

Disease Management in the Dutch Context

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Introduction

This book explores the extent to which ten characteristics of the concept of disease management are advisable in the long-term for certain types of patient care in the Netherlands. The care in mind for this concept covers certain patient populations as well as a number of health problems. For this purpose, the authors have taken as their starting point the following definition of disease management: *the programmatical and systematic approach of specific diseases and health problems by using the management instruments that aim at the advancement of quality and efficiency*. This definition is based on the literature study that was carried out by C. Spreeuwenberg for his research into the material covered in the first chapter.

The ten characteristics of disease management that were derived from the general literature by the aforementioned author are as follows:

1. relates to one health problem and is aimed at clearly-defined patient populations and sub-populations
2. methodological education and the advancement of self-management
3. orientation on the integration of the various parts of the care processes including preventive interventions
4. disease management protocols that are based on evidence-based diagnostics and treatment
5. classification of patients in clinical pathways based on sub-characteristics
6. substitution of care from physicians to nurses
7. use of information and communication technology
8. focus on the use of a range of management instruments such as benchmarking and feedback
9. large-scale and a robust organizational structure
10. direction and funding coming from a central point

The characteristics are thus classified according to patient care (characteristics 1 through 5) organization of the patient care (characteristics 6 and 7) and the management of patient care (characteristics 8 through 10).

The patient populations that were studied were those of cystic fibrosis (chapter 2), diabetes (chapter 3), depression (chapter 4), heart failure (chapter 5), and palliative patients (chapter 6). The choice for these patient populations was made by representatives of the Dutch Council for the Chronically Ill and Disabled (CG Raad). The idea was to cover a wide range of disorders affecting the young (cystic fibrosis) to the old (heart failure, palliative care) to psychiatric (depression) and somatic illnesses (other patient populations) and on the common disorders (diabetes, heart failure) and less common disorders (cystic fibrosis, palliative care). Authors were sought with a wide range of expertise on the development of integrated care for the patient population concerned. They used knowledge from five sources: 1) their own personal experience and expertise (see author information in appendix II), 2) recent published articles covering the period 1999-2004, specifically searched through Pubmed and Google; 3) the travel reports of Marianne Acampo who visited one location per patient group in the United States, 4) expert meetings in the spring of 2004 whereby leading care professionals for each patient population, project leaders and policy-makers in the area of integrated care in the Netherlands were present, and, 5) individual analytical and judgemental skills. On the basis of this last-mentioned factor, the authors reached their conclusions on whether or not disease management should eventually be introduced in the Netherlands for their respective patient populations. In short, their answer was: Yes, disease management is a desirable concept but only if...

The realization of this book has been made possible thanks to the efforts of the many contributors who are named in the acknowledgement section. It goes almost without saying that the final responsibility for the content of this book lies with the respective authors.

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1 Ten characteristics for an ideal disease management programme

Cor Spreeuwenberg

1.1 Introduction

Disease management is a health care concept that was developed in the United States during the nineteen-nineties and still needs to be refined. Although disease management is currently found all over the world, its various specific forms strongly depend on the health care system in which it is applied.

Disease management is a concept that could provide an answer to a number of problems in the current health care sector such as: increase in costs, higher inter-doctor variation, fragmented care, hardly any attention on how to positively influence bad professional behaviour, high degree of non-compliance, insufficient incentives for encouraging cost-awareness, inefficient health care and poor quality or inadequate medical content. Some of these problems have arisen because until recently the health care system worked on the basis of a duo partnership between 'patient and doctor'. In the privacy of the consulting room, individual care was given and decisions taken concerning diagnosis, referrals, treatment, and pharmacotherapy basically meaning that costs were ignored and bills sent to the health insurance company without any kind of control or responsibility for cost having taken place.

Disease management also links up with the phenomenon of a greying population as well as the increase in the number of chronically ill people. Those patients in the category of the chronically ill have different care needs to acute patients. Current care is not sufficiently geared to these changes meaning that health care for the chronically ill hardly fits with the nature of the specific disease-related problems and is therefore insufficiently effective. A health care system that is based on its own supply pays too little attention to the social and psychological aspects of the care process itself. Doctors often do not realize well enough that much of what goes on in and around a consultation makes the patients dependent on them meaning that they do not consider themselves to be the owner of their health problems. This is in spite of the fact that the effectivity of the treatment partly relies on the question whether or not patients act as if they are the owner of their problems. The way in which the care is given does not sufficiently stimulate patients to take responsibility for the various aspects relating to their disorder on which they themselves could have an influence. Here we think of such things as: healthy lifestyle, treatment compliance and accumulating a knowledge of the disorder in order to prevent the development of complications and be able to recognize and deal with any such complications should they occur. In this respect, the organization of the health care services is failing especially the chronically ill.

