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Clinical and economic features of categories of patients in defined populations

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- Rådd-djur! Kom hit ett slag med en knapp!

- Varsågod bara!
Ska det vara med två eller fyra hål?
Ben, plysch, trä, glas, metall eller pärlemor?
Enfärgade, brokiga, prickiga, randiga eller rutiga?
Runda, konkava, konvexa, platta, åttkantiga eller …

Ur Muminpappans memoarer
av Tove Jansson (1980).

Abstract

This thesis addresses the use of information from health care registers on an individual level, making it possible to elucidate the morbidity and comorbidity patterns in defined populations, and to allocate resources in primary health care (PHC) on this basis.

Study I aimed at assessing the annual direct and indirect costs of skin diseases caused by ultraviolet radiation. This cost-of-illness analysis used data on individual patients in one county council. Direct health care costs for diagnosing, treatment and secondary prevention as well as indirect costs caused by morbidity and mortality were calculated. The total annual cost-of-illness for skin diseases caused by ultraviolet radiation exposure in Stockholm in 1999 was approximately 162.4 MSEK. The indirect costs were about 56% of total costs.

In study II, patients utilising PHC in one municipality in Sweden were categorised into 81 groups. Grouping was done by the Johns Hopkins Adjusted Clinical Groups® (ACG) system. Data from two years were used retrospectively and the results were compared with data from other PHC centres in Sweden. The ACG instrument seemed to be a relevant tool for describing the outcome of work done by the PHC centre.

Study III was a one-year retrospective study based on encounters at publicly managed PHC centres in one county council in Sweden. The objective was to elucidate types of morbidity and categories of patients in terms of the ACGs in a large population. Types of morbidity in PHC seemed to be dominated by nearly equal proportions of 'Time limited', 'Likely to recur', 'Chronic' and 'Signs/Symptoms'. About one third of the patients had a constellation of two or more types of morbidity during a one-year period.

Study IV was a three-year retrospective study based on encounter data from the same centres as in study III. The objective was to monitor the proportion of residents encountering PHC, and to elucidate longitudinal variations in patterns of morbidity in terms of the ACGs. About three fourths of the population had a diagnosis-registered encounter with a general practitioner, and the number of patients encountering a general practitioner was estimated at about 90% of all county residents during the three-year period. The morbidity pattern was stable over the three years on both county and PHC centre levels.

Study V was a cross-sectional observational study where relative weights in terms of the ACGs were calculated to estimate the need for resources for each patient category, and these weights were applied to patients at a PHC centre. About 40% of the variation in patient costs was explained by the ACG weights, and about 10% was attributable to age and gender.

The studies illustrate that the retrieval of clinical data on an individual level can be used for grouping of patients on various levels. The limitations of the studies are mainly related to the quality of data registration.

In conclusion, this thesis illustrates that data on an individual level can be used for both clinical and economic purposes, either for describing characteristics of specific diseases, or for elucidating patients belonging to groups of combined types of morbidity. Patient based comorbidity categories yield a new view of the burden of morbidity in defined populations that provides the basis for further analysis of groups of patients.

Key words: ACG (Adjusted Clinical Groups), case-mix, comorbidity, cost-of-illness, health care register, patient classification, primary care, skin cancer, type of morbidity.

List of publications

I. Nilsson GH, Carlsson L, Dal H, Ullén H.
Skin diseases caused by ultraviolet radiation: the cost of illness.
International Journal of Technology Assessment in Health Care 2003;19:724-730.

II. Carlsson L, Börjesson U, Edgren L.
Patient based 'burden-of-illness' in Swedish primary health care. Applying the Johns Hopkins ACG Case-mix System in a retrospective study of electronic patient records.
International Journal of Health Planning and Management 2002;17:269-282.

III. Carlsson L, Strender L-E, Fridh G, Nilsson G.
Types of morbidity and categories of patients in a Swedish county. Applying the Johns Hopkins Adjusted Clinical Groups System to encounter data in primary health care.
Scandinavian Journal of Primary Health Care 2004;22:174-179.

IV. Carlsson L, Strender L-E, Fridh G, Nilsson GH.
Clinical categories of patients and encounter rates in primary health care – a three-year study in defined populations.
Submitted manuscript.

V. Engström SG, Carlsson L, Östgren C-J, Nilsson GH, Borgquist, LA.
The importance of comorbidity in analysing patient costs in Swedish primary care.
Submitted manuscript.

Contents

List of abbreviations

ACG	Adjusted Clinical Groups
ADG	Aggregated Diagnosis Groups
BCC	Basal cell carcinoma
CMM	Cutaneous malignant melanoma
CNI	Care Need Index
EPR	Electronic patient record
GP	General practitioner
ICD	International statistical classification of diseases and related health problems
PHC	Primary health care
UVR	Ultraviolet radiation
WHO	World Health Organisation

Introduction

This thesis focuses on groups of patients and possibilities for elucidating the clinical as well as the economic burden of illness in defined populations. The studies in this thesis use clinical data on an individual level to measure the societal cost for specific diseases and to describe categories of patients with various types of morbidity and comorbidity. The principal methodologies used in the five studies are classification of diseases, case-mix analysis, data retrieval and health economics, and the disciplines involved are Health Economics and Public Health Sciences.

Classification and case-mix systems

Decision-makers in health care are often troubled by deficient information and a lack of data for describing, measuring and assessing their own activities (Andreasson 1995). There are many reasons for this lack of adequate and reliable measures and methods of measurement in the health care sector.

One factor concerns how classification and grouping of activities are carried out. An initial grouping of activities is usually done from an administrative perspective and comprises a division into inpatient and outpatient care. An organisational grouping according to degree of specialisation is also common in primary, county, regional and national health care. Classification of individual patients is usually done from a disease perspective, based on diagnoses and using the classifications of diseases recommended by the World Health Organisation (WHO). To a great extent, the organisational structure of hospitals world-wide can be explained by the chapters in the international classification of diseases.

Existing classification methods

Classification has two different meanings that must be differentiated (van Bemmel 1997). First, there is the act of classifying defined as 'the coding of a description of an object by using codes or terms that are designators of the concept in a classification' (van Bemmel 1997). This is related to activities needed to assign an individual case to the right class and produce the right code in an efficient and reliable way. Secondly, there is the process of designing a classification, the coding. Coding is used to abstract patient data, and to support coding of detailed clinical patient data in the care of an individual patient (Cimino 1996).

The formal representation of diseases and health problems is in itself a complex chore (Cimino 1998), and there is ambiguity with respect to heterogeneous concepts such as location, symptoms, aetiology, syndrome, lesion, function, and process (Campbell 1979). Further, diseases and health problems are somewhat subjective descriptions of state of health and may or may not include certain symptoms or signs. The World Health Organisation (WHO) classification, the International Statistical

Classification of Diseases and Related Health Problems (ICD), is an example of a generally applied classification system with the aim of facilitating statistical compilations and syntheses of diseases and health problems (WHO 1993, WHO 1997).

In the area of primary health care (PHC), classifications varying somewhat from one another, depending primarily on whether the main emphasis is on symptoms and the reason for the visit or on an attempt to determine a definite diagnosis, have been discussed internationally. One of these is the International Classification of Primary Care (ICPC), which is directed at PHC and emphasises symptoms and reasons for contacts (Lamberts 1987). Developmental work in the area is continually ongoing in different international associations such as the European Federation of Classification Centres (EFCC). The Nordic Medico Statistical Committee (NOMESCO) is active in Scandinavia, and developmental work is underway in various WHO Collaborating Centres. In the UK and the US a common product, the Systematized Nomenclature of Medicine (SNOMED-CT®), has been developed (Price 2000).

Need for need-oriented perspectives

The above classification perspectives tend to result in a production-oriented view regarding activities performed, which is not in accord with the intentions of the latest health care legislation in Sweden. Instead, this legislation emphasises care on equal terms and the so-called principle of needs in the context of prioritisation (SOU 1995). The aspiration in many county councils in Sweden is to move increasingly away from supply-governed care and toward need-governed activities.

It is therefore of interest to use perspectives other than those focusing on diseases in terms of diagnoses as complements in identifying, describing and measuring results obtained in the health care sector (Starrin 1991, Svensson 1993, Starrin 1994). A point of departure can be the individual patient's perspective. With this approach, changes over time in individuals' state of health can be followed and expressed in a way that better elucidates the basic objectives of health care (Conrad 1987, Starfield 1992, Holmström 1993, Carlsson 1996).

The different classifications constitute the basis for the next step, i.e. grouping into meaningful categories, where the aim of the grouping can vary greatly. The international term for this is 'case-mix' (Hornbrook 1985). A case-mix system classifies cases into clinical groups that are similar in terms of certain characteristics. The cases can be patients, contacts, episodes or visits. The characteristics may be diagnosis, procedure, severity, need for resources, and capacity to benefit. Different case-mix systems have been constructed to handle different tasks – planning, prevention, describing the content, resource allocation, and cost reimbursement. No single system is applicable to every function (Hutchinson 1991).

Today, most case-mix systems utilised internationally use diagnosis or procedure measures as the basis for building different groups (Hornbrook 1985, Fischer 1997).

Even case-mix systems that contain the term ‘patient’ in their name are often built up according to episodes of care, and not primarily with the patient as the subject for grouping (Holmström 1993, Fischer 1997).

Groups of patients are in focus in this thesis, and the idea is to show that interesting patterns of morbidity and comorbidity will be visible when allotting patients into various groups depending on each patient’s constellation of different types of morbidity. Interest in the burden of diseases, so far with a focus on the spread of either one diagnosis or a group of diagnoses associated with the same disease, will then shift to interest in a homogenous group of patients with the same constellation of various diseases, and thus develop from the burden of diseases in a geographic area to the burden of illness in a defined population.

The burden of illness in defined populations is of interest in many respects, and will be elaborated upon in this thesis from two perspectives: the economic perspective, where the need for resources of various kinds and the costs of these resources are the focus; and the clinical perspective, where the contents and quality of health care and the mix of various categories of patients are featured.

Economic burden of illness

In managed care settings the need for resources to care for groups of patients is of utmost interest (Diderichsen 1997). In the planning phase, results from cost analyses must be used to determine what kinds of resources are needed for what patients and by what organisations of caregivers. These analyses can be of various types, depending on the aim of the study and the intended use of the results.

In the area of disease management, an economic evaluation of the consequences of diseases comprises a full analysis of all costs generated, where the calculations of these costs are dependent on a variety of probabilities. Cost-of-illness studies could then be useful in providing a view of the scope and the magnitude of the disease, and sensitivity analyses will shed more light on the prerequisites for the calculations (Gold 1996, Drummond 1997).

In the area of public health oriented health care, the distribution of resources to various caregivers comes into focus in order to provide health services to a defined population as efficiently as possible (Malmström 1998). So far, most cost data have been for diseases or diagnoses and procedures. Knowing the costs of groups of patients will come increasingly into focus in the management of PHC. Trials on patient-level clinical costing at hospitals in Sweden have been performed, but the first trial on patient-level costing in PHC was reported only recently (Landstingsförbundet 2003).

Ultraviolet radiation and skin disease

Exposure to ultraviolet radiation (UVR), both from the sun and from artificial devices, is a well-known aetiological factor in various types of skin diseases. The two most common malignant tumours of the skin are cutaneous malignant melanoma (CMM) and basal cell carcinoma (BCC). They have been among the most rapidly increasing malignant tumours in Sweden over the past 20-year period (Rigel 1996, Thorn 1998, Epidemiologiskt Centrum 2001). In the first year of this millennium the incidence of CMM in Sweden was estimated at 18.1 cases per 100,000 population per year and it was increasing by about 2.4% annually. The incidence of BCC in Sweden was increasing much more, by about 12% annually, although this disease has a much lower morbidity and mortality (WHO 1994, Altmeyer 1997, Wallberg 1991, Epidemiologiskt Centrum 2001). The other diseases caused by UVR are cutaneous squamous cell carcinoma of the skin, melanoma in situ, cancer in situ in skin, actinic keratosis, and melanocytic nevi.

The steady increase in the incidence of these diseases and the well-known aetiology emphasise the importance of prevention (MacKie 1992). Cost reduction strategies in health care include efforts to enhance both primary prevention, i.e. reduction of UVR exposure, and secondary prevention, mainly by early detection (Tsao 1998). An increased survival from CMM that is most likely attributable to early detection has been reported (Berwick 1996).

Allocation of resources to groups of patients in PHC

The burden of illness in a population has to be measured and analysed with accurate methods to enable the allocation of resources in an efficient and equitable way. In the planning process in health care, the idea is for resource allocation to correspond to the health care needs of the population. This distribution of resources is particularly important with respect to the funding of PHC centres, as there is greater variation in terms of need between localities than between regions or counties (Diderichsen 1997). Determinants of health care utilisation and health care costs are of great interest in this context, and a number of factors have been identified in empirical investigations (Campbell 1996). In a study from Canada, age and gender were found to explain only 5-9% of the variation in health care expenditures (Reid 1999a). The influence of morbidity and of socio-economic factors has also been investigated. Further, studies have shown substantial variation in hospital admission rates among general practitioners (GPs) due to socio-demographic patient factors associated with deprivation (Reid 1999b, Majeed 2000).

In countries with a national health care system, where public authorities are responsible for health care provision in regions and smaller areas, interest has focused on demographic and socio-economic determinants of health care needs. In this regard, the Underprivileged Area score (UPA), or the Jarman index, was developed in the UK (Jarman 1983). The index has been adapted to Swedish conditions, with weightings obtained from a random sample survey of GPs in Sweden, and renamed the Care Need Index (CNI) (Malmström 1998).

The localities used in CNI scoring are the Swedish Small Area Market Statistics (SAMS) owned by Statistics Sweden. Such small areas contain on average 1000 inhabitants. Ecological studies have established that the CNI correlates well with psychiatric morbidity, self-reported poor health, cardiovascular risk factors, mortality and obesity (Malmström 1999a and 1999b, Sundquist 1999).

In most county councils in Sweden the resource allocation system within PHC has been based on capitation schemes where age and gender have been the main criteria, with the addition of a few socio-economic factors. One example is the Stockholm County Council, where a 'need index' has been developed that takes age, gender and five socio-economic factors into account. This index has also been further developed by the use of drugs as an indicator for specific need among the population in a defined geographic area.

In countries with a health care system primarily based on individual health insurance, interest has focused on measures based on individual patients' characteristics. In the US, several instruments have been developed to compensate for differences in case-mix and to adjust for differences in risk (Reid 1999). In recent decades a number of case-mix systems have been developed for use as instruments for allocating resources, not the least of which is the world-wide Diagnosis Related Groups (DRG) system, where development and adaptation involved Nordic collaboration (Fetter 1980, Aas 1985). In outpatient care forms, actual development of reimbursement systems in the Nordic countries as well as internationally has otherwise been limited to hospital-based care and has been based on procedures and actions that have been carried out (Holmström 1993, Rigby 1993, Fischer 1997).

