Diagnosis of cutaneous T-cell lymphoma by insurance type before and after the Affordable Care Act: a national database study

Vignesh Ramachandran1,2 BS, Katherine E Park1,2 BS1,2, Jesal R Shah3 BS BA, Madeleine Duvic2 MD

Affiliations: 1Baylor College of Medicine, Houston, Texas, USA, 2The University of Texas MD Anderson Cancer Center, Houston, Texas, USA, 3Department of Medicine, University of Pennsylvania, Philadelphia, Pennsylvania, USA

Corresponding Author: Vignesh Ramachandran, 1 Baylor Plaza, Houston, Texas, 77030, Tel: 512-431-2236, Email: vigneshr@bcm.edu

Abstract

The Affordable Care Act (ACA) was implemented to increase health care access and reduce the uninsured in the age group between pediatric and Medicare populations (18-64). The association of the ACA with insurance type upon diagnosis (uninsured, Medicaid, non-Medicaid) has been investigated for otolaryngologic, gynecologic, and the top five non-skin malignancies. Such studies for cutaneous malignancies are lacking. We conducted a retrospective analysis of the prospective National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) cancer database to assess the impact of the ACA on new diagnoses of cutaneous T-cell lymphoma (CTCL) by insurance type. Unlike prior studies of other malignancies, we did not observe significant differences between rate of diagnosis of CTCL by insurance type before and after full implementation of the ACA in all states, expansion states, and non-expansion states. Skin cancers do not have screening guidelines and CTCL is an uncommon malignancy, both of which may contribute to these findings. However, Medicaid-expansion states were much closer to reducing the percentage of newly diagnosed uninsured patients with CTCL than non-expansion states. As such, it may be prudent to investigate intrinsic socioeconomic barriers to care in Medicaid patients to improve their access to care to decrease the uninsured population and improve outcomes.

Keywords: cutaneous T-cell lymphoma, CTCL, Affordable Care Act, ACA, Medicaid, diagnosis, population-based, Surveillance Epidemiology and End Results Cancer Database, SEER

Introduction

The introduction of the Patient Protection and Affordable Care Act (ACA) in 2010 ushered in the most prominent healthcare structural change since introduction of Medicare and Medicaid in 1965. This law was implemented in large part to increase the accessibility of health care and reduce the uninsured in the age group between pediatric and Medicare populations (18-64 years old), [1]. Although signed into law in 2010, the ACA formally introduced Medicaid expansion (allowing eligibility for individuals with household incomes up to 138% of the federal poverty line) and health insurance exchanges in January 2014 [2]. The years between 2010 and 2015 saw a dramatic decrease from 49 million to 29 million in the number of uninsured individuals in the United States [3].

Health insurance is associated with cancer screening, stage at diagnosis, type of treatment obtained, and outcomes [4]. Although statistics regarding the decreasing uninsured population are intriguing, the future of the ACA is uncertain. As such, it is necessary to evaluate how this policy
impacts outcomes in those patients most influenced by the policy (Medicaid and Medicare-ineligible adult patients). The association of the ACA with insurance type upon diagnosis (uninsured, Medicaid, non-Medicaid) has been investigated for otolaryngologic, gynecologic, and the top five non-skin malignancies [5-7]. Such studies for cutaneous malignancies are lacking.

Cutaneous T-cell lymphoma (CTCL) comprised a heterogeneous group of T-cell lymphoproliferative disorders affecting the skin with mean age of onset in the fifties [8]. Herein, we assess the impact of the ACA on new diagnoses of CTCL before and after its full implementation.

**Methods**

We conducted a retrospective analysis of the prospective National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) cancer database, which pools data from 18 registries encompassing approximately 34.6% of cancer diagnoses in the United States [9]. Institutional board review was waived as SEER-Medicare data are exempt. Inclusion criteria were: patients between age 18-64 years old eligible for Medicaid (Medicare insurance data unavailable in SEER), CTCLs with prevalence of ≥1%, and cases diagnosed from 2007-2015 (years with recorded insurance data). Exclusion criteria included: lymphoproliferative disorders that may have cutaneous involvement (lymphoma cutis), broad International Classification of Diseases for Oncology-3 (ICD) codes encompassing multiple heterogeneous diagnoses, and cases with “unknown” insurance designation. International Classification of Diseases for Oncology-3 used were: 9700/3 (mycosis fungoides), 9701/3 (Sezary syndrome), 9708/3 (subcutaneous panniculitis-like T-cell lymphoma), 9718/3 (primary cutaneous anaplastic large cell lymphoma), 9719/3 (extranodal NK/T-cell lymphoma, nasal type), and 9726/3 (primary cutaneous gamma-delta T-cell lymphoma). A total of 2,900 cases were analyzed. Standard mean differences with 95% confidence intervals (CI) were calculated for all cases diagnosed by insurance type (uninsured, Medicaid, non-Medicaid) in the United States before (2007-2013) and after full implementation of the ACA (2014-2015). This analysis was repeated for Medicaid expansion states and non-expansion states to assess the impact of this

