Chronic disease management in Europe

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Summary: Chronic conditions and diseases are the leading cause of mortality and morbidity in Europe. Managing chronic diseases has therefore become a health policy priority in many European countries. However, current approaches face substantial problems. This article briefly presents the main strategies to manage chronic diseases and summarises existing evidence on their effectiveness. Moreover, we describe common obstacles to effective chronic disease management. Finally, we conclude by outlining some of the actions policy makers need to take to improve the conditions for chronic disease management in Europe.

Key Words: Chronic Disease Management, Health Systems, Europe

Policy makers across Europe increasingly recognise that chronic disease management (CDM), the ongoing management of conditions over a period of years or decades, is one of the most important challenges that European health systems face. Chronic conditions and diseases are the leading cause of mortality and morbidity in Europe and research suggests that complex conditions, such as diabetes and depression, will impose an even larger health burden on societies across Europe in the future. The World Health Organization ‘Global Burden of Disease’ study estimated that, as of 2002, chronic or non-communicable conditions accounted for 87% of deaths in high income countries. By comparison, 7% of deaths were attributed to communicable conditions and nutritional deficiencies, and 6% to injuries. Worldwide, the proportion of deaths due to non-communicable or chronic diseases is projected to rise from 59% in 2002 to 69% in 2030.1

CDM embraces not only the ‘classical’ conditions such as cardiovascular disease, diabetes and asthma, but also many types of cancer and HIV/AIDS (as survival rates and times have visibly improved), mental disorders (for example, depression, schizophrenia and dementia) as well as certain disabilities (for example, visual impairment). CDM is a complex response over an extended period with coordinated input from a wide range of health professionals, as well as access to drugs and equipment and patient empowerment going beyond medical care into the social care setting. This is in contrast with most health care today, which is structured round acute, episodic models of care.

It has been shown that the economic implications of chronic diseases and conditions are severe from both the macro- and microeconomic perspectives. Chronic diseases impact on wages, workforce participation, labour productivity and hours worked. Often, chronic conditions contribute to early retirement, high job turnover and disability. Overall, disease-related impairment of households’ consumption and educational performance affects the gross domestic product (GDP) negatively. In addition, expenditure on chronic care is rising across Europe and consumes increasing portions of public and private budgets. Suhrcke and Urban2 demonstrated that the cost of chronic diseases and their risk factors, as measured by cost-of-illness studies, is sizeable, ranging up to 6.77% of a country’s GDP.

Policy makers across Europe have developed heterogeneous CDM strategies, such as disease management programmes (DMPs) or prevention and early detection interventions. However, research suggests that many of these current approaches to CDM face substantial structural problems and hence have failed to fulfil hopes and promises.3 This article briefly outlines the principal CDM strategies and summarises existing evidence on their effectiveness. We also highlight common obstacles impeding successful CDM and outline a series of steps that policy makers need to take to improve the conditions for effectively managing chronic diseases in Europe.4

CDM strategies

Disease prevention and early detection interventions aim to reduce the burden of chronic disease through activities that avoid impairment to health or reduce the likelihood of chronic conditions developing. Prevention includes primary,
secondary, or tertiary approaches that differ in aims and target groups. Primary prevention targets the prevention of illness by removing the causes, especially in periods of increased risk. Secondary prevention aims to treat disease at an early stage, when first observable and perceivable pathophysiological changes occur, so that people can be cured early or be prevented from further deterioration. Tertiary prevention activities intend to cure, alleviate or compensate for the impacts of a disease up the point where it can no longer be influenced.4

The specific prevention approaches adopted in a country vary according to the health care system and dominant political opinions. European countries place different emphasis on the responsibility of the community and the individual, depending on culturally anchored views about the role of the state and the autonomy of the individual.5 Overall, the effectiveness of prevention and early detection interventions is relatively well documented for risk factors such as hypertension, obesity or alcohol and tobacco consumption. In particular, research indicates that comprehensive approaches, combining several interventions are most effective. Compared to curative and acute treatment, a high proportion of prevention interventions have proven to be cost-effective. Even though prevention is a promising strategy for managing chronic diseases, it still plays only a secondary role in European health systems. Most countries have not yet reacted to the need for prevention of chronic diseases at a programmatic level.