Not only in the Netherlands, but also in many other countries, the increase in expenditure for health care has forced people to look at ways of controlling the costs whilst at the same time improving quality. The situation in the United States however, differs from that in other parts of the world. Whereas in Europe, for example, the governments were able to employ a set of policy instruments that suppressed growth for a number of years, due to their grasp on the financing system such as budgets, the American government did not have either the will or the possibilities for controlling the costs involved. Health care services in the US, except for people over the age of 65 who are covered by Medicare and the very poor, are privatized. Not all care is accessible for all citizens by a long run. The involvement of the government in the health care services is considerably less in the US than in Europe. There the market forces are considered normal and the costs of health care are considerably higher. Employers hold considerable interest in the health of their

employees. This is due, on the one hand to the fact that they pay towards the insurance premiums and therefore a large part of the costs of the health services and, on the other hand because productivity of the enterprise is partly dependent on absence through illness. Even more than in Europe, the task of driving back health care costs and the prevention of unhealthy people has become a dire necessity for citizens and health insurers alike.

In Europe the professional groups have, under external pressure and backed up by the government, used the problems of the health services in order to put things right by developing scientifically responsible evidence-based standards, guidelines and protocols. However, this does not guarantee changes because apparently it is not easy to persuade individual practising professionals to adhere to the agreed guidelines. Such aspects as improving the organization, monitoring the quality and possibilities of substitution of care are still not receiving enough attention. In the United States, the practising professionals are not in a position to put their house in order due to the competitive climate and the powerful position held by their professional organizations such as the American Medical Association. The situation whereby physicians did not seize the available opportunities and where it was of vital importance for health care employees to have control over health care spending produced an industry in the form of so-called health plans. This system was designed to see either a 'return on investment' (ROI) or the development of programmes in which the care could be delivered at least cheaper and often also with a higher quality. This industry has placed itself as a third party between the traditional caregivers and the patients.¹ Initially, many of these third parties were associated with the pharmaceutical industry, a branch that has both knowledge of operational control of production processes and the health care system. Because people feared that this situation could lead to an unwanted interference on the part of the pharmaceutical industry regarding the protocols and specific prescription conduct, the American pharmaceutical industry was later forced by law to reduce its involvement with disease management programmes considerably. The involvement of third parties and the protection of their own rights regarding this has put the concept of disease management into an unfavourable light. However, this criticism is not always justified. A number of programmes have produced results on achieving more suitability and an improvement in quality due to the fact that they were strictly managed as well as adhering to a 'stick and carrot' approach.

The difference between the American and the European situations means that the concept of disease management cannot just be transferred to Europe as it is. Although market forces in Europe are also gaining ground, we can foresee that the influence of the national states on the health care system will remain considerable and that the coming into being of a large number of non-insured people will not be easily accepted. Furthermore, it should be taken into account that the expenditure for health care per head in the United States is approximately one and a half times higher than that of Europe without this factor going hand-in-hand with demonstrable gains in health. The possibilities for reducing costs and return on investment are therefore not as favourable for the initiators of disease management in Europe as they are in the United States.

The concept does however, have a number of elements that can be adapted for use in Europe, such as, looking for suitable categories of patients so that they can all be treated in the same way according to protocols, and the use of management instruments for monitoring the care process. In addition, the emergence of a market for the reintegration of employees who have been declared unfit for work, shows that in Europe as well there are opportunities for third parties who want to take responsibility for the realization of certain care elements. Incidentally, disease management is not implemented entirely by third parties in the United States.² In an institution such as the Mayo Clinic, care providers are themselves responsible for the operational and content-oriented approach that is characteristic of disease management.

1.2 Definition

A number of definitions are currently in circulation for disease management. Epstein described disease management in 1996 as '*a systematic, population-based approach to identify persons at risk, intervene with specific programs of care, and measure clinical and other outcomes*'.³ Zitter defined disease management in 1997 as '*a comprehensive, integrated approach to care and reimbursement based on the disease's natural course*'.⁴ Since 2002, the Disease Management Association of America (DMAA) talks about '*a*

system of coordinated health care interventions and communications for populations with conditions in which patient self-care efforts are significant'.⁵ Zalta kept the definition of disease management much simpler by using a definition which was short and to the point: '*pro-active case management*'.⁶ This pro-active approach concerns the prevention of both the occurrence of diseases as well as the prevention of worsening of diseases and health problems.

