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Challenges in Building Disease-Based National Health Accounts

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Abstract

Background—Measuring spending on diseases is critical to assessing the value of medical care.

Objective—To review the current state of cost of illness (COI) estimation methods, identifying their strengths, limitations and uses. We briefly describe the current National Health Expenditure Accounts (NHEA), and then go on to discuss the addition of COI estimation to the NHEA.

Conclusion—Recommendations are made for future research aimed at identifying the best methods for developing and using disease-based national health accounts to optimize the information available to policymakers as they struggle with difficult resource allocation decisions.

Keywords

Cost of illness; cost allocation; productivity; efficiency; econometrics; health economics; cost-effectiveness; health care costs; medical expenditures; research design; national health accounts

Introduction

The substantial increase in the cost of medical care over the past half century has fueled intense debate over the value of medical care. Is it worth it for the United States to spend so much on health care? What could we do to increase the benefits of medical spending relative to the costs? These issues are central in the academic literature,[1-3] and in policy debates both in the U.S.[4,5] and abroad.[6-8] Yet, progress on these issues has been hampered by the lack of reliable information on the benefits of medical care relative to the costs, resulting in conflicting views of U.S. health care productivity. While some studies suggest that productivity growth has been reasonable in aggregate,[1,9] others indicate that there is substantial waste at the margin.[10-12]

To improve the value of care, interest has centered on revising the National Health Expenditure Accounts (NHEA) – the system which tracks U.S. health care spending – to more systematically measure the productivity of health care spending.[13,14] For policy purposes, the productivity (or value) of health care spending is measured by relating medical spending to health outcomes.

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This paper describes a framework for more systematically measuring productivity in health care via the creation of disease-based national health accounts, modeled on and existing alongside the NHEA. The disease accounts would provide a comprehensive picture of population health relative to health care spending (e.g., productivity) on a disease-by-disease basis. We focus herein on expenditures by disease – one important input to productivity assessment. We review the ongoing debate over cost of illness (COI) studies and the absence of methodological standards guiding their performance.[15-18] We close with recommendations for future research aimed at identifying the best methods for developing and using disease-based national health accounts.

National Health Expenditure Accounts

Aggregate data on medical spending have been compiled by the Office of the Actuary at the Centers for Medicare and Medicaid Statistics (CMS) since 1960.[19,20] The accounts track the flow of funds into and out of the health care system, providing detailed information on payer type (e.g. Medicare, private, out of pocket, etc.) and services purchased (e.g. hospital care, pharmaceuticals, etc.). Table 1 shows a typical table and its “sources and uses” matrix, with payers on one axis and services purchased on the other. The accounts, which are described in more detail by Heffler and Nuccio,[20] impose a specific set of accounting principles, ensuring that payers and services add up to the total.

The NHEAs contribute substantially to our understanding of medical spending. Yet they have limitations as well. Because they focus only on spending, the NHEAs provide no information on the value of health care spending, as they do not track the desired output of investment in health care – improved health. Indeed, these tabulations used to be termed National Health Accounts, but were recently renamed National Health Expenditure Accounts to reflect their focus on spending, not health per se. Further, the data are not necessarily at the right level of aggregation to measure value. To make these productivity calculations, one needs to understand spending at the same level as health outcomes, which are most naturally measured by disease. Thus, a central issue in expanding the NHEA is adding the more disaggregated (or micro) data needed to estimate disease costs.

Cost of Illness Studies

While the NHEAs measure aggregate spending, a separate literature has focused on measuring the costs of particular illnesses. Cost of illness (COI) studies quantify the economic impact of a disease and, together with prevalence, incidence, morbidity, and mortality, help portray the overall burden of disease in society. Segal provides a recent review of the COI literature.[21] The first analysis to distribute total personal medical spending by diagnosis was by Dorothy Rice in the early 1960s.[22,23] This was followed by a series of subsequent studies estimating disease costs in 1972 by Cooper and Rice,[24] 1975 by Berk and colleagues,[25] 1980 by Rice and colleagues,[26] and 1995 by Hodgson and Cohen.[27] Since the ongoing Medical Expenditure Panel Survey (MEPS) was started, COI studies have been more common, with papers reporting direct disease costs by Druss and colleagues for 1996,[28] Cohen and Krauss for 1997,[29] and Thorpe and colleagues for 2002.[30]