New professions, qualifications and settings were designed to meet the challenge of CDM in Europe. For instance, nurse practitioners, liaison nurses and community nurses have been introduced in several countries. In addition, the tasks and responsibilities of existing professional groups have shifted and expanded. For example, the UK and Scandinavian countries have implemented a ‘collaborative methodology’ as an instrument for managing chronic diseases by training physicians to have a guiding role through the health system.4 Finally, new settings were established over the last decade including nurse-led clinics, group practices and medical polyclinics in which general practitioners, specialists and other health professionals cooperate. Empirical evidence on the impact of new providers, qualifications and settings on the quality of care and efficiency is limited so far. Pilot studies indicate that new ways to organise provision at the structural, organisational or individual health professional level can help to meet the challenge of effective CDM. However, these approaches often suffer from fragmentation and a lack of coordination between different actors in the health system.

Disease management programmes have been implemented in many European countries. While no universal definition of DMPs exists, most definitions share three main features: a knowledge base, a delivery system with coordinated care components, and a continuous improvement process for a specific disease among a defined population.7 Further key elements of DMPs are presented in Figure 1.

In summary, DMPs can be regarded as a means to coordinate care, focusing on the whole clinical course of a disease. Care is organised and delivered according to scientific evidence and patients are actively involved in order to achieve better health outcomes. Structured DMPs for selected conditions were originally developed in the United States and subsequently adopted by a number of European countries, including Germany and the UK. The effectiveness of European DMPs has not been sufficiently evaluated. Large-scale population-based evaluations with rigorous research design are lacking. In part, this is due to the relatively short time period that has elapsed since DMPs have been established across Europe.3 Small-scale studies suggest that DMPs may have a positive impact on the process of care for congestive heart failure, coronary heart disease, diabetes and depression, while the evidence for asthma and chronic obstructive pulmonary disease is inconclusive. With regard to medical outcomes, the existing evidence is also inconclusive.

Most small-scale studies suggest that DMPs are hampered by a lack of coordination between professional groups, the absence of well-targeted financial incentives, as well as fragmentation in the health care sector.

Finally, integrated care models respond to the fact that chronic diseases can rarely be treated in isolation. Often patients suffer from several chronic diseases or conditions. Hence, while DMPs focus on one single disease, integrated care models are organised to achieve better integration of services across the whole continuum of care for various diseases. Integrated care models developed in the US have been influential in informing chronic care policies in Europe and elsewhere.3 European countries such as England, Germany and Spain have invested considerably to develop integrated care models inspired by experience in the US. Other countries, such as the Netherlands or France, have established provider networks which bridge the gap between ambulatory and inpatient sectors to achieve better integration of services across the whole continuum of care. The effectiveness of integrated care models is controversial. Large-scale population-based studies are lacking. Preliminary results from pilot studies suggest that some positive results may be generated, but given the complexity of integrated care models, again implementation, coordination and fragmentation are key challenges. Moreover, studies fail to indicate which components of integrated care are responsible for positive and negative results.

### Key challenges to successful CDM

The broad set of policy instruments to meet the challenge of CDM in Europe indicates that policy makers have invested considerable energy and resources. Never-

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**Figure 1: Disease Management Programmes - Key Elements**

- comprehensive care: multidisciplinary care for entire disease cycle
- integrated care, care continuum, coordination of the different components
- population orientation (defined by a specific condition)
- active client-patient management tools (health education, empowerment, self-care)
- evidence-based guidelines, protocols, care pathways
- information technology, system solutions
- continuous quality improvement

Source: Velasco et al, 2003.8
the presence of patients with chronic disease for funding towards incentives at the provider level. 11

approaches that simply take into account narrow goals may lead to an excessive focus on incentivised versus other tasks or areas of quality, as well as more gaming or better reporting, but without any improvements in quality.