One case-mix system, developed at the School of Hygiene and Public Health at Johns Hopkins University in the US to meet the need in an ambulatory care setting, is the Adjusted Clinical Groups® (ACG) system, which assigns patients to morbidity categories based on expected resource requirements for the health situation of that category of patients (Starfield 1991, Weiner 1991). The grouping algorithm enables each diagnosis to be classified as one out of 32 types of morbidity (Aggregated Diagnosis Groups), depending on five combined criteria: i) likely persistence of the condition, ii) grade of severity, iii) aetiology, iv) diagnostic certainty, and v) need for speciality care. Thus each ACG is used as an estimate for a group of patients with the same constellation of morbidities, thereby indicating the need for resources to take care of each category of patients. The system has been designed to predict the need for resources by defined populations and is of particular relevance for studying the health of populations (Hutchinson 1991). The objective of the ACG system is to show the burden of morbidity in a population as a basis for allocating resources (Majeed 2001, Reid 2001, Reid 2003). A more thorough description of the ACG system will be given below under the subheading 'The ACG case-mix system'.

The ability of the ACG system to measure individual comorbidity and the burden of illness in a population is of special interest from a PHC perspective, since a GP cares for a number of individual patients who often suffer from several diseases, all of which are normally treated by the GP. Data on each individual patient in terms of both costs and diagnoses were available at the PHC centre involved in the patient-level costing mentioned above. These prerequisites made it possible to apply the allocation feature of the ACG system in a PHC setting. Thus, for the first time relative weights among groups of categories of patients could be developed on the basis of cost data from Sweden.

Clinical burden of illness

The literature dealing with classification and grouping of the content of activities in health care is frequently based on a production-oriented view, with the hospital and inpatient care as reference. This is the case for the Anglo Saxon (Fetter 1980, Hornbrook 1982, National Casemix Office 1993, Hutchinson 1991) as well as the French (Trombert-Paviot 1997) and the German (Fischer 1997, Fischer 1999) language groups, and the Nordic countries are no exception (Aas 1985, Solstad 1991, Mo 1993). Hospital care establishes the norms, because hospital inpatient and ambulatory care constitute the largest proportion of total costs for health care. Consequently, the models and systems that have been developed have usually been based on hospital care and have thereafter been adapted to other branches of care. Descriptive models based on the distinctive character of less comprehensive areas of care have therefore not been developed at the same pace or with corresponding resources (Rigby 1993, McNamee 1993, Carlsson 1993, Rodrigues 1998, Hofdijk 1998).

In 1999 a national plan of action for development of health care in Sweden was proposed, with special emphasis on PHC and on finding a new system for classifying patients in addition to the present grouping based on diagnoses. According to the directives, this system was to be based on information at the individual patient level and was to describe care processes and activities as well as their outcomes (Proposition 1999/2000).

Need for individual-oriented grouping systems

The primary classification schemes are the basis for a secondary classification, or grouping, by a case-mix system. A review of secondary patient classification systems available in health care shows that the focus of the systems often is on the medical diagnosis or on treatment measures (Hornbrook 1982, Fischer 1997, Hofdijk 1998). The case-mix systems have mainly been characterised by a clinical view in which the disease condition of the patient is described. For the most part the differences concern which factors should be placed above the others in terms of importance, where sex, age, location, morphology and aetiology compete in terms of rank. In certain cases, the course of illness and descriptions of stages in a disease condition have also been included (Fischer 1997).

Coding and classification have so far mainly been used to produce statistical compilations with the focus on a clinical perspective (Socialstyrelsen 1997). The interest in clinical burden of illness in this thesis is in case-mix systems aimed at describing the results of work in PHC in a way that elucidates the primary work in this area, i.e. working on the individual patient's problems with a holistic approach and a public health-oriented view (Carlsson 1993, Åhgren 1997, Arnlind 1997).

Awareness of the need to develop measures of individual health conditions has gradually emerged (Williams 1999, Williams 2000, Murray 2000). Development of a more patient-oriented view as a complement to the epidemiological base has come about as a result of the fact that each patient often has several different diagnoses at the same time. In this connection it is of interest to note historical developments in medicine. The move toward increased specialisation and subspecialisation has decreased the profession's possibilities of having a holistic view of the patient. In the early 20th century, generalists of the time saw a risk that doctors with specialist training would only be able to concentrate on one diagnosis at a time, or only examine isolated parts of the patient's body at a time. It was thereby feared that a whole delegation of doctors would have to be summoned for a home visit (Reiser 1978).

The ACG case-mix system

In order to describe and analyse the burden of morbidity in a population, the morbidity and comorbidity status of each patient need to be measured, as well as the mix of groups of patients in a defined area. Case-mix analyses might thus show groups of patients defined by their morbidity status. The Adjusted Clinical Groups® case-mix system is the only instrument that comes close to using the patient as the subject for grouping, as patients are grouped along with their health status (Holmström 1993, Arnlind 1997).

The ACG system differs from most of the other case-mix measures in that it uses the patient as the subject for grouping (Starfield 1991, Weiner 1991). Assignment to each group is based on the health condition of each patient defined by all diagnoses registered regarding each patient during a period of time. The ACG system connects diagnoses in such a way that the health condition defined is not just the addition of the different diagnoses, but is instead a systematic combination of various types of morbidity that are used to construct groups of comorbidity conditions. The original hypothesis behind the ACG grouping was that diseases are not randomly distributed in a population. Instead, they tend to cluster in typical patterns. Patients using the most healthcare resources are not those with single diseases, but rather patients with multiple and sometimes seemingly unrelated conditions. This clustering of morbidity has turned out to be a better predictor of health services than the presence of specific diseases (Starfield 1991). Originally, the categories were based on data within the ambulatory care setting, but the system has been further developed in order to contain data from any provider of health care.

Unlike other case-mix systems, no information is included regarding procedures, actions taken or frequency of visits. The ACG categories are based on all diagnosis codes in the EPRs during a predetermined period of time in order to capture the complete picture of the condition of each patient. The main idea of the grouping is to build categories of patients that reflect the future need for resource consumption within health care.

The grouping of individuals in the ACG system uses data on individuals from a period of time, generally one year. Four items are needed: a personal identity number, the age and the sex of the person, and, if the person is a registered patient, a code for the patient's diagnosis.

The first step in the grouping procedure is to transfer each diagnosis code into one of 32 different groups of types of morbidity defined as Aggregated Diagnosis Groups (ADGs). This assigning is based on the character of the diagnosis in five dimensions simultaneously, namely duration, severity and aetiology of the condition, diagnostic certainty, and expected need for speciality care. The criteria for the five dimensions are listed in Figure 1.

Fig. 1. Criteria for grouping into Aggregated Diagnosis Groups (ADGs)

Duration of the condition (*'acute', 'recurrent' or 'chronic')* – How long will healthcare resources be required for the management of this condition?

Severity of the condition (e.g.*'minor and stable' versus 'major and unstable'*) – How intensely must healthcare resources be applied to manage the condition?

Diagnostic certainty (*'symptoms' versus 'documented disease')* – Will a diagnostic evaluation be needed or will sevices for treatment be the primary focus?

Aetiology of the condition (*'infectious', 'injury' or other*) – What types of healthcare services will likely be used?

Speciality care involvement ('*medical', 'surgical', 'obstetric', 'heamatolgy', etc)* – To what degree will speciality care services be required?

Thus each group of ADGs is a large cluster of diagnoses that are homogenous with respect to these criteria. In Table 1 some examples of which diagnoses are assigned to which type of morbidity are shown for all of the 32 ADGs. In some cases the examples are chosen to highlight the fact that different diseases can be assigned to the same type of morbidity depending on their similar condition in terms of need for health care resources.

Table 1. Example of ICD-10 codes assigned to the Aggregated Diagnosis Groups (ADGs)

ADG #	Description	ICD-10 code and term (Swedish PHC version)
1	Time Limited: Minor	H00- Stye
		M771P Epicondylitis
2	Time Limited: Minor-Primary Infections	B06- Rubella
		J11-P Influenza
3	Time Limited: Major	H33- Ablatio retinae
		L89- Ulcus decubital
4	Time Limited: Major-Primary Infections	J36- Peritonsillitis
		M86- Osteomyelitis
5	Allergies	J304P Allergic rhinitis
6	Asthma	J45-P Asthma
7	Likely to Recur: Discrete	M10- Podagra
8	Likely to Recur: Discrete-Infections	J310 Chronic rhinitis
9	Likely to Recur: Progressive	I64- Acute cerebral infarct
10	Chronic Medical: Stable	N40- Hyperplasia
		E119 Non-insulin-dependent diabetes w/o complic.
11	Chronic Medical: Unstable	N19-P Uraemia
		E108P Insulin-dependent diabetes w complic.
12	Chronic Speciality: Stable-Orthopaedic	M47- Spondylosis
13	Chronic Speciality: Stable-Ear,Nose,Throat	J380 Vocal cord paresis
14	Chronic Speciality: Stable-Eye	H40-P Glaucoma
15	No Longer in Use	- -
16	Chronic Speciality: Unstable-Orthopaedic	M929P Juvenile osteochondritis
17	Chronic Speciality: Unstable-Ear,Nose,Throat	H810 Ménière's disease
18	Chronic Speciality: Unstable-Eye	H20- Iritis
19	No Longer in Use	- -
20	Dermatologic	L570 Actinic keratosis
21	Injuries/Adverse Effects: Minor	L270P Drug exanthem
		S420 Clavical fracture
22	Injuries/Adverse Effects: Major	S430 Shoulder luxation
		F19-P Drug addiction
23	Psychosocial: Time Limited, Minor	F51- Sleeping disorder
		R48- Dyslexia
24	Psychosocial:Recurrent or Persistent,Stable	F79-P Mental retardation
		G442 Tension headache
25	Psychosocial: Recurrent or Persistent,Unstable	F20- Schizophrenia
		R410 Confusion
26	Signs/Symptoms: Minor	L80- Vitiligo
		R12- Pyrosis
27	Signs/Symptoms: Uncertain	D64-P Anaemia
		M51- Slipped disc
		R53- Asthenia

28	Signs/Symptoms: Major	D69- Purpura J90-P Pleuritis R55- Blackout
29	Discretionary	J33- Adenoids L84- Corn N600 Mammarcyst
30	See and Reassure	N841 Cervixpolypus K14- Disease of the tongue R002 Palpitation
31	Prevention/Administrative	Z000 Medical exam Z27-P Vaccination
32	Malignancy	C50- Breast cancer C64-P Renal cancer
33	Pregnancy	O32-P Foetal displacement
34	Dental	K05- Paradontitis

The second step in the grouping process is to collapse the ADGs to a manageable number of ADG combinations. The 32 ADGs are assigned to 12 Collapsed ADGs (CADGs). In this process three clinical criteria are used, namely i) the likelihood of the time limit of the condition, ii) the severity of the condition and iii) types of health services required for patient management of the type of morbidity. As an example, the four types of morbidity, ADG #1 (Time limited, minor), ADG #2 (Time limited, minor-primary infections), ADG #21 (Injuries/Adverse effects, minor) and ADG #26 (Signs/Symptoms, minor) are collapsed into CAGD #1 (Acute minor). Another example is that ADG #10 (Chronic medical, stable) and ADG #30 (See and reassure) are collapsed into CADG #6 (Chronic medical, stable).

The third step in the grouping process starts the allotment of patients into categories. The CADGs and the combination of CADGs are assigned to 26 Major Ambulatory Categories (MACs). The first eleven CADGs correspond to the first MACs; from MAC #1 to MAC #11. MAC # 12 includes all pregnancies. MAC #13 to MAC #18 are different types of combinations of two CADGs, MAC #19 to MAC #21 combine three CADGs, and MAC #22 and MAC #23 combine four different CADGs. MAC #24 includes all other combinations of CADGs. One MAC (#25) is designed for patients with no registered diagnosis, and the last MAC (#26) includes every infant less than one year of age, regardless of which CADG is involved.

The fourth and last step in the grouping process is allotting each patient into one out of the 82 ACGs. Each patient is placed in just one ACG, starting with the MACs and in some cases also depending on the age and/or sex of the patient. When the patient is assigned to MAC #24 with many ADGs involved, the allotment rules are dependent on the numbers of ADGs, sometimes the types of ADGs, and even here sometimes the age and gender of the patient. In Table 2 all ACGs are displayed.

Table 2. Adjusted Clinical Groups (ACGs) (version #6.0)

0100 Acute Minor, Age 1
0200 Acute Minor, Age 2–5
0300 Acute Minor, Age 6+
0400 Acute: Major
0500 Likely to Recur, without Allergies
0600 Likely to Recur, with Allergies
0700 Asthma
0800 Chronic Medical, Unstable
0900 Chronic Medical, Stable
1000 Chronic Speciality
1100 Ophthalmological/Dental
1200 Chronic Speciality, Unstable
1300 Psychosocial, without Psychosocial Unstable
1400 Psychosocial, with Unstable, without Stable
1500 Psychosocial, with Unstable and Stable
1600 Preventive/Administrative
1710 Pregnancy: 0–1 ADGs
1720 Pregnancy: 2–3 ADGs, No Major ADGs
1730 Pregnancy: 2–3 ADGs, 1+ Major ADGs
1740 Pregnancy: 4–5 ADGs, No Major ADGs
1750 Pregnancy: 4–5 ADGs, 1+ Major ADGs
1760 Pregnancy: 6+ ADGs, No Major ADGs
1770 Pregnancy: 6+ ADGs, 1+ Major ADGs
1800 Acute Minor and Acute Major
1900 Acute Minor and Likely To Recur, Age 1
2000 . . . , Age 2–5
2100 . . . , Age>5, w/out Allergy
2200 . . . , Age>5, with Allergy
2300 Acute Minor and Chronic Medical: Stable
2400 Acute Minor and Eye/Dental
2500 Acute Minor, Psychosocial, Without Unstable
2600 . . . , Unstable without Stable
2700 . . . , with Unstable and Stable
2800 Acute Major and likely To Recur
2900 Acute Minor and Major/Likely to Recur, Age 1
3000 . . . , Age 2–5
3100 . . . , Age 6–11
3200 . . . , Age>12, w/out Allergies
3300 . . . , Age>12, with Allergies
3400 Acute Minor/Likely To Recur/Eye and Dental
3500 Acute Minor/Likely To Recur/ Psychosocial
3600 Acute Minor/Major/Likely to Recur/Chronic Med: Stable
3700 Acute Minor and Major/Likely to Recur/Psychosocial
3800 2–3 Other ADG Combinations, Age 1–17
3900 . . . , Male, Age 18–34
4000 . . . , Female, Age 18–34
4100 . . . , Age>34