Cost-of-illness studies have been enormously influential. They have been used to compare the importance of different diseases, assist in the allocation of research dollars to specific diseases, provide a basis for policy and planning activities, and provide an economic framework for program evaluation.[31] The National Institutes of Health (NIH) have produced several summaries of cost of disease estimates (1995, 1997, and 2000),[32-34] and such estimates have been cited in Congressional testimony, official reports, and other publications.[35-37] Congress has even expressed interest in using COI estimates as a measure

for allocating research dollars among the NIH institutes[38] and Institute of Medicine panels have recommended their routine production.[39]

Cost-of-illness studies have their limitations too. Their methods and resultant cost estimates can vary substantially, provoking ongoing debate about their usefulness for policy purposes.[15-18] The debate, however, often obscures an important distinction between two types of cost of illness studies: 'disease-specific' studies, which measure the cost of a single disease, and 'general' studies, which allocate total spending to several diseases. The vast majority of COI studies are disease-specific, and it is to these studies that most COI methodological concerns refer.[15-18] Perhaps, the biggest issue in disease-specific studies is the adding-up constraint: it is not entirely clear what costs are associated with each disease, and how to ensure that all medical spending is allocated to one – and only one – disease.

Disease-Specific COI Studies

Disease-specific COI studies vary in a number of ways, in part because there is no standard COI methodology. Some studies produce prevalence-based (annual) COI estimates, while others produce incidence-based (lifetime) estimates.[40] Some studies include direct costs only, while others also include indirect costs, such as those related to lost productivity. Studies vary in their perspective, time horizon, use and rate of discounting, data sources, and underlying purpose. Frequently studies do not include all components of direct spending and may, therefore, underestimate COI. For instance, a COI study using Medicare claims data would miss patient out-of-pocket costs. At the same time, disease-specific studies risk double counting the costs of comorbidities and complications common to multiple diseases. If, for example, the costs of heart attacks are attributed to diabetes in one study, hypertension in another, and pre-existing coronary heart disease (CHD) in yet another, the combined cost of all diseases will be overestimated. Indeed, a systematic review of COI studies by Bernie Bloom and colleagues[16] found up to a 7-fold difference in estimated direct costs within a given disease. Further, the total median cost of the 80 diagnoses reviewed was more than twice the actual 1992 U.S. health care expenditures, and this ignored the majority of diseases for which there were no cost-of-illness estimates.

Over time, there have been calls for the development of standardized guidelines for performing and reporting COI studies,[15-18,41] analagous to those for cost-effectiveness analyses.[42] But standards can only go so far. In the case of the patient who has hypertension, diabetes, and a heart attack, to what condition should the heart attack be attributed? This is not a standardization question as much as it is a research motivation question.

General COI Studies

General COI studies allocate total expenditures for a population to a group of diseases. The methodology is usually top down: total costs for the health sector are used as the starting point and some fraction of the sector's costs are attributed to each of the diseases of interest.[21] The adding-up constraint makes general COI studies more methodologically sound *and* more readily aligned with the NHEA than are disease-specific studies.[15] Thus, we focus on general COI studies for the remainder of this paper.

General COI studies are not without limitations. As with the disease-specific studies, disease costs must be constrained to a national total to avoid double counting. General COI studies reduce (but do not preclude) this risk by creating disease groups that are usually mutually exclusive and exhaustive. Attribution issues in the setting of comorbidities remain a concern, though. If a person has diabetes and a prior MI, and is now taking an ACE inhibitor, to which condition should the costs of the ACE inhibitor be attributed?

The most common (though not exclusive) methodology for comorbidities is to assign each service to one condition, generally the **principal** diagnosis (in the example above, most likely the heart attack). However, this can result in substantial underestimation of costs for diseases that impact other conditions later on – for example, diabetes or hypertension.[43,44] Another issue common to both types of COI studies is how to separate out prevention and screening costs from treatment costs. One would not want to consider a mammogram for screening of breast cancer in the same bucket as chemotherapy for a diagnosed case. Both apply to the same disease, but they have very different implications for how to view medical spending.

Conceptual Framework for Disease-Based National Health Accounts

The full value of disease-based national health accounts lies in their potential to better inform the policy process than either the NHEA or COI studies alone. The NHEA capture comprehensive health expenditures, but their highly aggregated data (and lack of information on health) preclude many policy analyses. The more disaggregated national survey data include detailed information on expenditures *and* health. While they can support COI estimation and microsimulation modeling, the cost estimates may exceed national totals. Institutionalizing micro survey data within the macro NHEA framework allows side-by-side comparisons of health and spending, and ensures that expenditures are constrained to NHEA totals.[13] The combined analytic dataset builds on the strengths of each while addressing the weaknesses of the other.