From the subtle distinctions between the above variations on the definitions of disease management, it is clear that there are many different visions. Zitter considers the aim to be as follows: *to address the illness or condition with maximum effectiveness and efficiency, regardless of treatment setting(s) or typical reimbursement*'. Commercial organizations however, mostly emphasize the savings that can be made in the health care system.

In the Netherlands, the Health Management Forum (STG) defined disease management in 1997 as: *'the process of encouraging continuous improvement in the measurable outcomes of the care continuum (e.g. from prevention to reintegration) of a specific disease'*.⁷ This description has also been adopted by the sector organization for health care insurers in the Netherlands (ZN).⁸

Personally, I describe disease management as follows: *'the programmatical and systematic approach of specific diseases and health problems by using the management instruments that aim at the advancement of quality and efficacy'*.⁹

Characteristics

The question is whether or not these definitions are clear enough to distinguish disease management from other forms of health care. It would be more productive to look closely at the characteristics attributed to disease management. The DMAA only considers a programme as belonging to disease management if it satisfies seven characteristics:³

- identification of a clearly described target group
- adherence to evidence-based guidelines
- encouragement of collaboration with physicians and other professionals aimed at providing supportive roles
- orientation towards education and the self-management of patients
- management of process, results, and evaluation
- routine reporting and feedback
- care continuum and integrated approach

In the United States disease management is mainly concerned with secondary or tertiary prevention, support of the therapy, encouragement of treatment compliance and health lifestyle. The STG and the ZN attach a number of other characteristics in order to fit in with the situation in the Netherlands. These concern the integration of various elements in the care chain: prevention, diagnostics, treatment, support and guidance, rehabilitation, and palliation. I would add horizontal and vertical substitution of care to this list where it is justifiably possible.

- *Identification of a clearly-defined target group*

Disease management can be applied to specific diseases and health problems that can benefit from an improvement in the organization and harmonization or coordination of the care. The programme must, therefore have something to offer. The selection and identification of diseases and health problems that could be suitable for disease management takes place on the basis of numbers of patients, the below optimal use of guidelines, the potential for successful interventions and the reduction of consumption and costs. Initially, disease management is pointing itself in the direction of the 'big five' chronic diseases: diabetes mellitus, heart failure, hypertension, asthma, and the cerebral vascular accident. By now, other disorders such as COPD, chronic joint disorders, and back problems can be applied to the principles of disease management. However, admission to a programme with the targeted population approach of disease management must offer patients with the specific chronic disorders either benefits or a reduction in costs. This is often not the case for extremely ill patients for whom a different protocol is followed where the emphasis is put on medically specialized treatment. If a programme is aimed at behavioural changes and it is clear from the start that the intended changes for an individual will not be achieved, then admission to such a programme is of no use. Therefore, it is essential to clearly define the aim of the programme and to explicitly state the criteria for participation.

Gradually, it is becoming clear that differentiation between patients who all have the same specific disorder within the same patient category is unavoidable. This has to occur on the grounds of characteristics of the patient and/or the disorder, such as the degree of severity, the length of time that the patient has suffered from the disorder, the nature of complications, aspects on which the treatment approach concentrates, and the suitability of the patient to use certain technology such as the Internet. In this way, numbers of patients can be defined for which the approach is more or less identical and protocols can be drawn up.

Patients can be identified in various ways. The active searching out of disorders or problems that are as yet unknown to the people involved, does not come under the territory of disease management but under that of prevention. Disease management covers those people for whom there is a known risk factor, such as smoking, weight problem, high blood pressure, or for those people who have a known disorder for which the aim of DM is the prevention of deterioration. For the process of admission to a programme, registration data from general practitioners, pharmacists, hospitals, and other care providers can be used. Sometimes patients are admitted on the basis of further investigation.¹⁰

- *adherence to evidence-based guidelines*

Disease management leans strongly on the availability of 'evidence-based' guidelines. The aim of these guidelines is in the first place to offer high quality state-of-the-art care. Often, protocols are used that have already been accepted; this is the case in the Netherlands with the guidelines from the Dutch College of General Practitioners (NHG) or the guidelines from the Dutch Institute for Healthcare Improvement (CBO) or those of the scientific federations. Another reason for the importance of the protocol led approach is the change in care practice with substitution of care from physicians to nurses. This aspect characterizes disease management both in the United States and in the Netherlands. In order to realize this substitution, the presence of validated protocols is essential. The aims that are set out in the protocols, the desired outcome measurements and treatment methods also form the basis for the system of benchmarking which examines the extent to which the aims of the programme have been achieved.

