The future health (care) burden of chronic diseases in the Netherlands
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Chapter 8

General discussion
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8 General discussion

The overall aim of this thesis is to assess the (future) health care burden related to chronic diseases, and to identify incentives that can curb the expected increases in the health care burden. Chronic diseases have become a major public health problem as a consequence of the ongoing aging in the Dutch population. The drawback of this aging process is the increasing prevalence of chronic conditions and the concomitant rise in comorbidity, resulting in a large upward pressure on health services and related health care costs. In order to sustain a high quality health care system in the future, it becomes essential to find incentives that can curb the occurring gap between demands and supply of health care. Till now, health care systems have not adapted adequately to the changing health care demands of their populations. Mainly two solutions are proposed in health care policy to bridge the occurring gap between demand and supply of health care, namely a strengthening of primary prevention by promoting a healthy lifestyle and a reorganization of health care by means of disease management programs.

The research questions in this thesis were formulated as follows:
1. What is the impact of chronic diseases and comorbidity on the future health care burden?
2. What is the impact of trends in risk factors on the future burden of chronic diseases?
3. What is the impact of organizational shifts in health care on the future health care burden of chronic diseases?

To answer these research questions, two main research methods were used, namely medical record linkage and modeling techniques. Throughout this thesis diabetes mellitus and stroke are discussed as illustrative examples. In this closing chapter, we will briefly summarize the main findings of this thesis along the lines of the three research questions. Furthermore, we will discuss some methodological issues and the implications of the findings for health (care) policy and future research.

8.1 Main findings

To assess the future health care burden, we need data about the multidisciplinary health care utilization of patients with chronic diseases. To obtain these data we used medical record linkage techniques. At the time of the start of this thesis, these medical record linkage techniques were scantily used. Therefore, we performed a pilot-study to assess the technical possibilities and the usefulness of medical record linkage techniques for obtaining multidisciplinary health care utilization data (chapter 2). The pilot-study demonstrated that about 78% of the patients who were referred to a specialist by the GP could be linked to the hospital registration data. We concluded that the linkage is a useful and valuable tool to quantify the health care utilization of the chronically ill and to compare the health care utilization patterns of different patient groups. Medical record linkage techniques are increasingly used to create large datasets for health care statistics in the Netherlands.
The impact of chronic diseases and comorbidity on the future health care burden

We assessed the impact of comorbidity on multidisciplinary health care utilization in patients with diabetes (chapter 3). Forty-three percent of all diabetes patients has comorbidity. We observed a strong positive correlation between the number of comorbidities and the use of GP care, ambulatory specialist care and hospital admissions in patients with diabetes. Comorbidity was defined as vascular-related (heart disease, stroke, nephropathy and diabetic foot) and non-vascular related comorbidity (depression, neurological diseases, musculoskeletal diseases and cancer). We found no systematic differences between patients with either vascular comorbidity or non-vascular comorbidity, meaning that non-vascular comorbidity is an equally important utilization driver as vascular comorbidity. Preventing comorbidity in patients with diabetes could substantially reduce the health care utilization patterns of patients with diabetes and as a consequence the workload of GPs and medical specialists.

The impact of trends in risk factors on the health care burden of chronic diseases

We investigated the impact of trends in risk factors for stroke by using a dynamic model (chapter 4). The constructed dynamic stroke model showed that the number of stroke patients will rise continuously until the year 2020. Stroke incidence was estimated to increase from 1.8 per 1,000 in 2000 to 2.3 per 1,000 in 2020 for men (28% increase) and from 2.5 per 1,000 to 2.8 per 1,000 for women (12% increase). Stroke prevalence will increase from 7.7 per 1,000 in 2000 to 8.2 per 1,000 for men (7% increase) and from 7.2 per 1,000 to 8.9 per 1,000 for women (24% increase). A large part of this increase is inevitable as a consequence of the aging of the Dutch population. For the medium term, the increase in prevalence is marginally explained by the predicted changes in smoking behavior and the prevalence of hypertension. A reduction of smoking and hypertension rates in the population will substantially reduce the prevalence of stroke in the long run. New priority setting regarding primary prevention of stroke is necessary to reduce the number of stroke patients in the long run.

