SKIN

BRIEF ARTICLE

The Incidence of Imprecise ICD-10 Coding in Patients with Cutaneous T-cell Lymphoma: A MarketScan Database Study

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ABSTRACT

Background: The term "Primary Cutaneous T-cell Lymphoma" (primary CTCL), although used largely interchangeably with mycosis fungoides in the past, actually represents numerous non-Hodgkin lymphomas with highly variable and distinct characteristics. Accuracy of claims-based research studies of CTCL hinge on the precision of ICD-10 coding, but the incidence of imprecise coding for CTCL has not been extensively studied.
Objective: To determine the incidence of imprecise ICD-10 coding in CTCL patients in a large, commercial claims database.
Methods: We analyzed the Marketscan database from October 1, 2015 to December 31, 2018 to determine the proportion of patients designated only with the generic CTCL code in the absence of a code for a more specific diagnosis.
Results: Of 3,953 patients meeting the criteria for inclusion, only 107 (2.7%) had a generic CTCL code without a more specific diagnosis code.
Conclusions: These results suggest that the majority of CTCL claims are *precisely* coded, although until future studies investigate the *accuracy* of diagnosis, the results of claims-based studies in the realm of CTCL should be interpreted with caution.

INTRODUCTION

The term "Primary Cutaneous T-cell Lymphoma" (primary CTCL) encompasses a heterogeneous group of non-Hodgkin lymphomas which vary significantly in morphologic/histopathologic appearance, immunohistochemical profile, clinical behavior, and prognosis.[1,2] Although mycosis fungoides (MF) and Sezary syndrome (SS) represent the prototypic and classic forms of CTCL, recent diagnostic advancements have led to expansion of the classification schema put forward by the World Health Organization and the European Organization for Research and Treatment of Cancer (WHO-EORTC).[3] Therefore, more specific diagnoses should be used when possible and the overarching term, "CTCL," should be avoided in clinical settings, as this does not refer to a distinct entity and can cause confusion for the patient and for other clinicians when used to indicate a more specific diagnosis such as MF.[4] Furthermore, the use of diagnosis codes for "CTCL" without more specific codes for individual entities can impact treatment and survival data and nullify the utility of claims-based data used for research purposes, as previously demonstrated with other disease entities.[5,6] Consequently, our study aimed to determine the proportion of patients in the

MarketScan database (IBM, Armonk, NY) with any CTCL diagnosis who were designated only by the overarching "CTCL" code (C84.A0-A9) without a more specific code corresponding to an individual disease subtype.

METHODS

The MarketScan commercial claims database was queried from October 1, 2015 to December 31, 2018. All patients ≥18 years of age with a new diagnosis of any CTCL (indicated by an ICD-10 code for "CTCL" and/or a more specific CTCL subtype) with at least two outpatient encounters ≥6 months apart were included. The outcome of interest was the proportion of patients with encounters coded only with a generic "CTCL" ICD-10 code without a more specific code corresponding to a specific subtype of CTCL (such as MF or subcutaneous panniculitis-like T-cell lymphoma, for example).

RESULTS

Of 25,872,942 patients included in the MarketScan database during the timeframe of this study, 3,953 patients carried at least one CTCL diagnosis code and met the criteria for inclusion. Of these, only 406/3,953 (10.3%) had an encounter with a generic "CTCL" code listed (C84.A0-A9). Furthermore, only 107/3,953 (2.7%) exclusively had a generic "CTCL" code without additionally having a more specific diagnosis code such as MF (C84.0-C84.9). The remainder, 3,846/3,953 (97.3%), had at least one code corresponding to a specific CTCL subtype (**Table 1**).

DISCUSSION

Proper use of ICD-10 diagnosis codes has important implications not only for billing, but also for claims-based research, as the validity of such studies hinges on the ability to identify a complete, homogenous sample population.[5] This, in turn, depends on both the accuracy of diagnosis as well as the precision of coding (i.e. including codes for specific diagnoses when possible, and avoiding the sole use of "umbrella" codes for overarching disease categories). While the accuracy of diagnosis is not easy to assess through the use of a claims database, the precision of coding is. Our study revealed, somewhat unexpectedly, that based on a large commercial claims database, the ICD-10 coding for primary cutaneous T-cell lymphomas is favorably precise and largely in line with the current WHO-EORTC classification schema.