- *encouragement of collaboration with physicians and other professionals aimed at providing supportive roles*

Disease management is not an isolated activity but embraces preferably the whole of the health care system and all aspects connected with it. The structure of the health care system in the United States is such that much has been achieved if physicians can be supported by others for certain care aspects. For example, disease management in the US includes telephone interventions by trained nurses that are strongly aimed at prevention and promoting good health through education.¹¹ Especially in the nineteen-nineties, it was not uncommon for people with complicated forms of chronic disorders to be involved in various disease management programmes. Because of the disadvantages of this as well as the aspect of comorbidity that often accompanies chronic disorders, more complete and integrated programmes were developed later on.

Disease management hardly ever limits itself to only one element in the care process. Although programmes preferably cover a whole spectrum of care elements such as prevention, timely detection, diagnostics, treatment, and support and guidance, the inclusion of care elements in a programme must result in benefits as far as quality and cost reduction are concerned. One aspect that always applies to disease management is that the collaboration with physicians and other professional care providers should receive much attention.¹² It is important, also in the Netherlands that the programmes are developed together with general practitioners, specialists, nurses and paramedical staff and that the primary care providers are informed.

- *orientation towards education and the self-management of patients*

Such is the nature of chronic disorders that the aspects of education and the enhancement of self-management are at the core of the approach. This can take place on an individual level, through group sessions or by means of support given with the help of technology. The underlying idea of this is that patients who are well-informed on their disorder will be able to handle it more rationally, which as a consequence, will lead to a reduction in the use of medication and other expensive health care facilities. The problem here is that the

industries that are involved in disease management in the United States want to see a quick 'return on investment' on what they have put in. This cannot be achieved (at least for the short term) for a number of the activities stated below. The decision to pay attention to education and the enhancement of self-management means that the care, or at least part of it, will be transferred from the physician to another care provider.

- *management of process, results, and evaluation*

The use of management instruments in order to reach the aims is one desired characteristic of disease management. Whilst normally the care process allows for much professional autonomy and personal opinions on the part of the treating professional (which often means a strong variation between doctors) for disease management, there is a strong focus on central steering for both the care process and the care content. The care is not only strongly protocolled for content but attention is paid to the process elements of the provision of health care as well as actually achieving the results. In addition, efficacy is also an aspect that receives ample attention. One of the problems with the care process is that there is little harmonization in the provision of the care because dealing with just one care problem involves various organizations. The biggest gain in this kind of care can be expected in the area of collaboration where the agreements, protocols and results can be controlled or measured and the results are used in order to improve the care process. In order to steer the process efficiently, management information is absolutely essential. This information concerns not only production, funding and logistics, but also provides insight into the results of the health care itself. Therefore, information is collated on the following: patient characteristics, degree of severity of the existing health problems, complications, treatment, prescribed medication, treatment results, quality of life, costs, and patient satisfaction. The information obtained can be fed back to the care providers so that, where necessary, improvements can be made.

In order to generate this management information and streamline the care process, information and communication technology in good working order is an indispensable condition. The exchange of information between the various categories of caregivers proves to be problematic in daily practice.¹³ If disease management is to work well then the patient files from hospitals, general practices and home care organizations have to be interchangeable. Any existing blockades regarding legal and psychological aspects have to be abolished.¹⁴

- *routine reporting and feedback*

Management information is maintained for benchmarking purposes. This basically means 'an external measure used to compare against the internal value of a measure of interest, often in a normative (or best-practice) manner.'¹⁵ The results can therefore be weighed against an external standard or colleagues.