The disease-based accounts would be a supplement, rather than a substitute, to the NHEA. The basic framework we envision would start with the NHEA sources and uses matrix, and add disease categories as a third dimension. This three-way matrix would support multiple potential tables: ‘total expenditures by disease,’ ‘payors by disease,’ and ‘services purchased by disease’ would likely be among the first. The accounts would allocate total personal health care expenditures to a mutually exclusive, exhaustive set of diseases. While tables would follow NHEA standards for classification and completeness, the dimensions of the tables would largely be dictated by data availability. Therefore, while it is not necessary to show every category of spending in a table, those categories that are shown must be distributed completely.

To proceed, what is needed is a methodologically rigorous, empirically feasible way of bringing the NHEA and COI studies together in a common framework. In this section, we describe three major steps required to attain this goal: 1) identification and reconciliation of individual level (or micro) data to NHEA, 2) choice of disease classification system, and 3) attribution of expenditures to diseases. Throughout, we comment on gaps in data, knowledge, or methodology that would benefit from additional research. Finally, we outline an agenda of future research aimed at improving the methodological rigor and policy impact of disease-based national health accounts.

Identification and Linkage of Micro Data to the NHEA

Disease-based health accounts require micro data on spending by particular individuals to tell what is spent for particular conditions. At the same time, the micro data need to add up to national spending totals. A central challenge for disease-based national health accounts is identifying individual level data of sufficiently broad scope for linkage to the NHEA. In the U.S., this has proven difficult. Several recent COI estimates have used AHRQ's Medical Expenditure Panel Survey.[28-30] However, MEPS underestimates national spending and requires adjustment if it is to match NHEA totals. In 2002, for example, national cost estimates from MEPS accounted for less than 70% of NHEA totals partly due to the MEPS

restriction to the non-institutionalized population.[45] The Medicare Current Beneficiary Survey (MCBS) collects data on institutionalized Medicare beneficiaries that could be used to supplement MEPS. However, there is no straightforward way to link these surveys.

Ongoing work by AHRQ and CMS has made great strides in reconciling MEPS data to the NHEA,[45,46] and additional ongoing work has focused on linking MEPS and MCBS data for reconciliation to the NHEA.[13] These data set linkages and reconciliations are still progressing, and should allow better estimates in the near future.

While survey data are appropriate for high prevalence illnesses such as diabetes and cardiovascular disease, for lower prevalence conditions (or subgroup analyses) the national surveys suffer from small sample size problems. For low prevalence conditions, additional data are required, often in the form of population- or disease-specific registries. Another option is to combine the power of claims databases (convenience samples) with the representativeness of household surveys (probability samples), weighting the claims data to match the representativeness of the household survey. Claims data have additional drawbacks, however, including their limited accessibility and relative expensive to obtain.

Selection of Disease Classification System

While the issue of disease categorization is important, it has received little attention in the literature. When we talk about the cost of diabetes, should we separate type I and type II diabetes, or combine them? Should we differentiate people with complications from those without, or leave everyone in one bucket? There is no firm rule about what strategy is best, and as a result, different classification systems take different approaches. Most systems use the International Classification of Diseases, 9th or 10th revision codes as the basis of their classification. However, the number of disease “buckets” they employ and the combination of codes mapping into a given disease vary significantly across systems.

The validity of disease classifications can be optimized, in part, by grouping diagnoses into homogeneous, mutually exclusive, exhaustive buckets. Ironically, the first level categorization of the ICD-9-CM (the most frequently used system in the U.S.) violates this rule. Of the 17 chapters in the ICD-9 manual, some represent organ systems (e.g., circulatory diseases or respiratory diseases), while others represent conditions that span multiple organ systems (e.g., infectious and parasitic diseases, neoplasms). One additional category is reserved for “symptoms, signs, and ill-defined conditions.” As a result, the chapters range from too broad to too narrow.