The impact of organizational shifts in health care on the health care burden of chronic diseases

We studied the impact of organizational shifts in health care for diabetes patients (chapter 5) and stroke patients (chapter 6). We focused on diabetes service characteristics which can be considered as main features of diabetes disease management programs, i.e. the implementation of diabetes consultation hours and diabetes control schemes, multidisciplinary meetings and the implementation of specialized diabetes nurses. Although medical care utilization of diabetes patients varied largely between GP practices, we could not identify any diabetes service characteristic that substantially influenced medical care utilization. One of the policy reasons to develop disease management programs, besides improving the quality of diabetes care, was to curb the increasing health care demands and related costs. We found no evidence that the implementation of diabetes disease management programs will achieve that goal. However, more comprehensive data on the diabetes services provided, like the performed tasks and responsibilities of the specialized nurses, are needed to fully understand the impact of diabetes disease management programs.

To investigate the effects of disease management programs with respect to stroke we estimated the future burden of stroke in terms of health care costs for both ‘current practice’ and for ‘a nationwide implementation of stroke services’. We extended the constructed stroke model (chapter 4) with cost estimates which were derived from primary research (1;2). Based on the ‘current practice scenario’, the direct medical costs of stroke in the Netherlands were estimated to rise with about...
28% from €1.62 billion in 2000 till about €2.08 billion in 2020. The ‘stroke services scenario’, in which a nationwide implementation of stroke services was assumed, showed a substantial reduction of health care costs as compared with continuing current practice (€1.84 billion compared with €2.08 billion). The estimated hospital care costs in 2020 decreased with 38% compared to the current practice scenario (€590 million versus €366 million), which was caused by a shorter average length of stay in the hospital (from 20 days till 13 days). The implementation of stroke services will cause a substitution of costs from hospital care and institutional care to non-institutional care.

We compared our cost estimates from chapter 6 with a systematic review of the literature about stroke cost studies (chapter 7). Twenty-five studies were selected based on quality criteria. These studies used different methodologies, the costs estimates for stroke are approximately similar. The proportion of the national health care expenditures spend on stroke in the eight countries studied is unequivocal for the most recent studies, i.e., ≈ 3% of total health care expenditures. This finding was irrespective of the employed methodology (top-down versus bottom up and incidence based versus prevalence based). A shift was observed from the inpatient treatment cost (in the first year) toward outpatient treatment cost and long-term care costs (in the latter years). This shift in costs is consistent with our findings based on the stroke model.

Our stroke cost estimates based on our stroke model appeared to be higher (4.3% of the total national health care expenditures) than stroke cost estimates found in the review. These differences in costs can partly be explained by the more detailed patient-based cost data in our study in comparison with more aggregated cost data in the review, by the introduction of more expensive medical technologies in the recent years like CT-scans and thrombolysis, and an increasing percentage of stroke patients admitted to a hospital. Moreover, most included cost studies did not perform a sensitivity analysis and did not present 95%-confidence intervals. Therefore, uncertainty ranges around the presented point estimates are lacking, which hinder a good comparison of the different cost estimates.

8.2 Methodological issues
In this paragraph, we will discuss the strengths and weaknesses of medical record linkage (chapter 2-4) and modeling techniques (chapter 5 and 6).

Medical record linkage techniques
By using medical record linkage techniques we were able to create longitudinal datasets on the multidisciplinary health care utilization of different patient groups.

In this thesis, we provided detailed information on health care utilization of chronic diseases with respect to GP care and hospital care. However, no information about long-term care utilization was available. Future research should address the full chain of health care by additional linkages with other (health care) registrations, i.e. home care, rehabilitation and nursing home care. In addition, linkages with population registers like the Dutch Population Register data (Dutch abbreviation GBA) should be adopted to enrich current linkages with cause-of-death statistics (to fully understand the disease impact), and with additional statistics like income and household statistics (to gain more insight into high-risk groups) (3).