The results must have bearing on the goals or the process of the programme and may relate to the following:

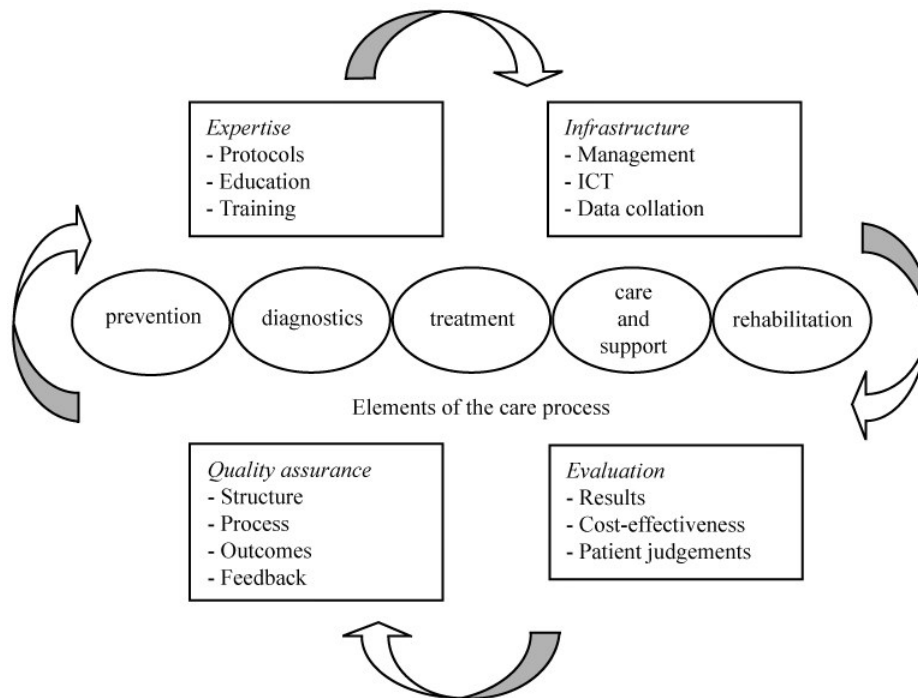
- clinical outcomes: for example, in the case of diabetes, the percentage of patients with a normal or abnormal HbA_{1c}, a normal or abnormal fundus or foot amputations
- the use of medication and facilities, the number of interventions and admissions
- financial results (return on investment)
- parameters of patient satisfaction and quality of life
- parameters that relate to the quality of the health care such as waiting times
- other data that could be important for the evaluation of the programme such as labour absenteeism and productivity.¹⁶

Benchmarking goes further than just an audit with which clinicians are familiar. Benchmarking requires the willingness of people to be open towards judgement from others as well as for accountability. Whilst in industry benchmarking is considered a quite normal means of assessing performance, for the health care sector introducing benchmarking is accompanied by a culture shock. One essential point here is that the data on which the benchmarking is based represents a valid and realistic picture of the health care services. Therefore, it is sensible to involve the care providers in the process of determining the criteria.

- *care continuum and integrated approach*

The STG and ZN apparently do not put much value on disease management programmes that only cover some aspects of the care. They emphasize the importance of the care continuum in their publications.¹⁷ They regard disease management as efforts that concentrate especially on the enhancement of chain-forming in the care process whereby separate parts and paths are integrated and brought together. Figure 1 shows the harmonization between the various elements of care content from the care chains and the various process elements. This bridges the gap between the American concept of *disease management* and the concept of *integrated care* as introduced by the WHO.

Figure 1.1



In summary, the following characteristics can be attributed to the concept of disease management.

1. relating to one health problem or aiming at clearly-defined patient populations and sub-populations
2. orientation towards the harmonization of the various parts of the care process
3. treatment that is strongly based on protocols and is evidence-based
4. methodological education of patients and their relatives and the advancement of self-management
5. large degree of reallocation of tasks from physicians to nurses
6. the use of modern information and communication technology and other technologies
7. large scale approach and classification of patients in clinical pathways based on sub-characteristics
8. focus on the use of a range of management instruments such as information based on benchmarking and feedback
9. external funding that is based on the enhancement of integration
10. a robust organizational structure with central steering by care providers or health care insurers

Disease management and care for the chronically ill

The strong emphasis that is put on secondary and tertiary prevention as well as cost-reduction means that disease management is especially applied to chronic disorders that have a number of common characteristics:¹⁸

- the patient population involved encompasses people who will suffer for the duration of their life
- the treatment mainly consists of a combination of pharmacotherapy and a change in lifestyle
- the direct costs of the patient care are on average so high that disease management will still deliver advantages in spite of the indirect costs involved with the programme.

