SHORT COMMUNICATION

Validation of Diagnoses of Atopic Dermatitis in Hospital Registries: A Cross-sectional Database Study from Finland

Miika KURKI[1,2], Suvi-Päivikki SINIKUMPU[1], Eetu KIVINIEMI[3], Jari JOKELAINEN[3] and Laura HUILAJA[1*]
*[1]Department of Dermatology, Oulu University Hospital and Research Unit of Clinical Medicine, University of Oulu, FIN-90029 Oulu, [2]Department of Dermatology, Kainuu Central Hospital, Kainuu Social and Health Care Joint Authority, Kajaani and [3]Infrastructure for Population Studies, Faculty of Medicine, University of Oulu, Oulu, Finland. *E-mail: laura.huilaja@oulu.fi*
Accepted Apr 19, 2023; Published Jul 10, 2023
Acta Derm Venereol 2023; 103: adv7266. DOI: 10.2340/actadv.v103.7266

Atopic dermatitis (AD) is the most common inflammatory skin disease with a chronic or chronically relapsing course. Its prevalence is approximately 10–20% in children and approximately 10% in adults (1, 2) and has been increasing worldwide in recent decades (3). The diagnosis of AD is based on clinical evaluation, and no diagnostic tests exist (4). As early as the 1980s, Hanifin & Rajka (5) proposed diagnostic criteria for diagnosing AD. Despite its extensive nature, their criteria are still widely used and are considered the "gold standard" when defining AD. Nevertheless, other, more simplified, criteria have also been developed (6). Depending on the setting, the sensitivity and specificity of these criteria vary (7, 8).

Routinely collected electronic health record (EHR) data are increasingly used for research purposes (9). In AD studies originating from health registry data, the disease definition varies widely (10). In Finland, the Finnish Institute of Health and Welfare maintains several registries, including, for example, diagnoses from EHR data originating from all Finnish public hospitals and the largest private hospitals. The accuracy of this registry has been studied widely (11), but, in the field of dermatology, the validity of diagnoses recorded in EHR in Finland is currently available only for psoriasis (12). As the diagnosis of AD is based on clinical evaluation only, the AD definitions used in studies utilizing routinely collected heath registry data vary and validation of diagnoses is encouraged (10). The current study analysed the validity of the AD diagnoses recorded in health records in 2 Finnish hospitals.

MATERIALS AND METHODS

In total, 300 patients who had a diagnosis of AD (defined as International Classification of Diseases – 10th revision (ICD-10) diagnosis code L20.0) registered at least once in any specialty in their records between 2002 and 2020 were randomly selected, using a computerized randomization program, by hospital archive personnel, from the database of a secondary care unit, Kainuu Central Hospital (n=150), and a tertiary care unit, Oulu University Hospital (OUH) (n=150), in Finland. Patients' EHRs in these hospitals were reviewed by an experienced resident or dermatologist. Predetermined clinical features based on the criteria defined by Hanifin & Rajka (5) were looked for. Furthermore, in the OUH subpopulation, based on written description and/or photographs in the EHR, the dermatologist/experienced resident made their judgement about the diagnosis ("verified AD diagnosis"; classified as (*i*) definite AD, (*ii*) no AD, or (*iii*) not enough data to retrospectively verify the diagnosis) based on UK working party diagnostic criteria for AD (6). In addition, the information about the specialty in which the AD diagnosis was recorded was also collected. This study was approved by medical directors of both participating hospitals. The study data were managed using RedCap data capture tools hosted by the University of Oulu. Counts and percentages are presented for categorical variables. Positive predictive values (PPVs) and their 95% confidence intervals (95% CI) were calculated using Wilson's score method.

RESULTS

The study population (n=300), were mostly females (n=185, 61.7%). Mean age at the time of the first AD diagnosis recorded in the hospital health records was 18.5 years (range 0–83) and mean age at the time of study was 32.4 years (range 3–89). Of all study subjects, 48.7% fulfilled the Hanifin & Rajka criteria. Of single criteria, chronic/chronically relapsing dermatitis was recorded most often, in 91.0% of the cases. Xerosis (81.0%), hand/foot dermatitis (49.7%), and facial pallor/erythema (37.3%) were the most frequently recorded minor criteria. The features of AD and fulfilment of AD criteria are described in detail in Table SI.

In the OUH subpopulation, when EHR were reviewed to verify the AD diagnosis, "verified AD diagnosis" was found in 90.8% (n=136/150), whereas 4.7% (n=7/150) of those with a recorded AD diagnosis code were judged not to have AD. In the OUH subpopulation, most cases (n=92/150, 61.3%) had their AD diagnoses recorded at least twice in the dermatology department, and 28.0% (n=42/150) had the AD diagnosis recorded once in the dermatology department. The distribution of the specialties in which the diagnosis code for AD was recorded is shown in Table SII. PPV for Hanifin & Rajka criteria was 51.1% and PPV for AD diagnosis recorded at dermatology specialty was 95.7% for 2 recorded diagnoses, and 88.1% if the diagnosis was recorded only once.