A more appropriate schema is AHRQ's Clinical Classification Software (CCS).[47] The CCS groups diseases with similar etiologies together, regardless of whether they cross organ system (and ICD-9 chapter) boundaries. This consistency, along with AHRQ's stewardship of the CCS (updated annually to capture the frequent changes to ICD-9 codes), make it an appealing instrument for standardization efforts. At the same time, though, use of the ICD-9 chapter structure as the foundation of many grouping systems has made mapping them to CCS challenging.[48]

A variety of commercial risk-adjustment tools (such as Episode Treatment Groups (ETGs), Medical Episode Groups (MEGs), and Diagnosis Cost Groups (DCGs)) have also been used as the basis for disease categorization schemas. To our knowledge, no comprehensive catalogue of these various schemas exists. But there have been two excellent recent reviews of many of these disease classification systems, one developed for clinical outcomes[48] and the other for risk adjusting costs.[49] Lu and colleagues compared seven grouping schemes – five for mortality and two for morbidity – and found limited comparability between them. The different schemes used different grouping logic, covered different ranges of codes, and

named some groups the same but defined them with entirely different diagnostic codes. Curiously, these divergent grouping schemes are the ones used to make most international mortality comparisons.[48] The second review, by the Society of Actuaries, made side-by-side comparisons of 12 risk-adjustment models, largely commercial products. The models varied markedly in the data fields used to define patient risk categories; some included age, sex, and/or secondary diagnoses, while others did not. Some included pharmacy and laboratory data, while others did not. The number of risk categories varied substantially, as did the proportion of expenditures that could be allocated to disease groups.[49]

Attribution of Expenditures to Diseases

Once the disease classification schema has been selected, the next step is to attribute spending to diseases. There are three distinct conceptual approaches to attributing medical costs to diseases, each with different implications for the unit of analysis The first approach is an 'encounter-based approach', estimating disease-specific spending by diagnoses listed on individual medical claims; the unit of analysis is the encounter (or claim). The second is an 'episode-based approach', estimating spending on all services considered to be involved in the diagnosis, management, and treatment of a specific condition. The unit of analysis is an episode, which may have variable lengths of time. The third is a 'person-based approach', identifying all conditions a person has and then using regression analysis to allocate total spending to particular diseases.

Encounter-based Approach

Most cost of illness studies take an 'encounter-based approach',[22-26,28-30] assigning claims to disease buckets based upon their coded diagnoses. Comorbidities are a major problem here; attributing each spending item for a patient who is both hypertensive and diabetic is not easy. The usual approach is to assign claims based on the primary diagnosis, but in practice this dilutes the apparent cost impact of many important risk factors. For example, if a person with diabetes, hypertension and CHD visits a doctor, to which disease should the costs be attributed? What if only coronary heart disease is listed on the encounter despite the fact that the diabetes likely contributed to the CHD? In the same vein, this method has difficulty accounting for downstream complications. If a person with diabetes has a heart attack several years later, is the subsequent spending a result of the diabetes or the heart attack? Most analyses would assign the downstream costs to the heart attack, which under-weights the future costs of diabetes.[43] These issues are particularly important in individuals with conditions like CHD, where multiple comorbid diseases are the norm, rather than the exception.

The principal advantage of the encounter-based approach is the ease with which costs are attributed to diseases. At the same time, though, a nontrivial portion of spending has no associated claims or valid diagnosis codes, such that these costs cannot be allocated to diseases. For example, many over-the-counter medications are not formally linked to a diagnosis. Finally, and perhaps most importantly, encounter-based COI estimates are not readily compared to health outcomes (which are measured at the person level), thereby hampering meaningful estimation of health care productivity.

Episode-based Approach

Increasingly, analysts are estimating disease costs using episode groupers – software programs with algorithms that organize claims data into clinically distinct episodes of care. A treatment episode can be thought of as "a series of temporally contiguous health care services related to the treatment of a given spell of illness or provided in response to a specific request by the patient or other relevant entity."[50] Episodes are natural to examine

because they group related claims regardless of which specific diagnosis is coded on the claim.

Still, episode-based disease costing faces a number of challenges. A central issue is how to identify the start and end point of an episode of treatment, and how to identify the groups of specific services and costs relating to a particular episode of care.[51-54] Episode groupers differ in how they do this, with no clear consensus on best practice. Comorbidity and joint cost issues are problematic as well, just as they are in the encounter approach. Other challenges include how to handle chronic disease episodes (length is often set arbitrarily at one year), what to do with complications of treatment (assign to a new episode or an old one), and how to handle medical treatments that do not fall neatly into a disease category (such as a screening study). Finally, while a number of different commercial episode groupers are already widely in use, they have received little scientific evaluation to date,[55] and the small but growing body of research by CMS[56] and others[57] points to very real differences in the output of different vendors' groupers. Pending further evaluation and standardization, it will be difficult to use these proprietary algorithms for public work.

Person-based Approach

The final approach to cost estimation is the ‘person-based approach.’ In this approach, a person's total annual health care spending is regressed on indicators for the set of conditions a person has. The coefficient on the disease dummy variable is the average cost of that condition, controlling for the other conditions the person has (i.e. the incremental additional cost of the disease).