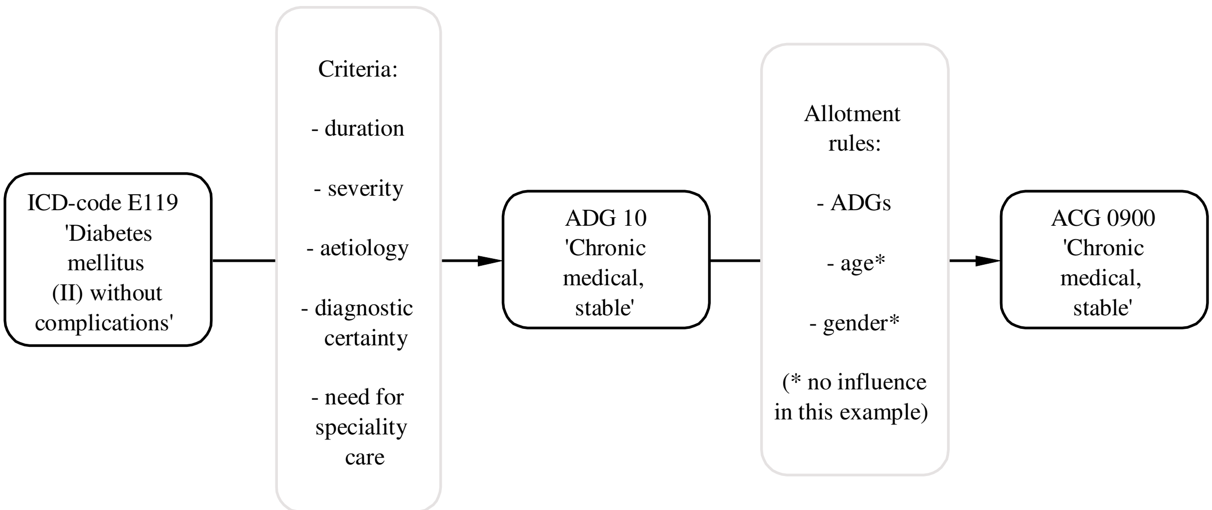
4210 4–5 Other ADG Combinations, Age 1–17, No Major ADG
4220 . . . , Age 1–17, 1+ Major ADGs
4310 . . . , Age 18–44, No Major ADGs
4320 . . . , Age 18–44, 1 Major ADG
4330 . . . , Age 18–44, 2+ Major ADGs
4410 . . . , Age>44, No Major ADGs
4420 . . . , Age>44, 1 Major ADGs
4430 . . . , Age>44, 2+ Major ADGs
4510 6–9 Other ADG Combinations, Age 1–5, No Major ADGs
4520 . . . , Age 1–5, 1+ Major ADGs
4610 . . . , Age 6–17, No Major ADGs
4620 . . . , Age 6–17, 1+ Major ADGs
4710 . . . , Male, Age 18–34, No Major ADGs
4720 . . . , Male, Age 18–34, 1 Major ADGs
4730 . . . , Male, Age 18–34, 2+ Major ADGs
4810 . . . , Female, Age 18–34, No Major ADGs
4820 . . . , Female, Age 18–34, 1 Major ADG
4830 . . . , Female, Age 18–34, 2+ Major ADGs
4910 . . . , Age>34, 0–1 Major ADGs
4920 . . . , Age>34, 2 Major ADGs
4930 . . . , Age>34, 3 Major ADGs
4940 . . . , Age>34, 4+ Major ADGs
5010 10+ Other ADG Combinations, Age 1–17, No Major ADGs
5020 . . . , Age 1–17, 1 Major ADGs
5030 . . . , Age 1–17, 2+ Major ADGs
5040 . . . , Age 18+, 0–1 Major ADGs
5050 . . . , Age 18+, 2 Major ADGs
5060 . . . , Age 18+, 3 Major ADGs
5070 . . . , Age 18+, 4+ Major ADGs
5100 No or Only Unclassified Diagnoses and Non-Users
5310 Infants: 0–5 ADGs, No Major ADGs
5320 Infants: 0–5 ADGs, 1+ Major ADGs
5330 Infants: 6+ ADGs, No Major
5340 Infants: 6+ ADGs, 1+ Major ADG
9900 Invalid Age

The grouping of patients by the ACG system is further illustrated by the following three examples, shown in figures 2, 3 and 4.

In the first example the patient, a male aged 61 years, has been registered as having just one diagnosis during the period measured – Diabetes mellitus without complications, coded as ‘E119’ (Fig. 2). In the first step of the grouping, the diagnosis ‘E119’ has been classified as a type of morbidity that is ‘Chronic medical, stable’ by using the following criteria: Duration – Chronic; Severity – Low; Aetiology – Medical, non-infectious; Diagnostic certainty – High; Need for speciality care – Unlikely. According to the principles of the ACG system this exact diagnosis is always characterised as a type of morbidity that is chronic, medical and stable, and is therefore assigned to ADG #10, ‘Chronic, medical, stable’, among the 32 different possible ADGs. In the next phase of the grouping of the patient, a scheme is followed indicating that ADG #10 is characterised as a chronic, stable type of morbidity, and when the patient has this type of morbidity alone, and nothing else in combination with this, there is just one ACG available among the 82 different groups, namely ACG # 0900, ‘Chronic medical, stable’. The ACG allotment process starts with defining how many ADGs there are for each patient, and if there is just one ADG, there will be no need for using the other rules regarding the patient’s age and/or sex.

Thus the grouping process, in detail, is as follows: ADG #10 is collapsed into CADG #6 ‘Chronic Medical: Stable’; CADG #6 is assigned to MAC #6 ‘Chronic Medical: Stable’, and the patient with one type of morbidity falling into MAC #6 is assigned to ACG #9.

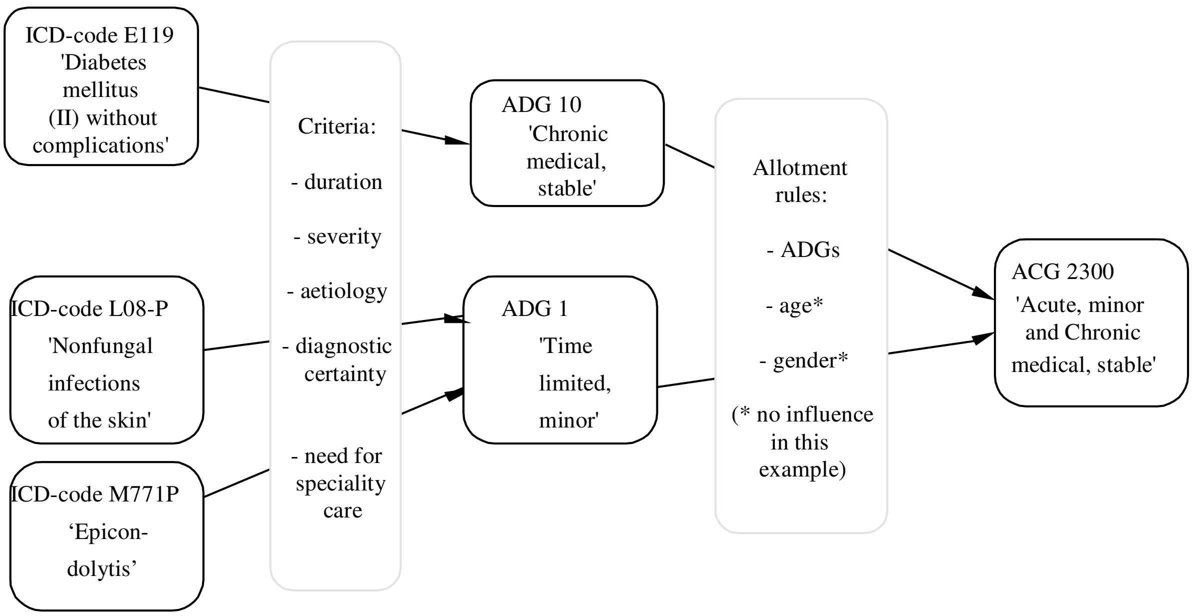
Fig. 2. Allotting a male patient, 61 years of age, with one diagnosis, to an ACG.



In the second example, the same patient has two more diagnoses during the period measured. The first diagnosis is the same as in the first example (diabetes mellitus), the second diagnosis is a nonfungal infection, coded as 'L08-P', and the third diagnosis is epicondolytis, 'M771P' (Fig. 3). In this example, the grouping also considers, apart from the diabetes code 'E119', the two ICD-10 codes 'L08-P'- and 'M771P'. Both these ICD-10 codes follow the same criteria for classification into ADGs: Duration – Acute; Severity – Low; Aetiology – Medical, non-infectious; Diagnostic certainty – High; Expected need for speciality care – Unlikely; resulting in ADG #1, 'Time limited, minor'. The patient thus has a combination of types of morbidity: ADG #1 and ADG #10. This specific combination of ADGs leads to the patient category ACG #2300, 'Acute minor and Chronic medical, stable', without any influence from age or sex.

Thus, the grouping process, in detail, is as follows: ADG #1 is collapsed to CADG #1; ADG #10 is collapsed to CADG #6; the combination CADG #1 and CADG #6 is assigned to MAC #15 'Acute: Minor and Chronic Medical: Stable'; and the patient with a combination of ADGs falling into MAC #15 is assigned to ACG #2300.

Fig. 3. Allotting a male patient, 61 years of age, with three diagnoses, to an ACG.

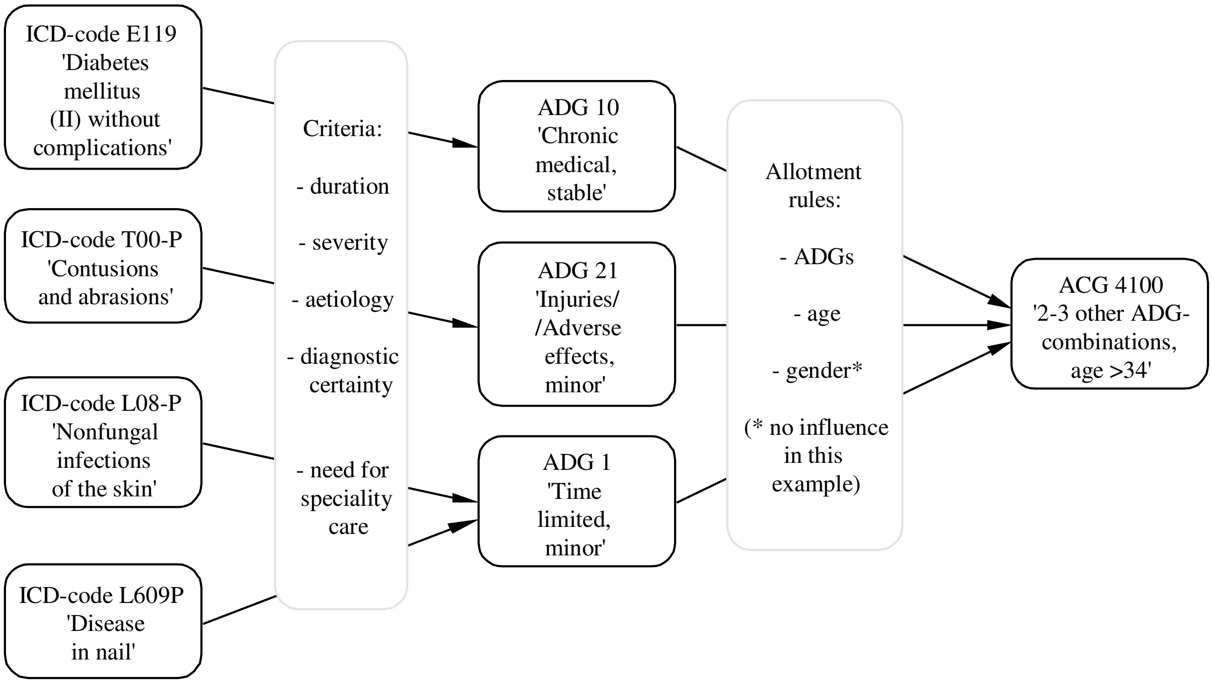


In the third example the grouping procedure is a bit more complex. In addition to the diseases above, the patient has been registered as having a fourth diagnosis during the period, a contusion coded as 'T00-P' (Fig. 4).

In this example, the patient has four different diagnoses. The ‘E119’ code has been shown to be classified as ‘Chronic medical, stable’, defined as ADG #10 (Fig. 2). The code ‘L08-P’ and the code ‘M771P’ both have been classified in the same way, resulting in ADG #1, ‘Time limited, minor’ (Fig. 3). The ‘T00-P’ type of morbidity falls into ADG #21, ‘Injuries/Adverse effects, minor’, using the following characteristics: Duration – Acute; Severity – Low; Aetiology – Injury; Diagnostic certainty – High; Need for speciality care – Unlikely. In this example the patient has a combination of ADGs #1, #10 and #21, meaning 2-3 combinations of ADGs that are not specified in the grouping scheme, consequently falling into the category of ‘2-3 other ADG combinations …’. There are four different ACGs available depending on the other allotment rules. In this case the age of the patient is utilised for allotment to an ACG. As the patient is over 34 years of age, the allotment is finalised and the patient falls into the category ‘2-3 other ADG-combinations, age >34’, which is ACG #4100.

Thus the grouping process, in detail, is as follows: ADG #1 is collapsed to CADG #1; ADG #10 is collapsed into CADG #6 as before. ADG #21 is also collapsed to CADG #1 because of the minor severity. That means that the combination of CADG #1 and CADG #1 and CADG #6 is assigned to MAC #24 ‘All other combinations not listed above’. The allotment rules for MAC #24 to assign a patient to one ACG start with a split between numbers of ADGs, namely 2-3 ADGs vs. 4-5 ADGs vs. 6-9 ADGs vs. 10+ ADGs. In this example 2-3 ADGs is applicable and the next split is in terms of age: 1-17 yrs vs. 18-34 yrs vs. 35+ yrs. If between 1-17 years of age the patient is allotted to ACG #3800, and if 35+ the patient is assigned to ACG #4100, as in this example. If the patient had been between 18-34 years there is the next split depending on sex; if male the patient is allotted to ACG #3900, and if female the patient is allotted to ACG #4000.

Fig. 4. Allotting a male patient, 61 years of age, with four diagnoses, to an ACG.



Studies on the ACG system

Research, development and documentation of the ACG system has taken place mainly in the US (Weiner 1996, Rosen 2001). Use of the ACG system in the US has primarily been as a tool for risk management (Madden 1998). A number of academic applications are ongoing world-wide, and some of them are relevant regarding future Swedish implementations, especially studies from Canada (Reid 2001, Reid 2002). Only a few European studies of the ACG system have been published (Juncosa 1996, Juncosa 1997, Juncosa 1998, Orueta 1999). Interest in ACG has increased in Sweden during the past year, as is also the case in other Scandinavian countries. The ACG instrument has been used in a number of trials in Sweden in preparation for routine use. It has been assessed and adapted to the Swedish setting (Carlsson 1993).

Aims

The overall aim of this thesis was to retrieve data on the individual level from health care registers in order to categorise patients in various types of groups for the purpose of monitoring, assessing and analysing morbidity patterns of groups of patients, and to estimate and calculate costs of various groups of patients.

The specific aims were

- To assess the annual direct and indirect costs of skin diseases caused by UVR by applying a model based on cost-of-illness analysis methodology (study I).
- To study the feasibility of the ACG case-mix system in describing the burden of illness in one municipality in Sweden by applying this tool to electronic patient register data at a PHC centre (study II).
- To elucidate types of morbidity and categories of patients in a large population in Sweden by applying the ACG case-mix system to encounter data in PHC (study III).
- To estimate the proportion of residents in a large population in Sweden with a diagnosis-registered encounter with a GP, and to elucidate annual variations of clinical categories of patients in terms of the ACG case-mix system (study IV).
- To explore the usefulness of the ACG case-mix system, in comparison with age and gender, in explaining and estimating patient costs on an individual level in Swedish PHC (study V).