This study has several limitations. First, due to the small number of patients meeting the criteria for conclusion, subgroup analysis aimed at comparing the precision of coding by geographic location or provider type (e.g. dermatologist vs. oncologist) was not possible. Moreover, the MarketScan database includes commercial claims only and therefore this data does not pertain to Medicare/Medicaid patients. Additionally, although the majority of CTCL encounters are being coded precisely, this does not necessarily imply that these terms are being used properly in patient interactions. Moreover, the precision of coding may not reflect accuracy of the diagnosis, which in terms of CTCL can be quite nuanced and cannot easily be assessed through the use of claims data. Future studies aimed at assessing the accuracy of CTCL diagnosis/classification by different groups of clinicians should be performed. Until such studies are undertaken, the results of any claims-based studies in the realm of CTCL

Table 1. Proportion of patients in Market Scan database with overarching "Cutaneous T-Cell Lymphoma" and individual primary cutaneous lymphoma/lymphoproliferative disorder subtype diagnosis codes

Individual Diagnosis Codes for 2018 WHO-EORTC Entities	CTCL ICD-10 Code (C84.A0, C84.A1, C84.A2, C84.A3, C84.A4, C84.A5, C84.A6, C84.A7, C84.A8, C84.A9) Listed n, (%)	CTCL ICD-10 Code (C84.A0, C84.A1, C84.A2, C84.A3, C84.A4, C84.A5, C84.A6, C84.A7, C84.A8, C84.A9) ***Not*** Listed n, (%)	Total n, (%)
No individual entity code listed (see rows below)	107 (26.4%)	0 (0.0)	***107 (2.7%)***
Any individual entity code listed	299 (73.6%)	3,547 (100.0%)	*3,846 (97.3%)*
Individual Entities*:			
Mycosis fungoides (C84.0, C84.00, C84.01, C84.02, C84.03, C84.04, C84.05, C84.06, C84.07, C84.08, C84.09)	270	2,379	
Sezary Syndrome (C84.10, C84.11, C84.12, C84.13, C84.14, C84.15, C84.16, C84.17, C84.18, C84.19)	24	124	
Adult T-cell leukemia/lymphoma (C91.50, C91.51, C91.52)	43	426	
Primary cutaneous CD30+ lymphoproliferative disorder/Cutaneous anaplastic large cell lymphoma (C86.6)	43	633	
Subcutaneous panniculitis-like T-cell lymphoma (C86.3)	2	43	
Extranodal NK/T-cell lymphoma, nasal-type (C86.0)	0	101	
Primary cutaneous peripheral T-cell lymphoma, NOS (C84.48)	25	219	

Table 2. Current subtypes of Cutaneous T-cell Lymphoma (as defined by the 2018 update of the WHO-EORTC classification for primary cutaneous lymphomas) and associated occurrence

2018 WHO-EORTC CTCL Subtypes	*Distinct ICD-10 Code?*	*Approximate Percentage of CTCL Cases[3]*	*Current "Best" Code in ICD-10*
Mycosis Fungoides	Yes	58%	N/A
Sezary Syndrome	Yes	2%	N/A
Primary Cutaneous Anaplastic Large Cell Lymphoma	Yes	10%	N/A
Lymphomatoid Papulosis[a]	No (Retired code)[b]	16%	Primary cutaneous CD30 positive lymphoproliferative disorder
Adult T-cell Leukemia/Lymphoma	Yes	<1%	N/A
Primary Cutaneous CD4+ Small/Medium T-cell Lymphoproliferative Disorder[a,c]	No	8%	PTCL, NOS
Subcutaneous Panniculitis-like T-cell Lymphoma	Yes	1%	N/A
Extranodal NK/T-cell Lymphoma, Nasal Type	Yes	<1%	N/A
Primary Cutaneous γδ T-cell Lymphoma	No	<1%	PTCL, NOS
CD8+ Aggressive Epidermotropic Cytotoxic T-cell Lymphoma[c]	No	<1%	PTCL, NOS
Primary Cutaneous Acral CD8+ T-cell Lymphoma[c]	No	<1%	PTCL, NOS
Chronic Active EBV Infection	No	<1%	PTCL, NOS
Primary Cutaneous Peripheral T-cell Lymphoma, NOS	Yes	2%	PTCL, NOS

[a]Lymphoproliferative disorder
[b]Previous code retired, but could be coded as "CD30+ Lymphoproliferative Disorder," which shares an ICD-10 code with Primary Cutaneous Anaplastic Large Cell Lymphoma
[c]Provisional entity in 2018 WHO-EORTC classification for primary cutaneous lymphomas
WHO=World Health Organization; EORTC=European Organization for the Research and Treatment of Cancer; EBV=Epstein-Barr Virus; NK=Natural Killer; NOS= Not Otherwise Specified*; PCTL=Peripheral T-Cell Lymphoma, N/A=Not applicable*

should be interpreted with an appropriate level of caution.

CONCLUSION

The low incidence of imprecise ICD-10 coding in patients with CTCL suggests that claims-based research studies in this population may be feasible which is important for these relatively rare diseases. Specific ICD-10 codes do not exist for some CTCL subtypes; this may account for a portion of the 2.7% of patients in this study with imprecise coding (Table 2).[3] Consequently, ICD-11 should incorporate specific codes for the newly-defined CTCL subtypes to help reduce the rate of imprecise coding even further. This will help to further refine the data gathered from clinical encounters, enabling more robust conclusions to be drawn from claims database studies performed in this population.

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