The person-based approach is designed to produce more valid estimates for patients with multiple chronic conditions, as it better captures expenditures for comorbidities and complications. That said, the regression specification is sensitive to how comorbidities are entered. A standard linear regression may not be right, since it imposes additivity of joint conditions. However, if one condition increases (or decreases) the costs of another, adjustment is needed to ensure that condition-specific spending does not sum to more (or less) than the total.[58] Another empirical issue is what interaction terms to include. For the most part, clinical expertise is needed to identify the appropriate group(s) of co-occurring diseases, which may represent a limitation for policy purposes.

An advantage of person-based cost estimation is that the costs of utilization events for which there are no valid claims or ICD-9 codes can still be attributed. Another attractive conceptual feature of person-based cost estimates is that they can be readily matched to health outcomes, such as mortality and quality of life, thereby providing the critical link between spending and health needed to more systematically measure value.

Which Approach is Best?

Conceptually, there is no ‘best’ method for allocating expenditures to disease groups. Rather, the most appropriate method will be contextual, depending largely on the question at hand and the target audience. For example, if the goal is to compare costs and health effects within a given disease, as is done in cost-effectiveness analyses, a person-based approach is likely best. In contrast, if price index construction is the goal, federal agencies may find an episode of treatment approach more meaningful. For evaluating changes in acute care spending patterns, though, real-time answers may only be possible with an encounter-based approach. In the long-term, what is needed is more empirical work to compare different approaches and to determine more definitively which is best under particular conditions.[57]

Discussion

Timely, reliable and complete information on medical spending relative to health is critical for sound policy making and planning. As calls for health care cost containment escalate, the need for such data has never been more apparent. We describe one option – the development of disease-based national health accounts – for systematically developing this knowledge base.

A number of methodological challenges will arise in implementing disease-based health accounts. We focus herein on three major steps: linking micro spending data with macro totals; determining a set of diseases for which costs can be measured; and allocating spending to particular conditions. Each of these steps involves conceptual as well as applied questions. Further, while some immediate ways to make progress exist, the difficult and longer term issues of data availability and reliability (while not discussed in detail here) will be central to the success of these efforts.

While additional research on disease-based medical spending is an important step in forming disease-based accounts, it is not the only step. Future research will need to address non-medical inputs to health (such as education and the environment), indirect costs of care (such as lost productivity, and caregiver costs), and measurement of population health.

Along these lines, it is important to note that existing national accounts, such as the National Income and Product Accounts, are not static. New measures of inflation are introduced, adjustments for changes in quality are developed, and so on. The key to the accounts is not that they are perfect, but rather that they have a coherent organizing structure that guides ongoing refinements. We envision the type of cost assessment we propose as a first step towards this broader agenda.

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Table 1

National Health Expenditures, 2006 (billions of dollars)

		Private					Public		
			Consumer						
Type of Expenditure	**Total**	**All**	**Total**	**Out-of-pocket**	**Private Insurance**	**Other**	**Total**	**Federal**	**State/Local**
Total	$2,106	$1,135	$980	$257	$723	$155	$970	$705	$265
Services and supplies	1,966	1054	980	256	723	74	912	664	248
Personal health care	1,762	964	891	257	637	73	798	618	180
Hospital	648	286	256	21	235	29	363	290	72
Professional services	660	426	388	102	287	38	234	176	58
Physician and clinical	448	295	266	46	220	29	153	126	27
Other professional	60	40	37	15	22	3	19	15	5
Dental	92	86	86	41	45	0	6	3	2
Other pers. health care	62	6	---	---	---	6	56	32	24
Nursing home & home health	178	60	54	39	15	6	118	84	34
Home health	53	13	12	6	6	1	40	30	10
Nursing home	125	47	42	33	9	5	78	54	24
Medical products	276	193	193	94	97	---	84	68	16
Prescription drugs	217	143	143	48	95	---	74	58	15
Other medical products	59	50	50	47	3	---	10	9	0
Durable equipment	24	16	16	13	3	---	8	7	0
Other non-durable	36	33	33	33	---	---	2	2	---
Administration	145	90	89	---	89	1	55	37	19
Public health	59	---	---	---	---	---	59	10	49
Investment	139	81	---	---	---	81	58	41	18
Research	42	4	---	---	---	4	38	33	5
Structures & equipment	98	77	---	---	---	77	20	8	13

Source: Centers for Medicare & Medicaid Services, Office of the Actuary: Data from the National Health Expenditure Accounts, 2006.