Materials and methods

Study I

In study I, the focus was on a group of patients that were diagnosed with skin diseases caused by or closely related to exposure to UVR.

Data used in study I came from patients living in the area of Stockholm County Council. There are approximately 1.8 million residents in Stockholm County, constituting about one fifth of the total population of Sweden. The ICD-10 diagnoses included were cutaneous malignant melanoma (CMM), basal cell carcinoma (BCC), cutaneous squamous cell carcinoma of the skin, melanoma in situ, cancer in situ in skin, actinic keratosis, and melanocytic nevi (including dysplastic nevi).

Most data in the study were from the year 1999. Almost 27,000 patients were involved in the study, about 1.5% of all residents in Stockholm County, of which about 14,500 were registered at hospitals and 17,500 in PHC, meaning that there was some overlapping. Most patients were cared for in ambulatory care settings; only about 400 were registered in inpatient care.

The cost analysis was performed from the perspectives of health care providers and society. Accordingly, both direct and indirect costs were considered (Drummond 1987). The cost-of-illness methodology was based on the prevalence of the diseases involved. A top-down method of calculating the cost of illness was used in which the total cost of illness was apportioned among the diseases included (Gold 1996).

When calculating direct costs, the costs of inpatient care were based on data from Diagnosis-Related Groups (DRG) discharge statistics. The costs for ambulatory care were based on the registered numbers and types of encounters for the included diagnoses. The costs for control and removal of nevi in PHC were included in the cost-of-illness, as they are included in secondary prevention for the diagnoses concerned. Diagnosis-related costs for PHC were estimated using patient data from a PHC centre in Stockholm, with an age distribution similar to that in the county as a whole.

Regarding indirect costs, these costs arise, in theory, from production loss resulting from absence from work, early retirement pensions and mortality (Henriksson 1998). In this study indirect costs were calculated for costs related to CMM, BCC and cutaneous squamous cell carcinoma of the skin. Data on short-term absence from work were based on diagnosis-related production statistics from the Stockholm County Council and were calculated on the basis of average salaries in Stockholm County (Statistics Sweden 1998). The costs for loss of production due to mortality were based on age- and gender-correlated data on average number of years of work until retirement for these patients. These costs were based on mortality figures and average age- and gender-related salaries in the Stockholm area (Statistics Sweden 1998). Costs related to reductions in quality of life were not estimated.

A 3% discount rate was used when calculating indirect costs (Ekman 2002).

Study II

Gagnef municipality, with about 10,200 residents, is a sparsely populated area in Dalarna county in Sweden. The PHC centre at Gagnef is responsible for all primary level care in the municipality, including psychiatric care. Files were retrieved from the electronic patient records (EPR) at the centre; these contained the encrypted identity number, age, and sex of each patient, and his or her diagnostic codes during the calendar years 1998 and 1999.

To adapt to the ACG software, version #4.5, which utilises ICD-9 codes, the Swedish PHC version of the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10) (Socialstyrelsen 1997), was mapped to ICD-9 codes by using a cross-walk based upon equivalence tables from WHO (WHO 1997).

In order to assess possible variability in implementing the ACG system in Sweden, the ACG results from Gagnef were compared with results of ACG-grouped data from Tibro PHC centre, where computerised records with coded diagnoses have been used since 1978. The municipality of Tibro in the western region of Sweden is similar to Gagnef in terms of numbers of residents and PHC resources.

Studies III and IV

These studies were carried out in Blekinge county council in the southern part of Sweden, with about 150,000 residents. Every one of the 13 publicly managed PHC centres had implemented the Swedestar® EPR system, which is problem-oriented and thus promotes the recording of diagnoses. Data concerning every GP encounter with a registered diagnosis were retrieved and included four pieces of information: the encrypted identification number, date of birth and sex of the patient, and the registered diagnostic codes. Data from 2002 were used in study III, and data from the calendar years 2001, 2002 and 2003 were used in study IV.

Because of differences between localities and organisational responsibility, data were retrieved from a total of eleven sites. Three sites comprised a combination of EPR databases for two PHC centres, and there was one acute PHC centre where patients from all areas were registered as if they belonged to this acute unit.

Version #5.01 of the ACG software was used in study III, and version #6.03i in study IV, both resulting in 82 ACGs. The grouping algorithm in version #6.03i is based on ICD-10 codes. The Swedish PHC version of the ICD-10 was mapped to the full ICD-10 codes by a cross-walk that is based on tables available from the Swedish National Board of Health and Welfare.

In study IV the variation over time within an ACG was calculated on the county level with the range of the annual proportion over the three years. On the PHC centre level the variation over time within an ACG was likewise first calculated with the range of the annual proportion for each one of the centres. Then the average range for all PHC centres was calculated. In order to get some statistical measure of the variance of the distribution of the ACGs at each PHC centre, a comparison was made between the three years using Friedman's test. The statistical software SPSS®, version 11.5, was used.

Study V

Two ordinary PHC centres in the county of Östergötland in southeastern Sweden were included in the study. Ödeshög PHC centre is situated in a rural municipality with about 5,600 residents. Ryd PHC centre, with a registered patient population of about 9,000, is located in Linköping, with a total of about 130,000 residents.

Data from EPRs from the years 2001 and 2002 were retrieved. Ödeshög PHC centre was involved in the study for the purpose of creating ACG relative weights. Data on each patient's costs at Ödeshög for both years were used in order to get a sufficient number of individual yearly costs in each category of ACGs. Ryd PHC centre was involved in order to explore the usefulness of the ACG system with relative weights as one variable in explaining – and predicting – the variation in patient-level costs.

When calculating each individual patient's costs at Ryd, data from all patient contacts during 2001 and 2002, both direct and indirect contacts, were extracted from the EPRs at Ryd, and specified both in terms of the date of the contact and the various categories of caregivers. The type of contact was specified, e.g. face-to-face encounter, telephone, house call or contact through a third party. These contacts were priced according to amount of time, the various categories of personnel, and according to other resources that were consumed. The yearly cost per patient was subsequently calculated by adding all the costs for all contacts for that patient during each year.

To explain the variation in patient costs in a concurrent setting, some statistical methods were applied in study V. The statistical software SPSS®, version 11.5, was used. Spearman's rho correlation coefficient was used for bivariate correlation for each year between the variables age, gender and ACG weights. A stepwise multiple linear regression analysis was performed to explore the variation in patient costs, with age, gender, and ACG weights as the independent variables. This was also done for both years.

Another stepwise multiple linear regression analysis was performed to explore the ability of ACGs to estimate the correlation between the variation in patient costs and other variables in a prospective model. Individual patient costs in 2002 was the dependent variable, and age, gender and ACG weights in 2001 were the independent variables. This was supplemented with the costs in 2001 as another independent variable.

Results

Study I

In 1999 the total annual cost-of-illness for skin diseases caused by UVR exposure in the Stockholm area was approximately 162 million SEK (MSEK). The direct cost for hospital inpatient care for all diagnoses was calculated at about 16 MSEK, for hospital ambulatory care at about 33 MSEK, and for PHC at about 20 MSEK. The indirect cost for the diseases concerned was about 91 MSEK, i.e. about 56% of total costs in 1999. All costs can be seen in Table 3.

Among the different diagnoses, CMM was predominant in hospital care, comprising about 70% of total costs; this was mainly due to the cost of mortality, which was about 88.5 MSEK. Sixty-four patients died from CMM and eleven from BCC or cutaneous squamous cell carcinoma, and depending on their age, the loss of production amounted to about 60 MSEK and 30 MSEK, respectively. The total cost for short-term absence from work was estimated at about 3 MSEK and was mainly due to CMM. About 90% of the cost in PHC was due to melanocytic nevi.

Table 3. Annual direct and indirect costs of illness (skin diseases caused by UVR exposure) among 26,848 residents in Stockholm in 1999, presented in SEK 1000. (CMM = cutaneous malignant melanoma, BCC =basal cell carcinoma, CSCC = cutaneous squamous cell carcinoma of the skin, MIS = melanoma in situ, CIS = cancer in situ in the skin, MN = melanocytic nevi, and AK = actinic keratosis)

Type of cost	**CMM**	**BBC/CSCC**	**MIS/CIS**	**MN**	**AK**	**Total**
Hospital inpatient care	10,674	5,154	382	240	0	16,452
Hospital ambulatory care	11,239	11,138	1,243	5,106	4,557	33,282
Primary health care	404	1,292	0	17,527	888	20,112
Pharmaceuticals	1,285	-	-	-	-	1,285
Total direct costs	*23,604*	*17,584*	*1,626*	*22,873*	*5,445*	*71,131*
Mortality	84,286	4,200	0	0	0	88,486
Morbidity	2,479	294	-	-	-	2,773
Total indirect costs	*86,765*	*4,494*	-	-	-	*91,258*
Total costs	**110,369**	**22,078**	**1,626**	**22,873**	**5,445**	**162,390**
Average cost per resident	4.1	1.2	0.1	1.3	0.3	9.0

Although the societal cost of skin diseases caused by UVR was found to be moderate, the findings are of interest as a basis for further studies on cost-effectiveness of prevention activities.

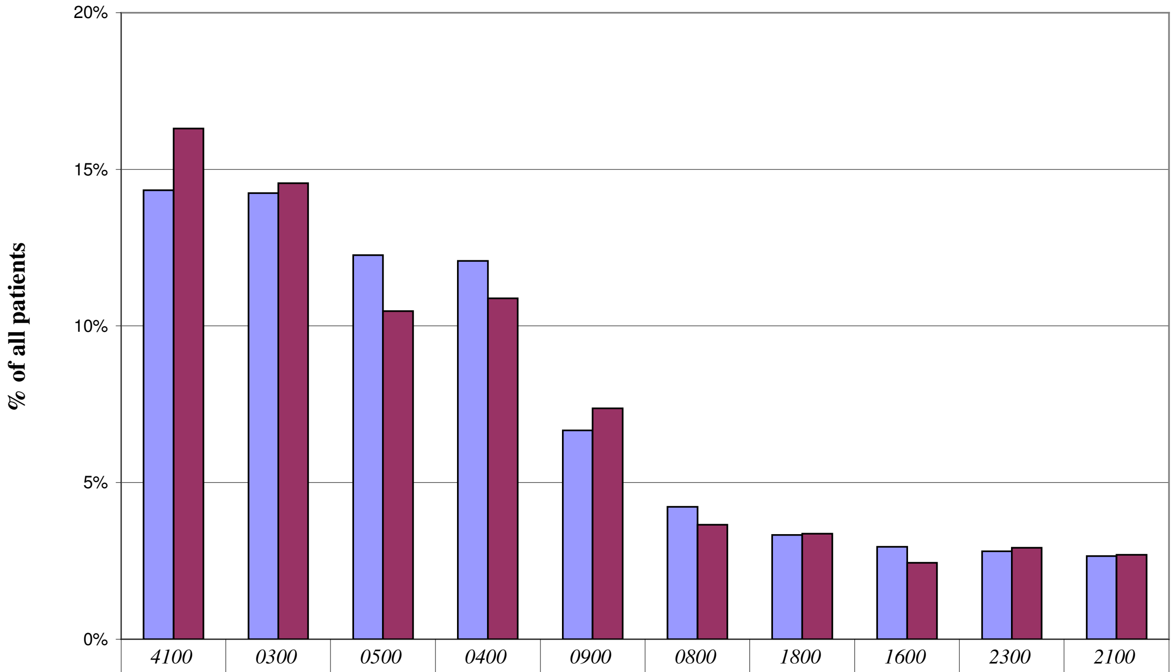
Study II

During 1998 a total of 5,660 patients had an encounter with a GP at the PHC centre in Gagnef, and in 1999 that figure was 5,415. The patients were grouped into ACGs according to the 81 different health conditions, depending on which diseases or problems were registered in their electronic patient record during each year. Application of the instrument was quite feasible, and the most frequent ACGs for each year are shown in Figure 5. Twelve categories are displayed; the other ACGs each have fewer than 2% of the total number of patients each year.

The material yielded a pattern showing a large number of patients with time-limited health conditions. For instance, ACGs #0300 and #0400 covered a fourth of the total number of patients. An acute condition is included in these two groups, often comprising simple colds, minor injuries and examinations to exclude serious illnesses. ACG #0800 and ACG #0900 represent chronic conditions, stable and unstable, respectively. One chronic condition, without being combined with any other types of morbidity, was registered for about 11% of all patients in Gagnef each year. A shift from an unstable condition to a stable condition could be seen in this group of patients. Another shift could be seen as patients moved from ‘simple’ to more ‘complex’ ACGs from 1998 to 1999.

Another pattern observed was that a large proportion of the patients had two to three different types of morbidity, the ADGs, simultaneously during the year in question. The ACGs running from #1800 to #4100 (twenty-four different ACGs) comprised this mix of two to three ADGs and constituted more than a fifth of the total number of patients at Gagnef. Of these, about 75% were placed in ACG #4100.

Fig. 5. Burden-of-illness in Gagnef – top ten ACGs in 1998 and 1999



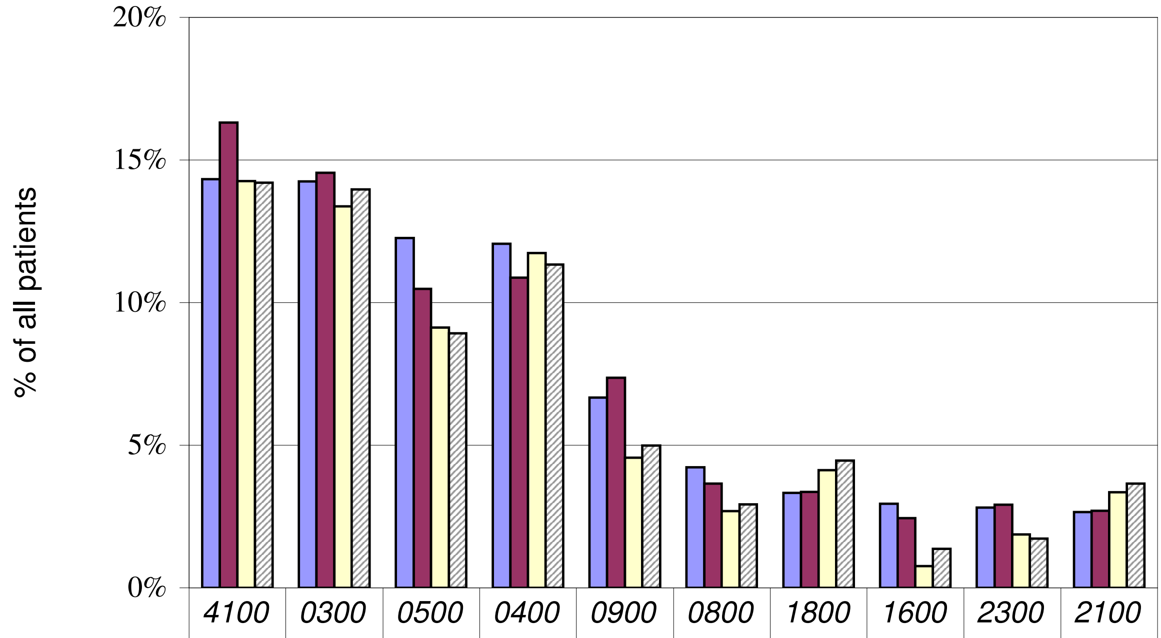
	4100	0300	0500	0400	0900	0800	1800	1600	2300	2100
Gagnef 1998	14%	14%	12%	12%	7%	4%	3%	3%	3%	3%
Gagnef 1999	16%	15%	10%	11%	7%	4%	3%	2%	3%	3%

ACG	Description
4100	2-3 Other ADG Combinations, Age >34
0300	Acute Minor, Age 6+
0500	Likely to Recur, without Allergies
0400	Acute Major
0900	Chronic Medical, Stable
0800	Chronic Medical, Unstable
1800	Acute Minor and Acute Major
1600	Preventive/Administrative
2300	Acute Minor and Chronic Medical, Stable
2100	Acute Minor and Likely to Recur, Age >5, without Allergy

Gagnef PHC centre was also compared with Tibro PHC centre, located in another county council in Sweden. Figure 6 shows the top ten ACGs from both years.