![Figure 1](image_url). Insurance rate trends for patients diagnosed with cutaneous T-cell lymphoma in all states (top), Medicaid expansion states (middle), and Medicaid non-expansion states (bottom).
policy on uninsured rates in states which did, or did not implement this aspect of the ACA. P values <0.05 were deemed significant.

Results
No significant differences were found between rate of diagnosis of CTCL by insurance type before and after full implementation of the ACA in all states, expansion states, and non-expansion states. Prior research, however, shows that Medicaid expansion led to decreases in patients with uninsured status diagnosed with gynecologic, otolaryngologic, and the top five non-skin cancers nationally (all states) and in states that expanded Medicaid, but not in non-expansion states [5-7]. In fact, according to a study by Soni et al., uninsurance among patients with newly diagnosed top-five non-skin cancer fell by one-third in the ACA’s first year [7]. Specifically, they demonstrated a decrease in the percentage of patients without health insurance for the following cancers: breast (-25.86%), prostate (-29.32%), colorectal (-33.75%), lung and bronchial (-32.67%), and thyroid (-32.98%), [7].

These results vary greatly from those depicted in this study. Results are presented in Figure 1 and Table 1.

Discussion
Many of the most common malignancies, such as colon cancer, gynecologic cancers, and breast cancer, have established screening guidelines covered under Medicaid, whereas skin cancers have no screening recommendations [3, 5]. Increased access to primary care facilities may facilitate screening for these malignancies. These cancers are also relatively well-known to the general public compared to CTCL, which is often diagnosed by specialists (i.e. dermatology). Cutaneous T-cell lymphoma is also less common than squamous cell carcinoma of the head and neck. Even though the latter has no screening guidelines, the sheer volume of malignancies may reflect in an appreciable decrease in uninsured population as a result of generally improved insurance coverage options after implementation of the ACA. These factors may lead to the prior studies’ findings of ACA reducing the number of uninsured patients diagnosed with these cancers, a finding not observed in our study.

Of the numerous health care policies implemented as part of the ACA to reduce the uninsured rate, Medicaid expansion has been the most important [5-7]. In our study, Medicaid-expansion states were much closer to increasing the percentage of new CTCL diagnoses in

Table 1. Percentages of diagnosed cases of cutaneous T-cell lymphoma in all states (left), Medicaid expansion states (middle), and Medicaid non-expansion states (right) before (2007-2013) and after (2014-2015) full implementation of the Affordable Care Act.
uninsured patients (-1.78%, P=0.20) compared to non-expansion states, which had an increased in newly diagnosed uninsured patients (+2.04%). Medicaid is a surrogate for socioeconomic status. For low socioeconomic patients, access to insurance may not offset additional hurdles such as lack of access to care (and specialty services), transportation, cost, education, and loss of insurance coverage during workup/treatment [10-14]. In an uncommon malignancy like CTCL, the impact of socioeconomic status may be amplified in patients’ ability to seek specialty care for diagnosis and treatment. Furthermore, prior investigation shows that outcomes in Medicaid-insured CTCL patients are worse than privately-insured patients [15]. Thus, further investigation into these factors and addressing them may be beneficial in amplifying the positive impact of the ACA, expanding its utility for more uncommon cancers and improving survival outcomes.

Limitations of this study include possible data entry errors, possible insurance status changes during the study period, lack of long-term data, and inability to include unknown insurance cases and non-specific ICD codes (9702/3 and 9709/3, N=2,308). It also does not include patients older than 64. However, the ages under investigation (18-64) are pertinent in study of the ACA and older age groups are beyond the scope of this study as such patients are eligible for Medicare, an insurance status not tracked in SEER.

Conclusion
This is a first-of-its-kind study of a dermatologic diagnosis, particularly in that we are evaluating the ACA’s impact on an uncommon malignancy like CTCL. Moving forward, it would be prudent to develop policy to address socioeconomic barriers to improve access to care and outcomes beyond insurance coverage.

Potential conflicts of interest
The authors declare no conflicts of interests.

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