A disadvantage of medical record linkages techniques is that some small selection bias will occur. Linkage probabilities between older and younger patients differ because of different rates of changes of address (4). Younger people move more often than older people and therefore have lower linkage probabilities since area postal code is one of the linking variables. Consequently, the hospital utilization of younger patients could be underestimated as compared to older patients.
Another methodological issue is the occurrence of false-positive and false-negative linkages, resulting respectively in an overestimation and an underestimation of health care utilization (5). This methodological problem will be solved when the so called Citizen Service Number (Dutch abbreviation BSN), which recently has been approved by the Dutch parliament (6), will be implemented. This BSN is a new national identification number and will replace the current social-fiscal number. The BSN will also be used for patient identification in the Dutch health care system. The usefulness of such a national health care number has already been demonstrated in the Scandinavian countries and specific parts of Canada, without comprising the privacy of their citizens (5;7-9). Within a couple of years, medical record linkages in the Netherlands will be performed with this BSN. Till then, medical record linkage on the basis of data of date of birth, gender and 4-digit postal code is a suitable solution.

Modeling approach
The main strength of dynamic models is that they provide an opportunity to estimate and understand the future dynamics in chronic disease epidemiology (10-12). The pitfall of dynamic models is that assumptions have to be made because of data inaccuracies which (might) affect the validity of the outcomes (13). To gain insight into the impact of the assumptions and the validity of the outcomes of such models, sensitivity analyses are performed. In sensitivity analyses the minimum and the maximum values of the most sensitive variables are used to test the robustness of the models and the assumptions made. Our stroke model appeared to be robust for most variables but appeared to be highly sensitive for changes in the epidemiological input data for stroke incidence and stroke prevalence. Currently, stroke incidence and prevalence estimated are based on multiple GP registrations, which however show large variations (14). Therefore, more effort is needed to gather valid epidemiological data.

Our modeling approach comprised only one disease, namely stroke. However, to describe future health care demands of the chronically ill more is needed than a single disease approach. Changes in public health of a population must be considered in coherence with multiple chronic diseases to understand fully the impact of changes in multiple risk factors as demonstrated in the 'competing risk' theory (10). Preventing a chronic disease will (in the future) be substituted by another chronic disease. For instance, a prevented stroke might result in the occurrence of degenerative chronic diseases e.g. dementia (10). Using a more elaborated model including multiple diseases (i.e. diabetes, stroke, cancer, coronary heart disease) and multiple risk factors (i.e. smoking, alcohol consumption, physical (in)activity, fruit and vegetable consumption) will result in a clearer understanding of the competing risk theory and the future burden of chronic diseases. These insights will lead to more well-grounded decisions whether or not an intervention is (cost)effective and should be implemented.

8.3 Implications for health (care) policy and future research
Our findings reveal several implications for health (care) policy and future research.

Comorbidity
Although comorbidity is a common phenomenon in patients with chronic conditions, no systematic information about the prevalence of comorbidity is available, partly caused by the lack of standardization on how to measure comorbidity in patients with chronic diseases. Prevalence figures of comorbidity strongly depend on the number of chronic conditions which are taken into account, the study population (e.g. general population vs. hospital population), and data collection (self-reported vs. medical registrations). These aspects considerably affect the prevalence figures of comorbidity.
Valid epidemiological information about the prevalence of comorbidity is essential for planning and organizing the complex care for chronic patients. More efforts are needed to standardize the methodology on how to measure comorbidity in order to fully understand the (future) health care burden of chronic diseases.

We demonstrated that comorbidity measured with a summary scale is a good predictor for the health care utilization pattern of chronically ill. On the other hand, several studies showed differential health effects of different pairs of chronic conditions (15-18). More insight is needed into the usefulness of different comorbidity measures (e.g. summary scale, dichotomous and disease-specific) in order to assess the impact of comorbidity on the future health (care) burden.

Current disease management programs often focus on a single chronic condition. These disease-specific care programs fail to address the broader needs of patients with comorbidity. Disease-specific disease management care programs need to be extended with additional care modules which must generic (non-disease specific) and focusing on both somatic and psychological conditions. Such a model will address the health care needs for the person’s entire constellation of comorbidities (19).

The first trial with such a model of integrated generic care for a wide range of chronic conditions like diabetes, cardiac diseases and respiratory diseases has resulted into improved health outcomes (20). In addition, comorbidity should be more integrated into the health care practice. Current guidelines and care protocols are focusing on one single disease and are not suitable for many patients with comorbidity (21,22). Future research should aim at providing insight into how clinical guidelines and disease management programs can best respond to the problems of patients with comorbidity.