The pattern shows that the proportion of patients with only one chronic condition, either stable or unstable, was clearly lower at Tibro than at Gagnef (5.0% and 2.9% compared to 7.4% and 3.7%, respectively, in 1999). The proportion of patients allotted to ACG #4100 at Tibro (14.2%) was somewhat lower than at Gagnef (16.3%). The proportion of patients included in ACG #1600, with prevention or administration as the only registered reason for the contact, constituted almost 2.4% at Gagnef but only 1.4% at Tibro.

Fig. 6. Burden of illness in Gagnef compared with Tibro – top ten ACGs in 1998 and 1999



	4100	0300	0500	0400	0900	0800	1800	1600	2300	2100
Gagnef 1998	14%	14%	12%	12%	7%	4%	3%	3%	3%	3%
Gagnef 1999	16%	15%	10%	11%	7%	4%	3%	2%	3%	3%
Tibro 1998	14%	13%	9%	12%	5%	3%	4%	1%	2%	3%
Tibro 1999	14%	14%	9%	11%	5%	3%	4%	1%	2%	4%

ACG	Description
4100	2-3 Other ADG Combinations, Age >34
0300	Acute Minor, Age 6+
0500	Likely to Recur, without Allergies
0400	Acute Major
0900	Chronic Medical, Stable
0800	Chronic Medical, Unstable
1800	Acute Minor and Acute Major
1600	Preventive/Administrative
2300	Acute Minor and Chronic Medical, Stable
2100	Acute Minor and Likely to Recur, Age >5, without Allergy

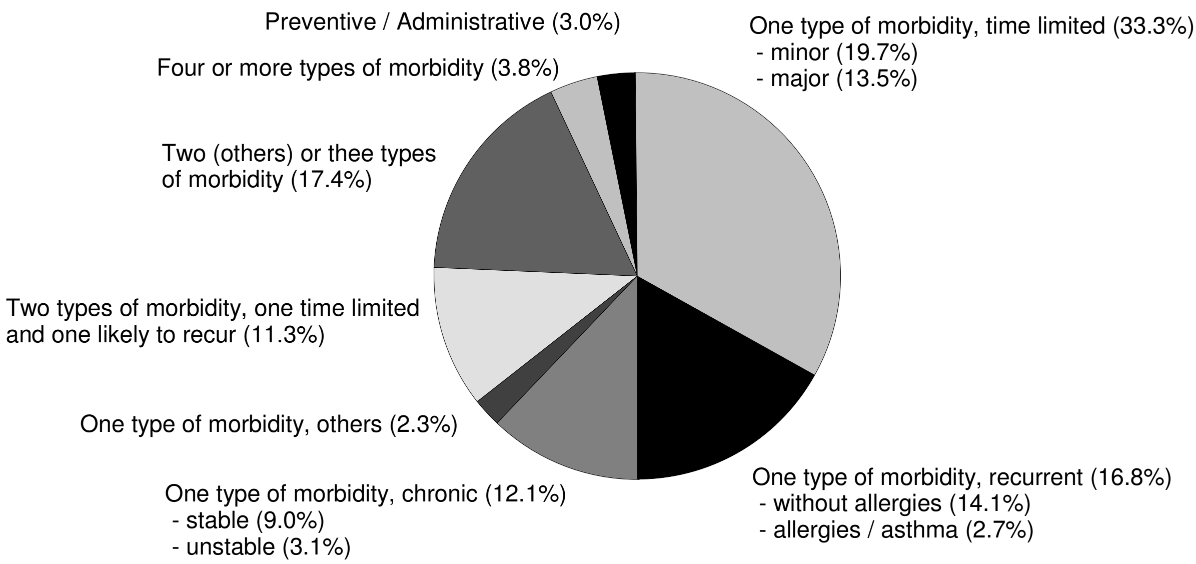
Study III

The results comprise all the 13 publicly managed PHC centres in Blekinge county council. During 2002 about 45% of the county residents had an encounter with a GP in which a diagnosis was recorded, with this figure varying between 35% and 51% at the various PHC centres.

In total about 107,500 patient encounters were registered in which a diagnosis was recorded, which was on average about 88% of all encounters, with a range of 75% to 96% for the various PHC centres.

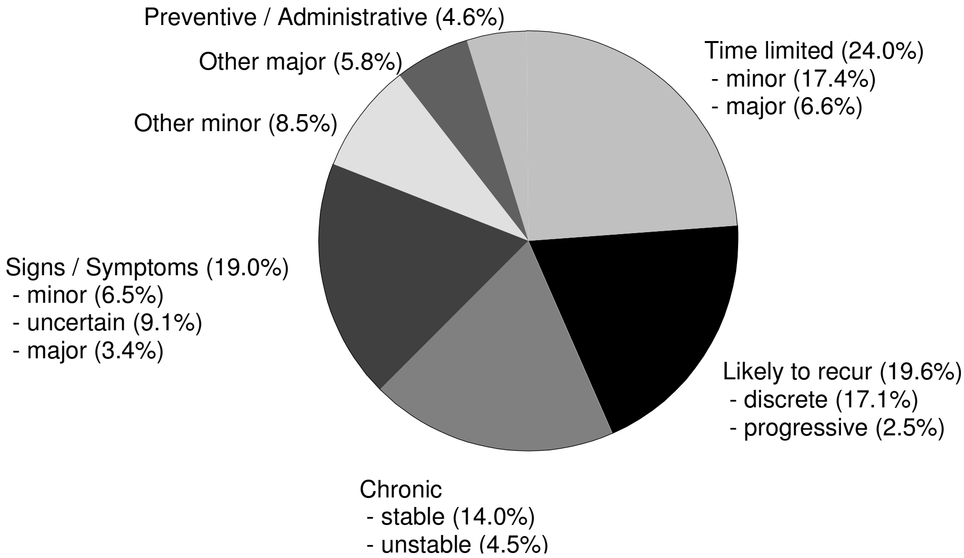
About 67,500 patients were included and thus grouped into ACGs. Figure 7 shows an overview of the distribution of all patients in terms of ACGs, combined into main groups and subgroups for the purpose of this study. About one third of all patients were categorised as having one and only one 'Time limited' health condition, another third of the patients had just one recurrent or one chronic health state, while the remaining third of all patients were categorised as having a combination of different types of morbidity. About 80% of all patients were captured in the ten most frequent single ACGs.

Fig. 7. Distribution of categories of patients in clusters of ACGs



The results can also be elucidated in another way by analysing which types of morbidity, in terms of ADGs, were the backbones of the categories of patients. Figure 8 shows the distribution ADGs, aggregated in larger groups and subgroups that were created for the purpose of this study. ADGs classified as 'Time limited' were the most frequent types of morbidity, constituting almost one fourth of the total number, followed by 'Likely to recur' and 'Signs/Symptoms' with about one fifth each.

Fig. 8. Distribution of types of morbidity in clusters of ADGs



Study IV

All the 13 publicly managed PHC centres in Blekinge county council were involved, and the data comprised the three calendar years 2001, 2002 and 2003. The population in the county was about 150,000, and it remained at about the same level during the three-year period.

The total number of patients registered with private GPs amounted to almost 28,000, or about 18.6% of all residents in the county, and these patients were not included in our study because of the lack of computerised data.

There were a total of about 120,000 patient encounters with a GP per year at all the 13 PHC centres. On average about 88% of the encounters had a diagnosis registered during the three-year period, with a range of 78% to 97% among the PHC centres.

There was a slight decrease in the number of patients included in our study during the three years, from about 72,000 in 2001 to about 67,000 in 2003. The proportions of all residents in the catchment area of each participating PHC centre each year are shown in Table 4.

Table 4. Number of patients included in the study at the 13 PHC centres and the proportion of patients included, based on the total number of residents in the catchment area, in 2001, 2002 and 2003

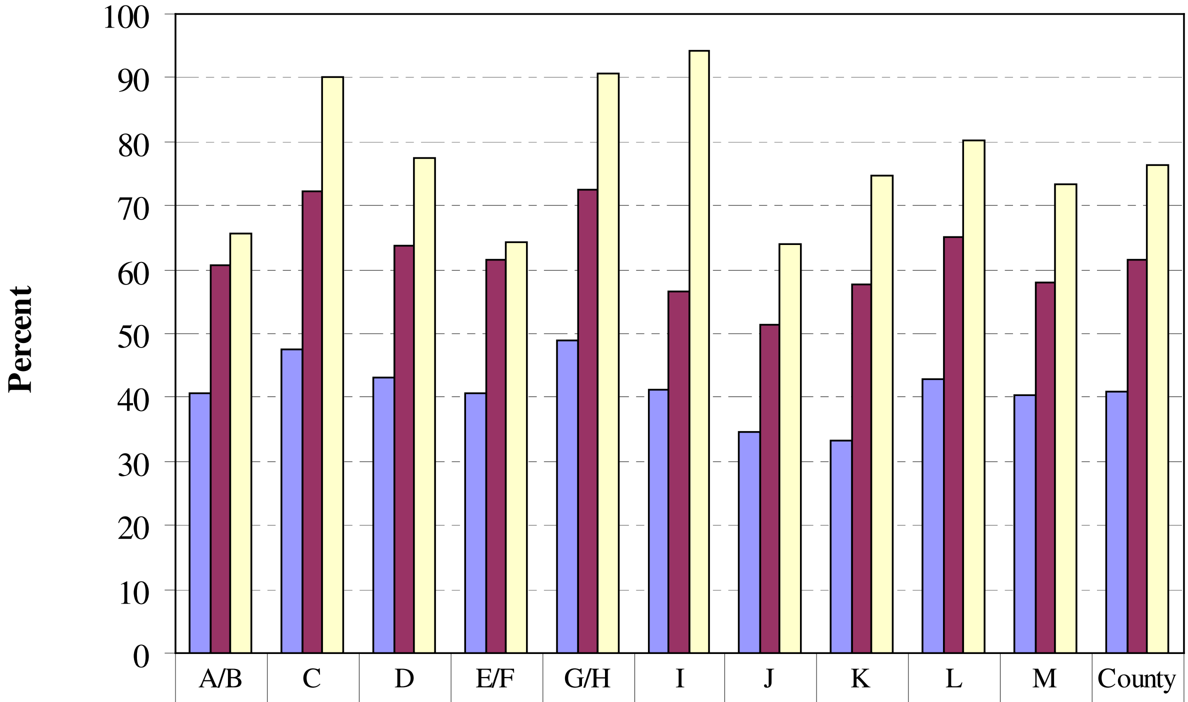
PHC Centre	2001 Patients (#)	2001 Prop. of residents (%)	2002 Patients (#)	2002 Prop. of residents (%)	2003 Patients (#)	2003 Prop. of residents (%)
A/B	9 814	43.9	9 012	40.4	9 063	40.4
C	9 007	56.1	8 203	51.2	7 631	47.3
D	2 645	38.8	2 619	38.5	2 939	42.9
E/F	6 950	45.2	6 632	43.2	6 242	40.4
G/H	6 166	52.9	5 798	50.0	5 675	49.2
I	7 557	44.7	7 606	45.2	7 190	42.9
J	5 273	36.3	5 135	35.3	5 980	41.1
K	6 248	38.7	5 853	36.1	5 606	34.6
L	6 480	46.9	5 823	42.8	4 516	33.3
M	7 365	44.9	6 238	38.3	6 568	40.0
N[1]	4 436	--	4 575	--	5 802	--
Total	71 941	45.0[2]	67 494	42.1[2]	67 212	41.0[2]

[1] Centre N was a PHC acute centre, and patients came mainly from PHC centres A/B, C and E/F
[2] Patients from PHC acute centre N not included

The proportion of residents in the county with a diagnosis-registered encounter with a GP during one calendar year was about 42.7% on average during the three-year period. By identifying each patient on a PHC centre level, it could be calculated that about 61.6% of all residents had an encounter with a GP within a two-year perspective, and about 76.5% when including all three years. That means that about 23.5% of the residents did not have a diagnosis registered by a GP during the three-year period.

The distribution of categories of patients for the three years in terms of ACGs, containing at least 1% of the patients included each year, is shown in Figure 9.