Financial flow and incentives

Common problems in the effective management of chronic diseases are financial flows and incentives, which do not motivate health professionals to engage in CDM. The importance of financial incentives is intuitive: however motivated some health care stakeholders may be to implement changes to improve chronic care, few will operate counter to their economic interest.9 Table 1 summarises examples of the use of financial incentives in CDM across Europe.

Different types of financial incentives are used in CDM to motivate providers and health professionals: they tend to focus either on the structure or processes of care.10 Only the UK general practitioner (GP) contract specifically includes a range of incentive payments focused on the delivery of particular outcomes. In general, there has been a gradual shift of focus from approaches that simply take into account the presence of patients with chronic disease for funding towards incentives designed to encourage specific kinds of structural and process responses at the provider level.11

The impacts of these incentives are rarely scrutinised. However, the US experience offers some insights: designs that set a few narrow goals may lead to an excessive focus on incentivised versus other tasks or areas of quality, as well as more gaming or better reporting, but without any improvements in quality.

Moreover, financial incentives influence various subgroups of providers or health professionals differently. Those with high, average or poor performance prior to the intervention react differently to financial incentives. Thirdly, mixed approaches, combining different payment schemes such as fee-for-service (covering all expenditures after a medical intervention retrospectively irrespective of the total amount and the quality of the service) and case fees (covering only a predefined fixed sum for a specific intervention) may mitigate negative effects of either approach applied alone.

Finally, Peterson et al.12 find that the size of the incentive clearly matters: a significant percentage of income has to be variable before providers or health professionals can be expected to change their behaviours. Overly large incentives on the other hand may motivate health professionals to concentrate excessively on incentivised goals at the expense of other implicit targets.

Some evidence has also been generated about the Quality and Outcomes Framework (QOF) for GPs in the UK. This established pay-for-performance at the GP practice level by monitoring outcomes and quality variables. Typically about 25% of practice income is dependent on quality rewards.

While some controversy exists about the impact of the programme, positive outcomes with regard to quality of care, especially chronic care, have been identified.13 In particular, patients seem to benefit from the provision of more systematic care. In addition, structures are important since improvements in the quality of care tend to generate (measurable) benefits only in the long-term. Hence, health professionals and providers can only be effectively incentivised to improve chronic care, if a certain ‘continuity of care’ is ensured.

Table 1: Financial incentives in European health systems

<table>
<thead>
<tr>
<th>Financial incentives targeting the individual</th>
<th>Financial incentives targeting structures of care</th>
<th>Financial incentives targeting processes of care</th>
<th>Financial Incentives targeting outcomes of care</th>
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<tr>
<td>Piloting ‘year of care’ payments for the complete package of CDM required by individuals with chronic conditions. For example, based on validated ‘care pathways’ for diabetes (DK; UK)</td>
<td>Per patient bonus for physicians both acting as gatekeepers for chronic patients and setting care protocols (FR)</td>
<td>Points for reaching process targets (UK: GP contract)</td>
<td>Points for reaching outcome targets (UK: GP contract)</td>
</tr>
<tr>
<td>Additional services (for example, patient self-management education) only reimbursable if physicians and patients participate in DMP (GER)</td>
<td>Bonus for DMP recruitment and documentation (GER)</td>
<td>1% of overall health budget available for integrated care (GER)</td>
<td></td>
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<tr>
<td></td>
<td>Points for reaching structural targets (UK: GP contract)</td>
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Note: DK = Denmark; FR = France; GER = Germany; UK = United Kingdom
Source: Authors’ own table based on Busse and Mays, 2008.10
– Individuals or professional groups compensated for separate activities rather than for cooperation.
– Rivalry over resources and power between professional groups.
– Overlapping responsibilities and non-transparent accountability between divisions within providers and between different providers.3

In addition, high levels of professional concern among physicians with regard to shifting competencies to other professional groups, such as nurses or general practice, can pose considerable challenges to the coordination of chronic care.14 Finally, the absence of training for staff meant to perform these new roles is a serious problem.

