

Use of Administrative Databases to Assess Reproductive Health Issues in Rheumatic Diseases



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KEYWORDS

- Administrative databases • Reproductive health • Rheumatic diseases
- Adverse pregnancy outcomes • Epidemiology

KEY POINTS

- Administrative databases used in epidemiologic research are large datasets collected as part of the billing and administrative components of clinical care that can be used to study health care delivery and outcomes.
- Administrative databases offer several advantages for the study of reproductive issues in women with rheumatic diseases: they provide large sample size to assess rare outcomes and/or exposures, provide population-based samples allowing generalizability of findings, and facilitate selection of control groups.
- However, several methodologic issues should be addressed when using administrative databases for the study of reproductive health outcomes, such as timing of pregnancy onset, mother-child linkage failure, incomplete capture of early fetal loss, and correlated observations.

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INTRODUCTION

Because of the relative infrequency of pregnancy in women with rheumatic diseases, collecting datasets of sufficient size with reliable data can be challenging. Administrative databases, registers, and other sources of big data can be interesting data sources to address important research questions on reproduction in women with rheumatic diseases. There are many different types of administrative datasets worldwide, and it is important to understand the type of data present and unavailable in each dataset, validity and potential misclassification of data, and the ability to link maternal data with infant data. This article discusses the advantages and methodologic issues associated with administrative database use for the conduct of observational studies on reproductive issues in women with rheumatic diseases.

ADMINISTRATIVE DATABASES

Administrative databases used in epidemiologic research are large datasets collected as part of the billing and administrative components of clinical care that can be used to study health care delivery and outcomes. The collection of these data is not primarily for research purposes. However, the increased availability of such data has fueled research by allowing for more rapid collection of data on subjects with rare diseases in sufficiently large numbers. Some administrative data sources (ie, population-based registers) are representative of a large population of individuals, unlike subjects who may voluntarily participate in a clinical cohort or subjects who are seen exclusively at tertiary care medical centers and must often provide informed consent to be included. Similarly, large numbers of control subjects can be identified within the dataset who may represent nondiseased individuals as comparators, whose data are collected in the same fashion as cases of interest. Additionally, as the data are generated at the time of the encounter, it is systematic and prospectively collected, without the inherent biases of recall of past exposures, or self-selection by volunteer status. Of course, differences in health care utilization may affect the appropriate selection of control populations. Similarly, confounding by indication may influence the extent of resources used based on the individual's underlying disease status. For example, a systemic lupus erythematosus (SLE) patient may be more likely to be hospitalized than a similarly aged healthy individual for a given set of symptoms.

CLAIM-BASED DATABASES

Because the United States does not have a nationwide health system or systematic capture of medical data, the ability to collect comprehensive medical data on a truly population-based cohort is necessarily limited. However, several datasets are available that may be relevant to research into pregnancy outcomes in rheumatic disease populations. Perhaps the most commonly used are administrative data based on medical claims, either by publicly funded insurers (eg, Medicaid) or private insurers (eg, MarketScan commercial databases). These data are quite valuable in that they often contain inpatient and outpatient visits listing diagnoses and procedures and prescription medication data linked to individuals. Unfortunately, because of the fragmentation of health care in the United States, individuals may not retain extended enrollment with any specific insurer, making long-term evaluation across multiple pregnancies more difficult. Numerous algorithms are currently used to maximize sensitivity and specificity of diagnoses made on claims data.^{1,2} Additionally, important variables may not be captured in claims data, including lifestyle variables (eg,

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