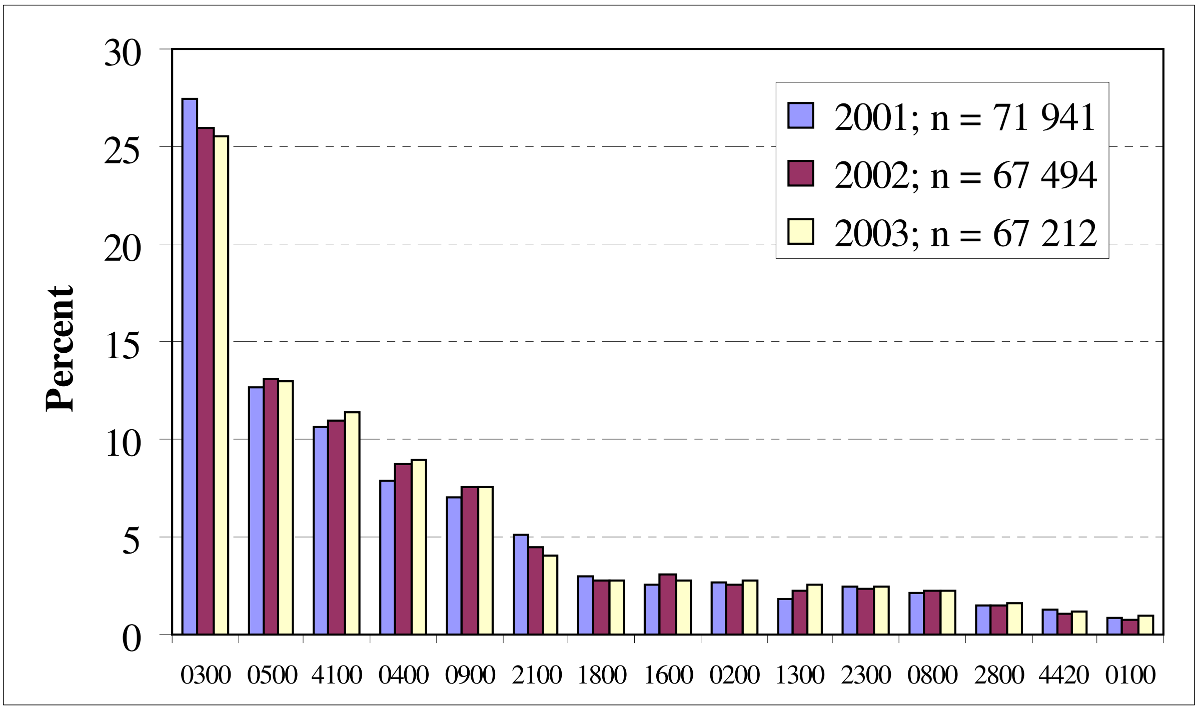
Fig. 9. Proportion of residents with a diagnosis-registered encounter with a GP at 13 PHC centres (A-M), and the average on the county level for the time periods: calendar year 2003, calendar years 2002-2003, and calendar years 2001-2003



	A/B	C	D	E/F	G/H	I	J	K	L	M	County
One year	40.6	47.6	43.2	40.7	48.9	41.1	34.6	33.2	42.7	40.3	41.1
Two years	60.8	72.2	63.6	61.6	72.6	56.6	51.4	57.7	65.0	57.9	61.6
Three years	65.5	90.2	77.5	64.3	90.6	94.2	64.0	74.7	80.1	73.2	76.5

The variation among categories of patients on the county level is presented in Figure 10. The overview gives the distribution, for the three years, of ACGs containing at least 1% of the patients included each year. In total, 92 patients, or 0.05% of all patients included, could not be defined in terms of ACGs due to incorrectly registered dates of birth. On the county level the three-year range was 0.4% on average. The maximal range was 1.9%, and this was in ACG #0300, 'Acute: Minor, Age 6+'. The ten most frequent single ACGs comprised about 80% of all patients.

Fig. 10. The distribution and three-year range of ACGs in Blekinge County Council during the period 2001-2003, excluding ACGs comprising < 1% of the patients

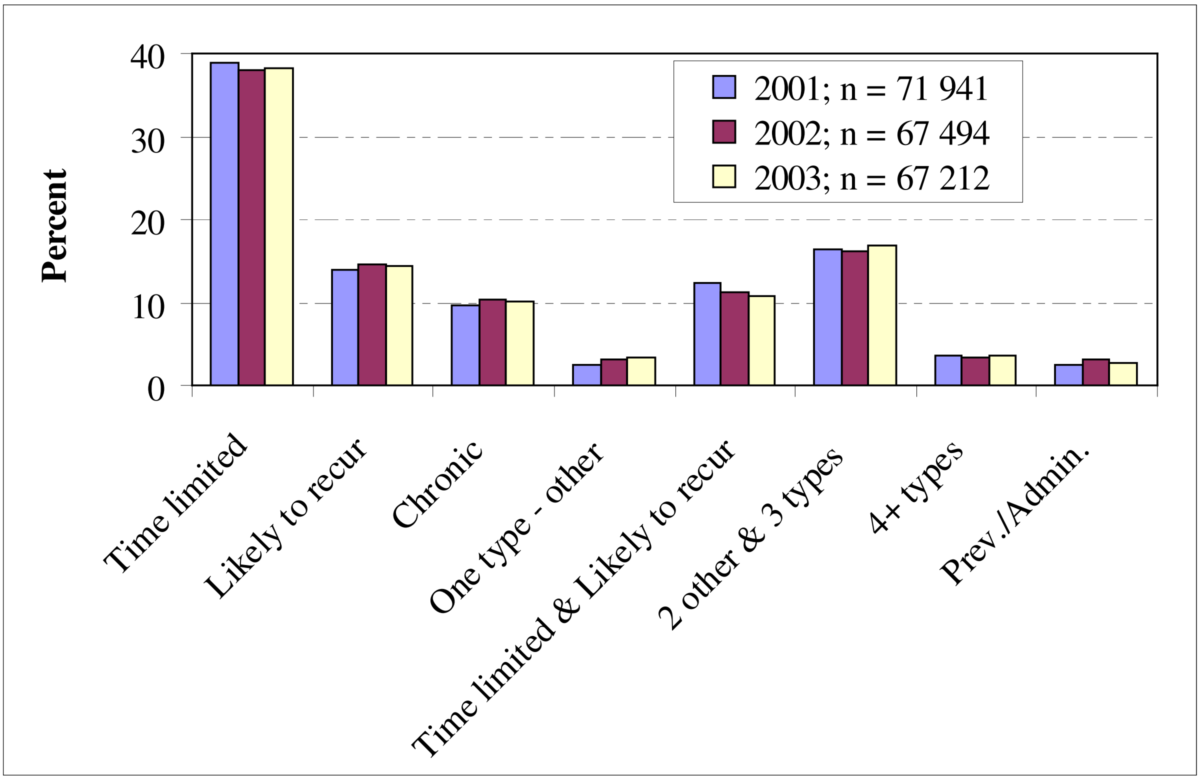


Range (%)	ACG (#)	Description
1.9	0300	Acute: Minor, Age 6+
0.4	0500	Likely to recur, without Allergies
0.7	4100	2-3 Other ADG combinations, Age >34
1.0	0400	Acute: Major
0.6	0900	Chronic: Medical, stable
1.1	2100	Acute: Minor, and Likely to recur, Age >5,w/out Allergy
0.2	1800	Acute: Minor, and Acute: Major
0.6	1600	Preventive/Administrative
0.2	0200	Acute: Minor, Age 2-5
0.7	1300	Psychosocial, without Psychosocial unstable
0.2	2300	Acute: Minor, and Chronic: Medical, stable
0.1	0800	Chronic: Medical, unstable
0.1	2800	Acute: Major, and Likely to recur
0.2	4420	4-5 Other ADG combinations, Age >44, 1 Major ADGs
0.2	0100	Acute: Minor, Age 1

In figure 11 the 82 different ACGs have been aggregated into more basic clinical groups, in the same way as in study III above.

About 38.9% of all patients were categorised as having one and only one health condition, characterised as ‘Time limited’, in 2001, and the corresponding figures for the following years were 38.0% and 38.2%, respectively. The proportion of patients with a constellation of two or more types of morbidity was 31.5% on average per year. The three-year variation was about 0.5% on average in these clusters, with a maximum of about 1.0%. The lowest range between the three years for an ACG cluster was about 0.1% and the highest value was 1.5%.

Fig. 11. The distribution and three-year average range of ACGs in Blekinge County Council during the period 2001-2003, aggregated into eight basic clinical groups



Basic clinical group	Range (%)	ACGs included and aggregation principles
Time limited	0.9	One type of morbidity - time limited
Likely to recur	0.5	One type of morbidity - recurrent
Chronic	0.7	One type of morbidity - chronic
One type – other	0.8	One type of morbidity - others
Time limited & Likely to recur	1.5	Two types of morbidity - time limited and likely to recur
2 other & 3 types	0.6	Two (other than the two above) or three types of morbidity
4+ types	0.3	Four or more types of morbidity
Prev./Admin.	0.6	Preventive/Administrative

Regarding the variation on the PHC centre level, the average three-year range among all ACGs was about 1.2%, with a maximum of about 3.0%. No statistically significant differences in the distribution of the ACGs at each centre were found between the three years.

Study V

The mean cost per patient at Ödeshög was higher compared with Ryd both in 2001 and 2002, as shown in Table 5. At both PHC centres the variation in individual patient costs within age groups was considerable in both years. The mean cost for women was about 30% higher than for men.

Table 5. Characteristics of patients at Ryd and Ödeshög PHC centres

	Ödeshög		Ryd	
	2001	2002	2001	2002
Number of patients				
- enrolled	5 600	5 600	9 000	9 000
- contacting the PHC	4 075	4 122	5 163	6 539
- diagnosed by a GP	3 073	3 144	4 478	5 358
Number of diagnoses/patient	2.07	2.04	2.28	2.17
Mean age	45.8	46.9	36.4	35.9
Proportion of females	54.2	53.3	52.1	57.9
Mean costs per patient (SEK)*	3 331	3 293	2 356	2 265
Mean ACG weight	1.0 **		1.07	1.19

* Swedish Crowns
** 1.0 since individual patient costs for the two years together were the basis for the weights

At Ödeshög, which was used for the creation of ACG weights, about the same number of patients were diagnosed by a GP both years. These patients were grouped by the ACG instrument and the results for both years were the basis for constructing ACG weights. The relative weights ranged from 0.3 to almost 4.2 – the mean weight being 1.0 by definition. At Ryd, which was used for the evaluation of ACG weights, about 4,500 patients were diagnosed by a GP the first year, but this figure grew to almost 5,200 the second year. There were also some differences between the years in terms of proportions of age groups and gender.

The variation in individual patient costs within each ACG was substantial, as can be seen in Table 6.

Table 6. The most frequent ACGs, distribution of patients, mean and range for costs per patient in Swedish crowns (SEK) at Ryd PHC centre in 2001. (N = 4 478)

		Costs per patient (SEK)		
ACG #	Description	N	Mean	Range
0300	Acute minor age 6+	646	1 048	90 – 15 755
4100	2-3 other ADG comb age >34	555	3 812	153 – 44 693
0500	Likely to recur without allergy	458	1 048	90 – 12 905
0400	Acute major	356	1 480	50 – 14 773
0900	Chronic medical, stable	307	1 542	90 – 19 271
2100	Acute minor & Likely to recur	174	2 120	90 – 13 455
1800	Acute minor & Acute major	160	2 540	530 – 27 116
2300	Acute minor & Chron. med. stable	115	2 416	106 – 11 332
2800	Acute major & Likely to recur	103	2 613	220 – 34 406
0800	Chronic medical, unstable	102	2 630	90 – 16 034
1600	Preventive / Administrative	98	978	90 – 4 267
4420	4-5 ADG, 1 major age >44	93	6 523	683 – 33 465
	Total	3 167		

The correlations between individual patient costs and other variables at Ryd were calculated, and Spearman's rho showed a correlation of 0.633 for ACG weights, 0.308 for age, and 0.119 for gender in 2001. In 2002 the results were similar.

Age, gender and ACG weights, as independent variables in a stepwise multiple regression analysis, together explained 38.5% of the individual patient costs in 2001, and this figure was 34.3% in 2002. In 2001, ACG weights explained 37.7% of the variance, while age and gender added 0.8%. Age and gender alone explained 11.4%. In 2002 the results were similar.

Replacing the ACG weights from Ödeshög with relative ACG weights from Ryd, and from other areas abroad, resulted in about the same or lower adjusted R^2 values: 0.377 (Ryd), 0.203 (USA), 0.320 (Manitoba, Canada), and 0.337 (British Columbia, Canada). Table 7 shows the relative weights applied to the ACGs at Ryd.

Table 7. Relative ACG weights from Ödeshög compared with relative weights from other areas

		Relative weights				
ACG #	Description	Ödeshög	Ryd	USA	Manitoba	B.C.
0300	Acute minor age 6+	0.55	0.39	0.18	0.23	0.27
4100	2-3 other ADG comb age >34	1.33	1.47	1.11	0.97	0.79
0500	Likely to recur without allergy	0.46	0.38	0.25	0.26	0.21
0400	Acute major	0.61	0.56	0.42	0.35	0.27
0900	Chronic medical, stable	0.60	0.58	0.33	0.37	0.34
2100	Acute minor & Likely to recur	0.95	0.81	0.43	0.51	0.56
1800	Acute minor & Acute major	1.06	0.95	0.71	0.60	0.72
2300	Acute minor & Chron. med. stable	1.02	0.95	0.53	0.60	0.63
2800	Acute major & Likely to recur	1.11	1.00	0.91	0.72	0.54
0800	Chronic medical, unstable	0.96	0.98	1.02	0.59	0.49
1600	Preventive / Administrative	0.48	0.34	0.14	0.22	0.14
4420	4-5 ADG, 1 major age >44	2.06	2.56	2.76	1.85	1,53

The costs of individual patients in 2001 turned out to be the most important factor, by 22.0%, for predicting the individual patient costs at Ryd in 2002. The ability of the ACG weights alone to predict patient costs the next year was 14.3%.

Discussion

Activities in the area of health care can be described in many ways, depending on the aim. The development of descriptive systems has been motivated to a great extent by the fact that the area in question has been large in scale and/or of great economic significance. The methodology for describing PHC and its outcomes has largely followed developments in inpatient care or hospital oriented systems. Statistical compilations of disease groups and patient contacts have been the prevailing way of describing the outcomes of PHC. There is a need to develop methods for elucidating the main features of PHC, with emphasis on the core idea of this sector, which is to be the first tier of care for persons with signs of medical problems. Thus both the economic and the clinical burden of illness should be described in terms that are relevant to the primary level of care with its focus on patients and groups of patients as well as the whole population in a catchment area.

Economic burden of illness

When dealing with the management of groups of patients with specific diseases, estimating the cost-of-illness for each disease can be of importance (Drummond 1987, Henriksson 1998). In study I, a cost-of-illness approach was used to calculate the economic burden of skin diseases caused by UVR exposure in the Stockholm area in 1999. The resulting total costs in study I were found to be moderate, but given the rising incidences of these diseases, the potential for cost increases in the future is significant.

Study I investigated cost-of-illness mainly by using data sources from day-to-day health care with a top-down approach, and the double counting of costs is considered to have been avoided. However, this approach may underestimate the true costs, since some of the diagnosis-related data are probably missing in day-to-day health care registration in both hospital ambulatory care and PHC. Diseases in other organ systems (e.g. cataracts) and certain skin diseases (e.g. lentigo solaris) that could be considered as being caused by UVR were excluded. Furthermore, only CMM was included in the indirect costs, and costs for early retirement pensions were not included at all, which would have further underestimated the costs. The limitations regarding diagnoses could also lead to an underestimation. However, the vast majority of clinically relevant diseases are considered to have been covered in the study.

The indirect costs in study I constituted about 56% of total costs for the diseases. Defining, calculating and estimating indirect costs is in some respects controversial. The traditional human capital theory was used in the study, which can be criticised, and which may have caused some underestimations in our results (Gold 1996). On the other hand, most cost calculations in the study were based not on general national data, but rather on data from specific registers in the Stockholm region, such as oncology registers on an individual level, patient-based statistics on all diagnosis-related production in the county council, and data on salaries of residents in the county, standardised by age and gender in accordance with the population in that region.

In constructing a model for prevention and management of these diseases, estimating the total cost-of-illness is of central importance. As prevention strategies include both reduction of UVR exposure and earlier detection, cost-effectiveness is complex. The effect of primary prevention is also difficult to estimate due to the long time span of the effect. Another issue in this respect is that public awareness of skin cancer caused by UVR and the increase in primary prevention are generating costs in PHC.