Information and communication technology

Another obstacle to the effective management of chronic diseases in Europe is the lack of efficient use of information and communication technology (ICT). Expectations with regard to the former were high. Abstract models and a number of small-scale pilot studies suggested that multiple benefits could be generated through the employment of computerised data collection and decision support systems and data collection. In particular, the use of evidence-based medicine, supported by electronic protocols and clinical pathways, was considered attractive since improvements in the quality of medical outcomes and efficiency gains seemed to be achievable.

However, experience to date does not suggest that ICT has generated large benefits. In many European countries, ICT initiatives suffer from unexpected difficulties, budget-overruns and high costs. In addition, no well-grounded empirical evidence of the benefits of ICT has been generated. Pilot studies have however identified a number of common problems: functional interoperability within health systems is not given; no practical tools are offered on how the vast data which modern information technology is able to store, can be translated into meaningful information for health professionals; and public concerns about data protection are not adequately addressed.

Evaluation

Furthermore, many aspects of CDM are not properly evaluated. The effectiveness and cost-effectiveness of various preventive and treatment interventions are not well established. Policy makers are therefore not optimally equipped to make informed decisions to shape the future of CDM.

Pharmaceutical and medical innovation

It is essential that the important role of pharmaceutical and medical innovation continues to be recognised. A new type of pharmaceutical, for example, personalised medicine, may lead to better medical outcomes, adherence and improvement in patients’ quality of life. At the same time, the development of innovative pharmaceuticals, especially pharmaceuticals and therapies targeting rather small population groups effectively at high costs, poses huge challenges with regard to authorisation and reimbursement.

Conclusion

Given these structural and organisational problems with CDM, policy makers in Europe can clearly contribute to improving the conditions for effective CDM.

With regard to financial incentives, making the payment schemes of different professional groups compatible is a prerequisite to the facilitation of cooperation in multidisciplinary teams. Different financial incentives for members of the same medical team may frustrate common efforts, as economic interests may motivate demands for different approaches to treatment. Moreover, continuity of care needs to be one of the key preconditions for payer or provider investment in CDM programmes, since any net returns from up-front investments tend to be made five years after installation while the benefits of avoiding severe complications tend to be collected only five to ten years after prevention.

As a consequence, health systems with a traditional focus on ‘patient choice’ of providers, little enrolment with particular providers and/or payment using fee-for-service as the key approach for reimbursement, all of which lead to relatively low continuity of care, face the greatest difficulties in aligning financial incentives with the goal of promoting better CDM. Given the former, policy makers should consider strengthening or introducing financial incentives conducive to ‘continuity of care’.

To enhance coordination, policy makers need to decide early on whether a radical departure from the given structure is needed for more effective coordination, or whether reform can build on established norms, institutions and practice. Structurally, policy makers need to map out both clearly shared and clearly separated responsibilities of the actors involved in the delivery of chronic care. Moreover, the balance between local autonomy and central authority during reform and routine operation needs to be defined. Operationally, there is a need to provide sufficient funding to enable reform, while at the same time compensation schemes conducive to cooperation rather than emphasising professional separation need to be established. Finally, the workforce needs to be prepared to fulfil their new roles: hence adequate training and mutual learning and communication need to be initiated.

In the face of globalisation and the European common market for goods and services, which increasingly penetrates health care markets, policy-makers need to ensure that standards and methods of evidence-based evaluation are internationally accepted and possibly harmonised. There is also a need to increase the transparency of procedures and policy decisions. Moreover, to overcome ICT problems connected to functional interoperability within health systems and to address public concerns on data protection, policy makers need to take the lead in introducing adequate technical standards and regulatory frameworks.

Finally, policy makers need to develop a clear position on the market authorisation and reimbursement of highly effective but costly personalised medicines. Furthermore, new criteria may be needed to assess interventions and treatments in CDM, since cure is rarely the medical goal. Hence incorporating concepts such as ‘quality of life’ more explicitly into marketing authorisation and reimbursement decisions should be considered.

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