REVIEW

Review of patient registries in dermatology

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Background: Patient registries are datasets containing information on patients with a particular disease or patients who are undergoing a specific treatment.

Objective: Our objective was to search for and catalog the types of registries being used in dermatology and investigate their characteristics and uses.

Methods: We searched Google, the Registry of Patient Registries, Orphanet, and ClinicalTrials.gov to compile a list of dermatology disease registries. We also conducted a literature review on the uses of dermatology registries using PubMed.

Results: We identified 48 dermatology patient registries, with 23 distinct diseases represented. We also identified 11 registries used for postmarketing surveillance of skin disease.

Limitations: Our search was limited to registries in English.

Conclusions: Registries are commonly used for the study of rare dermatologic diseases and for postsurveillance monitoring of systemic therapies in more common dermatologic diseases, such as psoriasis. (J Am Acad Dermatol http://dx.doi.org/10.1016/j.jaad.2016.03.020.)

Key words: clinical trial; international; postmarketing surveillance; psoriasis; rare dermatologic disease; research.

INTRODUCTION

Patient registries are databases of standardized information about patients with a common diagnosis or those who are undergoing a common treatment. Patient registries are of particular importance in the field of dermatology. Dermatologists are expected to recognize and treat >3000 dermatologic conditions.[1] Many of these diseases are rare and seldom seen in the clinic. Researching rare conditions relies on patient populations and data identified through rare disease registries.[2] Registries for conditions such as psoriasis have helped to evaluate long-term safety data for immunosuppressive drugs.[3] Registries also offer data regarding incidence and prevalence of skin cancers, and promote long-term data surveillance for these conditions. The purpose of this study is to identify and catalogue available dermatology registries and review the different characteristics and uses of patient registries.

METHODS

We searched Google, the Registry of Patient Registries, Orphanet, and ClinicalTrials.gov and compiled a list of dermatology disease registries

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using many key words, including dermatology and registry and (skin disease) and registry. We categorized these registries based on information found on registry websites and in articles found via PubMed. Registries were catalogued by disease and region/country of use and were accompanied by links to the registry website. We excluded skin cancer registries from our analysis because melanoma and other skin cancer cases are often reported to state or national cancer registries. We performed additional searches in PubMed and Google to gather information on registry uses and limitations. Several key word combinations were used, including (dermatology condition) and registry characteristics, registry and rare disease, and registry and postmarket surveillance.

CAPSULE SUMMARY

- Patient registries are databases of standardized information about patients with a common diagnosis or treatment.
- The characteristics, uses, and limitations of 48 dermatology patient registries are described.
- Dermatologists may consider referring patients for enrollment in registries and using information from registries in clinical practice.

RESULTS

We identified 48 dermatology disease registries (Table I). In total, 23 dermatologic diseases were represented. Psoriasis was the most commonly represented disease, represented in 10 of the registries. The registries we identified receive funding from various sources, including academic institutions, government funds, and patient advocacy groups. We identified 11 registries used for postmarket surveillance of skin disease (Table II). Nine of these registries are for psoriasis patients treated with systemic therapy, while the others enroll patients with hereditary angioedema. Studies derived from registries offer some advantages and disadvantages compared to clinical trials (Table III).

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