So far no studies have examined the economic impact of these skin diseases as a whole at this detailed level. The cost-of-illness study was performed mainly by using data from registers, and there is always a question of precision in terms of what diagnoses have been registered by the various caregivers. This registration issue will be even more crucial when the clinical aspects of the burden of illness are dealt with later in this chapter.

In study V, the costs that were calculated were limited to direct costs and only to resources used within PHC. The results from an earlier study concerning cost analysis on a very detailed level and based on the cost per each patient in contact with the PHC centre in question were used in study V (Landstingsförbundet 2003). These costs were the basis for constructing relative ACG weights that were used in explaining the concurrent cost at another PHC centre.

In study V the ACG weights were found to be a major factor in a concurrent model in explaining patient costs during one and the same year. Age and gender explained about 11% of the individual patient costs, and when the ACG weights were added, the explanatory ability was improved and reached 38.5%. Patient categories with more complex constellations of types of morbidity were generally more resource consuming, indicating the influence of comorbidity. When estimating costs the next year in a prospective model, the ACG weights constituted the second most important factor, while the costs the preceding year were the major factor.

The results in study V were in accordance with findings in a Canadian study based on physician claims, where age and gender explained 9% of the variation in costs, a figure that increased to 53% when Aggregated Diagnosis Groups were added (Reid 1999). In a Spanish study in which prospective registration of diagnoses that was independent of registration of other medical information, and in which the number of GP consultations (without cost estimation) was used as outcome measure, the corresponding figures were 7% for age and gender and 50% when ACGs were included (Juncosa 1996). The ability of the ACGs to estimate about 15% of individual patient costs in the following year in our study is in line with a claims-based study in the US (Reid 2002).

With respect to the cost calculations, the contact-based analysis of individual patient costs can be considered sufficiently detailed to provide a reliable distribution of costs between patients. Registration of patient contacts in the EPR was a prerequisite for enabling the caregiver to record medical information, and consequently the dropout rate was low.

The creation of ACG weights was limited by the fact that not all patients were included; inclusion comprised only those with at least one diagnosis. However, since the costs of all patients without any diagnosis constituted no more than 2.5% of the total, this limitation probably affected our results to only a minor degree. A further limitation of the ACG weights was that the population of Ödeshög was small. This was mitigated to some extent by aggregating data from two consecutive years. Nevertheless, there were still some ACGs with only a few patients, making these weights uncertain. Constructing weights for a larger population might have resulted in greater explanatory ability. However, weights provided by the ACG software (The Johns Hopkins ACG® Case-mix System. V6.0 - April, 2003), based on a reference population of 2,000,000 subjects in the US, gave an adjusted R-square as low as 0.20 in the Ryd population, compared to Canadian weights from Manitoba and British Columbia with adjusted R-squares of 0.32 and 0.34, respectively. Hence, data from the Swedish PHC centre in Ödeshög were found to yield more useful relative weights for a Swedish PHC setting compared to weights based on statistically well-founded data from the US and Canada.

In study V it was concluded that the ACG system might be used for describing and explaining concurrent resource consumption in PHC as well as for estimating future costs for health care in a prospective model. However, more research and development is needed in this area. As one example, a more comprehensive database on Swedish costs per patient in PHC is needed in order to increase the precision of the relative ACG weights and thus make the grouping into patient categories reflect the need for resources on the first tier of care in Sweden in an adequate and reliable way. Efforts to construct a more comprehensive database on costs per patient in PHC are ongoing in Sweden. Such analyses should lead to a higher degree of certainty when using relative ACG weights. The possibility of integrating data on drug prescriptions, as is indicated in a new version of the ACG grouping software, might improve the usefulness of the system in a concurrent as well as in a prospective model.

In study V it would have been advantageous to test the significance of a socio-economic variable such as the CNI (Malmström 1998) in explaining and estimating patient costs, but this was not applicable due to the small number of individuals at the Ryd PHC centre and, as a consequence of this, the skewed distribution of CNI scores. Other allocation rules that have been implemented in most county councils in Sweden today, using age and gender and sometimes a few socio-economic variables, have so far been able to explain only a very small part of the correlation with resource consumption (Reid 2002). Individual socio-economic data, as well as other health related measures, will probably be needed in future studies in order to reinforce the explanation and estimation of individual patient costs.

Clinical burden of illness

In study II the burden of illness among patients was described in terms of groups of patients with different health conditions. The results from the ACG grouping revealed a picture of the health situation of patients visiting a PHC centre that differs from the traditional epidemiological view. Diagnoses and diseases were not the end foci – instead, the patients' health conditions were described based on registered data about diagnoses over a period of time. In this way variability of the health situation in populations became apparent, enabling comparisons to be made between various groups of patients and over time (Starfield 1991, Weiner 1991).

The analysis in study II showed a tendency over time indicating that PHC was handling patients with more mixed, more complex or more severe states than earlier. This shift to more 'complex' ACGs can partly be explained in the light of what has happened at the hospital level. The number of beds available for inpatient care has been reduced in favour of more outpatient contacts. Also, referrals from PHC have been limited due to the diminishing number of beds and the increasing workload at hospital clinics.

The differences shown between Gagnef and Tibro regarding patients with psychiatric or psychosocial disorders might be due to the fact that psychiatric services in Gagnef have been integrated into PHC for almost ten years.

By analysing the results on the ADG level in study II, it was possible to elicit more detailed information. As an example, during 1998 the patients in Gagnef were registered for a mean of 1.7 different ADGs, and 40% of those patients were grouped to two, three or four different types of illness during the year. The corresponding figures for 1999 were a mean of 1.8 ADGs per patient and 42%, respectively. Although this was a marginal shift, this analysis also showed that the PHC centre in Gagnef had encountered a somewhat smaller number of patients, although the cases were 'worse' during 1999 compared to the previous year.

An analysis at the ADG level also revealed great variations in terms of number of types of illness per patient. In Gagnef a slight increase from 1998 to 1999 could be seen, from 1.7 to 1.8 ADGs per patient, while the corresponding figures in Tibro were 2.1 ADGs per patient for both years. Various ways of registering diagnoses in the EPRs may be one explanation for the differences observed in Gagnef and Tibro. The Tibro records showed more diagnoses per patient – 2.3 unique diagnoses per patient compared to 1.8 in Gagnef. One reason could be that Tibro has been engaged for a long time in improving the quality of registration of diagnoses, and this PHC also has many years' experience in working with computerised patient records (Britt 1998, Nilsson 2002).

In study III, data from 2002 were analysed for patients in publicly managed PHC in Blekinge county council. Time limited health conditions were most frequent, and the two most common categories of types of morbidity were 'Time limited' and 'Recurrent', without any other type of morbidity, and these comprised 50.1% of all patients. The predominant categories of patients were those with only one type of morbidity.

Some patients might have visited more than one centre during the calendar year. Each PHC centre gives each patient a unique identification number, and to ensure the integrity of individual patients, no attempt was made in this study to establish the extent to which patients were registered at more than one centre.

The period for data retrieval in study III was one year, which has been experienced as appropriate for capturing each patient's actual status. Depending on recording routines, there could be reason to use data from two years or more to be sure of obtaining information on diagnoses of relevance to the patient's condition.

In a study from Canada it was concluded that patients with high usage of physician services have multiple and complex health problems, and are five times more likely to have six or more different types of morbidity than other patients (Read 2003). This approach using the ACG system, with types of morbidity and categories of patients, might provide the basis for further analysis of groups of patients.

In study IV the main findings were that three fourths of the residents visited a GP during the three-year period, and a vast majority of the patients had a diagnosis-registered encounter during that period. Further, the annual variation in clinical categories of patients according to ACGs was small in statistical terms. The stability over time provides reasons for using the ACG system both for estimating the proportion of encounters with a GP among the population and for elucidating categories of patients for the purpose of analysing and managing PHC.

One limitation in study IV, as well as in study III, was the assumption that persons living in the geographic catchment area of a particular PHC centre will visit that centre. This has not been analysed, as administrative data were not captured in our study. Further, some patients may also have visited more than one of the 13 PHC centres during a calendar year, and the patients could not be traced between the centres. Regarding the PHC acute centre, the number of visits of the patients could be traced back to their regular PHC centre, but not the number of individuals. Taking these limitations into account, this county-based approach is considered to be advantageous due to the large population, which probably makes the results fairly representative for PHC in Sweden.

The proportion of the population in study IV with one or more diagnosis-registered encounters with a GP at the 13 PHC centres during a three-year period seems fairly high (76.5%). If it had been possible to include encounters at the 15 privately managed units, this proportion would doubtless have been larger. Taking into account that not all encounters have a registered diagnosis, the proportion of residents with any encounter with a GP in the three-year period is most likely significantly higher. This indicates that in this respect PHC comprises the first tier of care for the great majority of the population in the county, and the figures in study IV are probably representative for PHC in Sweden. Information from EPRs in PHC therefore seems to be useful for further application of the ACG system.

In study IV the annual variation of clinical categories of patients according to ACGs was small in statistical terms. At the same time, a large proportion of the population met with a GP and a majority of these patients had a diagnosis-registered encounter during the study period. The ACG system therefore might be used for both elucidating categories of patients and predicting the proportion of encounters with a GP among the population.

The resulting relatively small three-year variation of ACGs in study IV can be considered in two ways. Firstly, it seems that the true distribution of clinical categories of patients measured as ACGs is robust in a three-year perspective, which can be expected due to the large population and the short time span. This might indicate that the ACG system is a valid instrument for measuring the burden of morbidity in a population over time, and that it might be used for planning purposes by PHC managers. However, further research is needed to analyse the variations over a longer period. Secondly, it seems that the ACG system as an instrument is stable, which has so far received little attention. The figures on the three-year range (<1%) are low and in line with the results from other studies (Starfield 2003, Engström 2004). The ACG system therefore seems to be useful for demonstrating the distribution of, as well as predicting, clinically meaningful categories of patients in Swedish PHC, and it ought to be an interesting area for further research and development.

The time span of the constellation of morbidity is of interest. In study IV the constellation of morbidity of every individual was measured year by year, as well as by means of all diagnoses registered during the whole three-year period. Taking more types of morbidity for a patient into account when grouping will result in a more comprehensive constellation of morbidity (Majeed 2001b). However, the morbidity present at one time might not be relevant at another time, at least not three years after the first measurement. More studies on this issue are currently ongoing in Blekinge county. A preliminary report from the PHC research unit in Blekinge indicates that a period of about two years might be appropriate for capturing diagnoses that are not registered in a timely way.

The diagnostic code has been used as the basis for the patient's condition in studies II, III and IV. The way in which the process of diagnosing is carried out is crucial both for the grouping and for confidence in the results of the grouping. The homogeneity of the coding is of significance in this respect and has been found to be high when the same EPR system is used (Nilsson 2000). Every grouping system must handle problems concerning definitional gliding (Hornbrook 1982). In the ACG system the exact diagnostic code is not of prime interest. The crucial point is that it belongs to the right cluster of diagnoses in terms of ADGs, resulting in the expression of each patient's health status as a combination of different types of morbidity. Routines regarding registration of diagnoses in PHC also have an impact on the ACG grouping in another respect. When new monitoring systems are implemented, there is an increased risk of opportunities for the results to be used for manipulative purposes (Fetter 1980, Tucker 1996). Although the ACG instrument is said to contain minimal risks for 'diagnosis creep' in the sense that a larger number of visits or more procedures will not result in a shift in terms of ACGs, the results of the ACG grouping will increase the 'complexity' of the status of the patients if more morbidities of different kinds are registered in the patient's record during the same period of measurement.

It should also be stressed that in studies II, III and IV, data were confined to what was recorded in the PHC registers, and no data were collected from other sources such as hospital departments. Consequently, there is no 'true total' of each patient's actual status in terms of morbidity (Wahls 2004).

According to study II, the patient categories in terms of ACGs provided a reasonable view of the entirety, while at the same time providing prerequisites for a more detailed analysis. The focus in study II was on assessing whether the ACG system could be a useful method for reflecting the health situation in the population in a meaningful way, and thereby constitute a complementary addition to current descriptive systems. The approach using the ACG system, with types of morbidity and categories of patients, yields a new view of the burden of morbidity in a defined population that provides the basis for further analysis of groups of patients. This complement to the statistics of diagnoses and diseases may support quality improvement in PHC focusing on clinically meaningful patient categories with their combined health states.

In study II, data from two consecutive years were used. Although the ambition was not to highlight the differences between the years, the results were interesting and lead to development of the time dimension, which was done in study IV. Study III demonstrated the feasibility of the ACG grouping system when applied to information from PHC centres at the individual level and when applied at the county council level.

In study V, the ACG weighting appeared to be sensitive to the accuracy with which physicians enter diagnoses into the EPRs. The coding situation in PHC in Sweden is reported to be quite accurate, but there is still a need for improved quality (Nilsson 2003). Due to the organisation of EPRs at Ryd, a more complete registration of diagnoses was done there than at Ödeshög, resulting in a higher mean ACG weight albeit lower mean patient costs. Measures will be required to reduce this variation and enhance the quality of diagnostic coding in PHC. However, it is unrealistic to expect that this problem can be totally eliminated, as the criteria used for diagnostic labelling by different physicians have been shown to vary (Britt 1998). Thus, introduction of methods that might compensate for variations in the completeness of physicians' registration of diagnoses could increase the usefulness of the ACG system.

Burden of illness in defined populations

In the review of existing systems describing PHC activities in more result-oriented terms, including public health aspects, interest has been concentrated on the ACG system, which focuses on the patient's health condition and presents a picture of the situation in PHC that differs from prevailing descriptions (Weiner 1998, Tucker 1996).

One of the original ideas in creating an ACG system was to describe the health situation in a defined population using the current health condition of each individual judged according to the degree of risk that the individual will need care in the future. The basis for this view is that diseases tend to be clustered around individuals, instead of being statistically distributed in a geographic area or covariate with social or socio-economic factors (Starfield 1991). For this reason, application of the ACG instrument can be adequate in a health care system based on getting a grip on individuals' problems in first-line care. Swedish PHC, as well as the rest of Scandinavian PHC, constitutes, at least in theory, such first-line care, and this is true to an even greater extent today in co-operation with primary municipalities or the equivalent (Carlsson 1996).

One of the strengths of the ACG system is that the full spectrum of illness for all persons in a population can be elucidated instead of describing an episode or a process of care. The system is person-oriented and patients are assigned to categories according to the condition of each individual. One of the most embarrassing shortcomings in other case-mix systems is that the assigning of patients is based on numbers of visits or procedures, which could provide a reason for suspecting diagnosis creep or other unintended incentives.

The double functions of the ACG system, its descriptive ability in a clinical perspective and its use as a basis for resource allocation, comprise the foundation for development of the software and various kinds of applications world-wide. In the studies included in this thesis, four versions were used; version #4.5 in study II, version #5.01 in study III, version #6.0 in study V, and version #6.03i in study IV. From version #5 and onwards a new feature was introduced, making it possible to trace the types of diagnoses that have been used in the grouping of each patient into the ACGs. These types of diagnoses form about 190 'Expanded Diagnosis Clusters' (EDCs), organised into 27 'Major Expanded Diagnosis Clusters', mainly following the chapters of the WHO classification, 9^{th} revision. The idea is to facilitate the analysis, giving a quick view of which types of diagnoses are assembled around each patient in each ACG. This development is based on earlier work by Ronald Schneeweiss and colleagues in which 'Diagnosis Clusters' were introduced (Schneeweiss 1983).

