at possible barriers to care as a whole including distance, healthcare coverage and rurality. With continued long-term follow-up of our patients, we may be able to explore whether there are disparities in survival in our patient cohort.

Recently, Kaur et al. looked at single institution survival data in head and neck cancer patients from rural versus urban areas. They found no significant difference in overall survival, but there were differences in treatment modalities, with rural patients more likely to receive chemotherapy versus surgery likely secondary to more advanced disease.¹⁸ Again, data are mixed between recent studies which shows that there are likely factors other than distance from cancer centre that are driving disparities in care.

Financial burden and financial toxicity are terms related to direct and indirect healthcare costs. The financial burden found in patients undergoing radiation therapy is the highest among patients being treated for breast and head and neck cancer.¹⁹ Giuliani et al. found that of head and neck cancer survivors who were employed at the time of diagnosis, 48% of them were forced to reduce work in some capacity, and 32.8% did not return to work

at all following treatment for their head and neck cancer.²⁰ It has been found that even when not actively receiving treatment for cancer, expenditures among cancer survivors were higher than those among similar individuals without cancer.²¹ Though we did not evaluate financial burden in our patient population, this is a topic that needs further exploration especially in the follow-up and surveillance setting following chemotherapy and radiation therapy treatment.

Furthermore, there are SEER data analysed by Osazuwa-Peters et al. that support evidence that suicide risk among head and neck cancer patients especially rural patients is higher.²² This is a cause for concern since our patient population has large rural representation. Especially because of COVID-19, support groups as well as the availability of psychological treatment have been diminished, as in-person gatherings and appointments were discontinued and psychotherapy services became overwhelmed. With this in mind, telehealth may be of further help in bridging these gaps with an emphasis on coping mechanisms and suicide prevention.

Limitations in our chart review include limited patient population. We present only single institution data for the past 5 years (with 2021 data being incomplete) in patients with head and neck cancer. We also only analysed data from patients who were consulted and subsequently treated at our facility. We did not take into account patients who chose to forego treatment completely or who opted to be treated at a different centre due to difficulties with transportation or for other reasons.

Prior to initiating this project, we realised that Oklahoma has many barriers to care. However, the number of head and neck patients travelling > 50 miles for treatment, those living in rural areas and the number of patients reliant on publicly funded insurance were surprising and highlight some of our limitations. Examining our specific patient population has brought to mind several initiatives we can take to help bridge these gaps in care and improve cancer care for our present and future patients. This opens up the gate to further quality improvement studies involving patient satisfaction and outcomes.

Conclusions

At this time, potential disparities in healthcare availability to rural patients must be acknowledged and addressed. Resources such as community health initiatives, more creativity in the mobile health space, better transportation systems to cancer treatment centres, affordable/free lodging for those travelling great distances and better coordination of care between cancer specialists will aid patients who are at risk for delayed care, increased financial toxicity and poorer outcomes.

Supplementary Material. To view supplementary material for this article, please visit <https://doi.org/10.1017/S1460396922000127>

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Conflict of Interest. None.

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