**Primary prevention**

In this thesis, we demonstrated that primary prevention i.e. changing trends in risk factors will result in small, but important, health benefits in the medium-term. In the medium term, the health benefits of primary prevention will be overshadowed by the effects of the ongoing aging of the population. However, these results were based on the effects of primary prevention for only one disease (stroke) and only for two risk factors (smoking and hypertension). In reality, the health benefits of primary prevention will be larger and therefore are underestimated in our analyses. In the long run, primary prevention will result in large health gains. Large investments with a long time-horizon are needed in order to prevent chronic conditions by primary prevention.

There is an ongoing debate about which primary prevention strategies are the most effective (23–25). More research is needed to gain insight in the costs and benefits of (primary) prevention interventions. Particularly long-terms effects of (primary) prevention interventions, and effects of (primary) prevention interventions on target groups are still gaps in knowledge (26). Also more efforts are needed to strengthen primary prevention within disease management programs. Patients with chronic conditions should routinely be screened on multiple risk factors and multiple chronic diseases (targeted prevention). New policy measures resulting in new (financial) incentives are needed to really integrate (primary) prevention in (primary) care and disease management programs.

**Organizational shifts in the health care system**

We demonstrated that a nationwide implementation of stroke disease management programs, so called stroke services, can lead to a substantial reduction in costs for stroke. Major components of stroke service are a hospital unit, protocol based care, special staff training and agreements about transfers from the hospital to another institute to reduce hospital discharge delay (27). The effects of stroke services are well evaluated and have demonstrated to improve the functional status and
quality of life for patients (1;2;28;29). Continuing efforts are needed to implement stroke services throughout the Netherlands.

Also diabetes disease management programs are currently implemented on a larger scale in the Netherlands (30-33). However, there is a lack of demonstrated effects of these organizational shifts on the health care burden of diabetes in well-designed evaluations (32). Preceding the implementation of diabetes disease management programs, evaluation studies need to be performed in order to establish its beneficial effects.

An interesting issue is whether common elements of disease management programs can be translated to other chronic diseases (34). More research is needed to investigate by which ‘causal pathways’ effective stroke services have achieved a reduction in the health care utilization. Multiple ‘causal pathways’ are described in the literature, namely quality improvement, utilization management and productivity improvements (35;36). Quality improvement encompasses increased use of effective medication and improved self-care, thereby preventing complications and comorbidities. Utilization management in disease management programs concerns reduction in the overuse of health care demands of chronically ill by preventing duplicative tests, facilitating timely discharge from the hospital and eliminating inappropriate prescriptions. Productivity improvements could result from task delegation and task substitution for instance to offload work of GPs to less costly (specialized) practice nurses or to deliver care (i.e. education programs) by using the Internet.

Disease management can pursue all causal pathways, but targeting pathways for different chronic diseases might lead to better results (35;36). Insight into the different causal pathways of the success of stroke disease management programs will help to determine for which patient groups disease management programs could be beneficial.

Disease management programs in the Netherlands still exist on a limited scale for most chronic diseases. Most initiatives are found for diabetes and stroke (37;38). One of the delaying factors for a widespread implementation of disease management programs is the multiple sources of funding in the Dutch health care system. This should be tackled by new legislation. Currently, the Ministry of Health, Welfare and Sports have proposed a Diagnosis Treatment Combination (DTC) for primary care as a possible solution (39). Currently, the diabetes DTC for primary care is implemented and evaluated in 10 frontrunner regions (30). Results of this evaluation are expected at the beginning of 2009. When the Diabetes DTC for primary care is successful, the concept of an integrated financing system can probably also be implemented in other disease management programs like COPD, rheumatoid arthritis, and chronic heart failure.

Another delaying factor for the widespread implementation of disease management programs is a delay in the transfer of knowledge about effective implementation strategies between health care providers (40). Effective implementation strategies like the Breakthrough series (41) must spread out disease management programs more efficiently and faster throughout the health care system (40).

Chronic care is becoming increasingly important in the next coming decades due to the aging of the population. Prevention and disease management programs should receive higher priority in research and policy, in order to reduce the future health (care) burden of chronic diseases.
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