The new #6 version of the ACG system has been developed to build four to five risk factors into the system to enable identification of groups of patients at risk. The version is therefore called 'ACG-PM', with 'PM' standing for 'Predictive Model' (ACG version #6.0 2003). An example of studies showing comorbidity patterns is a recent study from Canada, where it was concluded that patients with high usage of physician services have multiple and complex health problems and are five times more likely to have six or more different types of morbidity than other patients (Reid 2003).

Version #6.03i differs from the other versions in that the grouping algorithm is based on ICD-10 codes. In late summer of 2005 version #7.0 was released, where the choice between ICD-9 and ICD-10 codes can be made before grouping. In parallel with this version, an ACG-grouper has been developed that is based on the codes used when prescribing drugs. However, the National Drugs Codes (NDC) utilised in the US are not the same as in Europe, where the Anatomical Therapeutic Chemical Classification System (ATC) codes are used. However, with support from experts in the area of pharmacology, it might be possible to construct a cross-walk, and measures have been taken in order to accomplish this.

One issue must be addressed regarding the various inputs involved in the ACG grouping procedure. Obvious limitations in studies II-V were that patient data from PHC were retrieved, but no data from hospitals regarding the patients. In this respect the ambition to reflect the true state of each patient was not fulfilled. In developing methods to measure the need of groups of patients, or the need of populations, a more complete pattern must be taken into account, even if it is presently difficult to link different types of EPRs to each other (Arnlind 1997, Hofdijk 1998).

Data from encounters with a GP at privately managed PHC units in Blekinge county council were not retrievable because of the lack of electronic databases. This reduced the number of patients in studies III and IV by approximately 20 % on a county council level. The relatively low figures for two PHC centres might be explained by the fact that a large proportion of the private PHC units in Blekinge are located in this area. However, this should not have significantly influenced either the morbidity pattern in terms of ADGs or the distribution of ACGs.

When implementing systems that use different diagnostic codes, the technical mapping between the different coding systems is a possible source of error. This was recognised in study II, and a manual review of diagnosis codes according to ICD-10 in relation to ICD-9 was therefore carried out. Swedish PHC centres currently use a short version of ICD-10 (‘KSH97P’), and this catalogue was compared with the ICD-9 codes. Using equivalence tables from WHO (WHO 1997), it was possible to reduce the number of diagnosis codes used so that a manageable cross-over table with fewer that 1,000 lines could be created. Due to the inherent difference in terms of logic between the two diagnosis classifications, it is impossible to attain complete correspondence (Woods 1993). In total, only 10% of all relations between ICD-10 and ICD-9 are unique, i.e. with a one-to-one relation (judged based on the total list comprising more than 22,000 codes). Using the reduced crossover table that was created, the correspondence between the utilised codes from the two diagnosis systems is very roughly judged to be about 75-80%. The mapping from the KSH97P to the full version of ICD-10, which was used in study IV, has been much easier to fulfil, and very few codes are thought to be missed.

There may be differences between American and Swedish views regarding the initial assigning process into ADGs that might result in questions regarding the credibility of the ACG instrument in Swedish PHC. Thus far, evaluations as well as the views of health care professionals have indicated that the degree of correspondence between the US and Sweden, as well as the UK, with regard to the way of thinking in ADG grouping is sufficiently positive to warrant continuing the trials and appraisals of the ACG as a descriptive tool (Carlsson 1993a, Majeed 2001a and b).

Additional analyses may also be done on the PHC centre level concerning, for example, the constellation of morbidity for various groups of patients with specific diagnoses in a perspective of several years. In the future, the ACG system may provide a basis for more comprehensive analyses such as studies on clinical outcomes. As mentioned in study V, there is also a need to integrate other health related measures such as functional and self-perceived health status measures.

In connection with these studies, it is worthwhile mentioning an important issue in the area of public health. Too many measures and systems are using data based on what has been produced, ex post facto, and on what resources have been used in this process. Instead, in terms of health promotion there is a great need for systematic research on adequate measures and relevant analytic tools to understand and define more population-oriented and needs-based systems (Jarman 1983, Proposition 1999/2000).

Conclusions

Skin diseases caused by UVR exposure resulted in moderate economic losses in the Stockholm area. It was feasible to apply a model based on cost-of-illness analysis methodology to assess the annual direct and indirect costs of skin diseases.

The ACG system seems to be a feasible and relevant tool for describing the features of PHC within a municipality. The ACG grouping, which focuses on patient-based burden of illness, thus offers a complementary addition to current statistics on encounters, diseases and procedures, and may therefore be of interest with respect to planning and follow-up in PHC.

In PHC, the predominant types of morbidity are 'Time limited', 'Likely to recur', 'Chronic' and 'Signs/Symptoms', in nearly equal proportions. The majority of patients in the county can be categorised as having only one type of morbidity, and about one third of all patients can be classified as having a constellation of two or more types of morbidity during a one-year period.

The annual variation of categories of patients according to the ACG system was small on both the county and the PHC centre level. About three fourths of all residents had one or more diagnosis-registered encounters with a GP during the three-year period. The ACG system therefore seems useful for elucidating the distribution of categories of patients in Swedish PHC.

The comorbidity, expressed by the individual constellation of morbidities in the ACG system, was associated with a large proportion of the variation in PHC costs. Age and gender could explain individual patient costs to a minor degree. Accordingly, the ACG system has the potential to be a useful instrument for describing and explaining past resource consumption in PHC, even on the PHC centre level, as well as estimating future costs for health care. The ACG system appears to be sensitive regarding the accuracy with which physicians register diagnoses.

Sammanfattning på svenska (Summary in Swedish)

Denna avhandling riktar intresset mot delvis helt nya sätt att beskriva vårdens innehåll och verksamhet såväl ekonomiskt som kliniskt. Fokus ligger på att få till stånd en beskrivning av sjukdomsbördan i definierade befolkningsgrupper – i en kommun, en region, eller ett landsting – genom att gruppera patienter på ett sådant sätt att kliniska och befolkningsmässigt intressanta karaktäristika kan belysas. Information från befintliga register i hälso- och sjukvården med uppgifter om enskilda individer har använts för att sammanställa information om olika grupper av individer. En epidemiologisk ansats har således valts, men inte med fokus på diagnoser och sjukdomar, utan med en inriktning mot grupperingar som bygger på de enskilda patienternas samlade sjukdomstillstånd. Det övergripande syftet med denna avhandling är att spegla sjukdomsbördan i avgränsade populationer såväl ur ett ekonomiskt som ett kliniskt perspektiv.

Delarbete I är en hälsoekonomisk totalkostnadsanalys där såväl de direkta som de indirekta kostnaderna för en sjukdomsgrupp beräknats för en geografisk region. Syftet var att belysa kostnaderna i sjukvården och i samhället för en grupp av patienter med sådana hudsjukdomar som bedöms vara orsakade av eller relaterade till ultraviolett strålning. Studien visar en hälsoekonomisk cost-of-illness-analys av dennna patientgrupp. Uppgifter från främst register inom hälso- och sjukvården för invånare i Stockholms län för år 1999 inhämtades, med uppgifter om såväl kostnader rörande denna sjukdomsgrupp som generella kostnader. Totalt drabbades ca 27 000 patienter av de definierade sjukdomarna, varav ca 400 patienter inom slutenvården, drygt 14 000 inom öppenvården vid sjukhus, och ca 17 500 inom primärvården. Den totala årliga kostnaden för dessa sjukdomar i Stockholms län uppskattades till 162,4 MSEK, och de indirekta kostnaderna utgjorde ca 56% av den totala kostnaden. Den samlade kostnaden visade sig vara förhållandevis låg för denna sjukdomsgrupp men ändå av visst intresse eftersom insjuknandet i de aktuella diagnoserna ökade. Kostnadsbilden för patientgrupper med UVR-relaterade hudsjukdomar bedöms vara användbar vid planering av samhällsinriktad prevention.

Delarbete II handlar om patienter som anlitat primärvården i en kommun, och hur dessa kan föras samman till grupper med avseende på vars och ens sammansatta bild av sina hälsoproblem, med ledning av de diagnoser som registrerats vid läkarkontakter under en period av ett år. Syftet med studien var främst att pröva användbarheten av ett grupperingsinstrument, Adjusted Clinical Groups® (ACG), som utvecklats vid School of Hygiene and Public Health vid Johns Hopkins universitet i Baltimore i USA. Studien syfte var att pröva ACG-systemet för att beskriva sjukdomsbördan i en definierad befolkning. Uppgifter inhämtades om samtliga primärvårdskontakter för de båda kalenderåren 1998 och 1999 vid Gagnefs vårdcentral i Dalarna, med ca 10 000 individer i upptagningsområdet. Gruppering av patienterna gjordes till någon av totalt 81 ACG-grupper. De uppgifter som användes vid grupperingen var avidentifierat personnummer, kön, ålder samt läkarregistrerad diagnos. En jämförelse gjordes med Tibro vårdcentral i Västra Götaland för att pröva systemets användbarhet vid skilda journalsystem och dess möjligheter att få fram uppgifter för ACG-gruppperingen. ACG-systemet gjorde det möjligt att visa en annan bild av befolkningens hälsoläge än den som traditionellt speglas genom sammanställning av diagnoser och diagnosgrupper. Systemet visade sig användbart vid tillämpning inom primärvården och resultatet bedömdes ge en bild av vårdtyngden vid en vårdcentral som kompletterar traditionella sammanställningar av diagnoser, sjukdomar och sjukdomsgrupper.

I delarbete III tillämpades ACG-systemet med patientdata från ett helt landsting. Syftet med studien var att redovisa sjukdomsbördan för olika grupper av patienter på ett kliniskt relevant sätt, sorterade efter vars och ens samlade sjukdomsbild, baserat på i primärvården registrerade diagnoser under ett kalenderår. I studien användes uppgifter från samtliga enheter som bedriver primärvård i offentlig regi i Blekinge läns landsting, med en total befolkning på ca 150 000 invånare. Data från den privat drivna primärvården kunde inte inhämtas då dessa uppgifter inte var datoriserade, vilket innebär att ungefär 20% av primärvårdens patienter i landstinget inte fanns med i denna studie. Gruppering gjordes med hjälp av ACG-systemet på samma sätt som i delarbete II men med en senare version av systemet. Det huvudsakliga syftet i studie III var att beskriva de ingående sjukdomstyperna och de resulterande patientkategorierna efter en gruppering med ACG-systemet. Den bild av sjukdomsbördan som framträdde utifrån de 82 ACG-grupperna, var att ungefär två tredjedelar av patienterna hade en (och endast en) sjukdomstyp under året, medan resterande tredjedel hade en kombination av två eller flera olika sjukdomstyper. De vanligast förekommande sjukdomstyperna kunde delas in i fyra proportionellt ungefär lika stora grupper av tillstånd: ”Tidsbegränsade, övergående”, ”Troligen återkommande”, ”Långvariga”, samt ”Sjukdomstecken/Symtom”.

I delarbete IV har uppgifter från tre på varandra följande kalenderår använts, även här från den offentligt drivna primärvården i Blekinge läns landsting, och grupperats med hjälp av ACG-systemet. Syftet var dels att uppskatta hur stor andel av befolkningen inom ett område som har kontakt med primärvårdsläkare under en tidsperiod, och dels att belysa olika populationers sjukdomsbörda över tid. Resultatet visade att ca 90% av invånarna i landstinget hade kontakt med primärvården under hela treårsperioden. Variationerna över de tre åren för respektive vårdcentral visade sig vara så små att inga statistiskt säkerställda skillnader kunde påvisas mellan åren.

I delarbete V var syftet att åskådliggöra sjukdomsbördan i en definierad befolkning även i ekonomiska termer, genom att utnyttja ACG-grupperna som grund för relativa ekonomiska vikter. Genom att utnyttja ett utvecklingsarbete vid Ödeshögs vårdcentral i Östergötland som lett till att det går att beräkna årskostnaden för varje patient har denna kostnad per patient utnyttjats för att skapa relativa vikter för varje ACG-grupp, sedan vårdcentralens patienter grupperats enligt detta system. Därefter har uppgifter från Ryds vårdcentral i Linköping i samma landsting samlats in och ACG-gruppering har gjorts, där de relativa vikterna från Ödeshög har använts och även jämförts med relativa vikter från ACG-bearbetningar från andra länder. Det visade sig att ACG-grupperingen förklarade variationen i kostnaden per patient ungefär fyra gånger bättre än vad faktorn ålder och kön kunde göra. Möjligheten att använda sig av ACG-systemet för fördelning av resurser till primärvården bedömdes dock vara beroende av en tillförlitlig diagnosföring.

Vid beskrivning av sjukdomsbördan i ekonomiska termer är det viktigt att kunna bedöma graden av säkerhet vid beräkning av främst de indirekta kostnaderna för de i delarbete I valda diagnosgrupperna. Humankapitalmetoden, som beräknar produktionsförlusten ur ett samhällsperspektiv, har använts. Beräkningarna har delvis kunnat preciseras genom att uppgifter från den egna regionen har använts. I delarbete V har relativa ACG-vikter beräknats som grund för allokering av primärvårdsresurser. Det finns dock ett behov av att konstruera svenska relativa vikter på ett tillförlitligt sätt inför kommande tillämpning av resursallokering med hjälp av ACG-systemet.

Sjukdomsbördan i klinisk mening, som den redovisats i delarbete II, III och IV, lyfter fram frågan om graden av tillförlitlighet vad gäller diagnossättning i primärvården, och därmed risken att inte på ett relevant sätt fånga det aktuella samlade tillståndet för respektive patient. Det föreligger vidare vissa problem av generell art med att tillämpa ett instrument från ett land som i många stycken har en annan sjukvårdsstruktur än Sverige.

Avhandlingen visar att det i dag är möjligt att beskriva sjukdomsbördan i en befolkning i både ekonomiska och kliniska termer genom att använda information från befintliga register i hälso- och sjukvården. Genom att fokusera på den enskilde patienten och grupper av patienter med likartade tillstånd kan detta ske på ett sätt som kompletterar traditionell rapportering av diagnoser, sjukdomar och deras utbredning i befolkningen. ACG-systemet, med dess gruppering av individer efter det samlade aktuella tillståndet hos var och en, har visat sig användbart som beskrivningsinstrument för att redovisa och analysera sjukdomsbördan hos patientgrupper i en avgränsad befolkning. ACG-systemet skulle framöver även kunna användas för att fördela resurser till svensk primärvård med stöd av relativa ACG-vikter, baserade på beräkningar av kostnad per patient i svensk primärvård. Ett sådant utvecklingsarbete kan grundas på användning av uppgifter från befintliga datoriserade patientjournaler inom primärvården, kombinerat med ett intresse hos vårdgivaren att registrera flertalet av de problem som tillsammans kan belysa patientens verkliga tillstånd.

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