DISCUSSION

Less than half of the cases in this study had a diagnosis of AD based on Hanifin & Rajka criteria recorded in the EHR. This is clearly less than reported previously in a systematic review, which found a sensitivity of 87–96% for Hanifin & Rajka criteria (8). When analysing the details of this criterion, the study found that low sen-

sitivity is mostly due to missing minor criteria, since nearly 70% of all cases had the required ≥3 basic criteria in their EHR. In comparison, a more recent study from the USA (13) analysing health records in quaternary medical care found the sensitivity of AD diagnosis to be only 29.9%, which is comparable to the current findings. They concluded that the unconfirmed AD diagnosis is most likely due to inadequate documentation of Hanifin & Rajka criteria rather than misdiagnosis. This is most likely true in the current study population as well: for example, although AD mostly has early onset (14), this was reported in only one-fifth of those aged >16 years at the time of the study. In addition, there were also many other minor criteria, such as Dennie-Morgan folds, which were rarely reported, despite being common features in AD patients (14). It is highly likely that, in daily patient care, clinicians do not record in detail all the findings they observe/find out from patient history; instead, only the major points are recorded in the EHR, for reasons such as lack of time, for example.

In the subpopulation, we analysed the reliability of the recorded diagnosis more closely, based on the specialty in which the AD diagnosis was recorded. It was found that, if the diagnosis was recorded by a dermatologist, 90.8% of cases were judged to have AD. However, among these, only slightly over half of the cases fulfilled the Hanifin & Rajka criteria by their EHR. This further supports our assumption that, even if the Hanifin & Rajka criteria are still the most frequently used when defining AD in clinical trials (15), they are too extensive for everyday use. Less extensive criteria have been proposed (6), but in the current study setting we did not analyse their validity in Finnish EHR.

The strengths of the current study are that it was performed in 2 independent hospitals at different levels of healthcare, and EHRs were reviewed by dermatologists (LH, SPS) or an experienced resident (MK). As a limitation we were unable to define the negative predictive value or specificity of the AD diagnoses recorded in the EHR, since the study had no control population.

In conclusion, this study demonstrates that patients with AD can be reliably identified from hospital EHR by 2 dermatologists' recorded ICD-10 codes for AD. Retrospective use of Hanifin & Rajka criteria to determine AD leads to unnecessary exclusion of many patients, both children/adolescents and adults.

The authors have no conflicts of interest to declare.

REFERENCES

1. Silverberg JI, Hanifin JM. Adult eczema prevalence and associations with asthma and other health and demographic factors: a US population-based study. J All Clin Immunol 2013; 132: 1132–1138.
2. Bylund S, von Kobyletzki LB, Svalstedt M, Svensson Å. Prevalence and incidence of atopic dermatitis: a systematic review. Acta Derm Venereol 2020; 100: adv00160.
3. Weidinger S, Novak N. Atopic dermatitis. Lancet 2016; 387: 1109–1122.
4. Wollenberg A, Kinberger M, Arents B, Aszodi N, Avila Valle G, Barbarot S, et al. European guideline (EuroGuiDerm) on atopic eczema: part I – systemic therapy. J Eur Acad Dermatol Venereol 2022; 36: 1409–1431.
5. Hanifin JM, Rajka G. Diagnostic features of atopic dermatitis. Acta Derm Venereol 1980; 60: 44–47.
6. Williams HS, Burney PG, Hay RJ, Archer CB, Shipley MJ, Hunter JJA, et al. The U.K. Working Party's diagnostic criteria for atopic dermatitis. Br J Dermatol 1994; 131: 383–396.
7. Thyssen JP, Andersen Y, Halling AS, Williams HC, Egeberg A. Strengths and limitations of the United Kingdom Working Party criteria for atopic dermatitis in adults. J Eur Acad Dermatol Venereol 2020; 34: 1764–1772.
8. Brenninkmeijer E, Schram M, Leeflang M, Bos à J, Spuls P. Diagnostic criteria for atopic dermatitis: a systematic review. Br J Dermatol 2008; 158: 754–765.
9. Brunner PM, Silverberg Si, Guttman-Yassky E, Paller AS, Kabashima K, Amagai M, et al. Increasing comorbidities suggest that atopic dermatitis is a systemic disorder. J Invest Dermatol 2017; 137: 18–25.
10. Dizon MP, Yu AM, Singh RK, Wan J, Chren MM, Flohr C, et al. Systematic review of atopic dermatitis disease definition in studies using routinely collected health data. Brit J Dermatol 2018; 178: 1280–1287.
11. Sund R. Quality of the Finnish Hospital Discharge Register: a systematic review. Scand J Public Health 2012; 40: 505–515.
12. Haverinen S, Vihervaara A, Löyttyniemi E, Peltonen S, Koulu L, Tasanen K, et al. Validation of psoriasis diagnoses recorded in Finnish Biobanks. Acta Derm Venereol 2020; 100: adv00297.
13. Hsu DY, Dalal P, Sable KA, Voruganti N, Nardone B, West DP, et al. Validation of International Classification of Disease Ninth Revision codes for atopic dermatitis. Allergy 2017; 72: 1091–1095.
14. Langan SM, Irvine AD, Weidinger S. Atopic dermatitis. Lancet 2020; 396: 345–360.
15. Silverberg JI, Hong HC, Thyssen JP, Calimlim BM, Joshi A, Teixeira HD, et al. Comparative efficacy of targeted systemic therapies for moderate to severe atopic dermatitis without topical corticosteroids: systematic review and network meta-analysis. Dermatol Ther 2022; 12: 1181–1196.