As previously stated, patient education and the enhancement of self-management are important cornerstones of disease management. Both can be supported in many ways with new technology. Firstly, there are technological possibilities for improving communication between patients and care providers such as e-mail or Internet and the use of CD-ROMs. Websites now exist where patients can put questions and receive answers and where the patients learn how to ask questions on the way in which he/she wants to be treated. In addition, there is now adapted computer software (the so-called Health Buddies) that can help the patient to adhere to an agreed treatment regime and take certain measurements, collect this information and communicate it back to the health professional. Technology can also help people to monitor certain measurements and consequently work out how much medication for example, insulin or anticoagulants, should be administered.¹⁹ In most cases, it is not the doctor but the specialized nurse who is responsible for patients working with this kind of technology.

1.3 Disease management in an international context

The costs of disease management programmes in the United States and the United Kingdom have been driven back amongst other things by contractually limiting both patients and care providers in their freedom to treat. The introduction of standard treatment methods means that cheaper materials and medicines can be purchased.²⁰ In the United States, patients involved in the PACE programme for the 'frail elderly' hand over a number of their rights to the programme meaning that they can no longer appeal to health care services outside the programme.

Due to the fact that in the United States disease management is mainly focussed on the reduction of costs, many disease management programmes are restricted to patient populations where benefits can be achieved with relatively simple measures in short or middle-term periods. In most cases, these programmes are therefore intended for high-risk patients. Less attention is paid to the patient who is in a relatively good condition at the moment but will possibly incur high health costs in the future.²¹

The European perspective

In Europe the concept of disease management is not widely known. However, the situation is changing fast. In those countries that until recently had a national health service, such as England, Spain and Sweden, the governments contract out parts of the health care services to third parties. In England these possibilities are being exploited by a number of recently set up Primary Care Trusts. In Spain, Insalud (the Spanish National Health Service) has contracted out disease management programmes for heart failure and diabetes in Barcelona and Madrid. The same applies for the health authorities in a number of Swedish districts (counties). In Switzerland, the various cantons each have their own financing and insurance systems. Although this situation makes commercial disease management a less attractive proposition, some organizations are playing an active role. In Germany, national government is trying to use disease management as a lever to break up the traditional authority of physicians in the organization of the health care system. Nowadays, the German insurance authorities are managing to develop large disease management organizations with support from the government that is laid out in legislation. The general picture is that although much is being tried out and experimented with there is still no question of large-scale implementation.

The Dutch variants of disease management

Disease management in the Netherlands is still in a developmental phase. Often, the programmes are an incremental sideline of building on an existing collaborative project. The approach is often limited to transmural collaboration whereby care providers remain autonomous in their own area of expertise. There are hardly any examples of disease

management programmes where third parties take over the health care services of existing providers or make contracts with them for care models containing enough of the characteristics of disease management.^{22,23} As far as the Dutch language is concerned, a proposal has been made to use the term 'zorgprogrammering' (freely translated here as care programming). However, this does not do sufficient justice to the robust nature of disease management and its characteristics.

In the Maastricht area of the Netherlands, some programmes have been set up that resemble disease management. These have developed as a result of experimenting with the possibilities for the substitution of care (physicians to nurses) from within existing transmural collaboration projects. These programmes do not involve any third parties. Much hard work is still being carried out in order to achieve the desired level of expertise regarding information management and exchange, education and self-management.

Reaching the stage of a mature form of disease management is hindered, amongst other things, by the structure of the funding of the Dutch Health Care Sector. It is expected, however, that the introduction of the so-called transmural diagnosis and treatment combinations (DTCs) and the possibilities that these will bring in order to command the performance of subcontractors, will stimulate further development of disease management.

1.4 Advantages and disadvantages of disease management

In spite of the initial great expectations, even in the United States it has been established that there are no magic bullets for improving the quality and the efficacy of health care.²⁴ In one large Canadian study, prevention and prescribing habits were seen as the most favourable aspects of the approach of management towards health problems. These three elements are part of the concept of disease management. In addition, it is plausible that other factors will increase the quality and the efficiency of the care. These factors include: a more businesslike approach, a more disciplined behaviour from the practising professionals, more structured collaboration, more possibilities for substitution and a larger feedback of results and behaviour.

One attractive point of disease management is that the various care elements are brought together to make one whole. One thing that has to be carefully considered is which care problems can and which cannot be accepted for such an integrated approach.

Disease management also holds disadvantages or dangers. At present, primary care services function reasonably well in the Netherlands. The primary care services can undoubtedly draw many advantages from intensifying collaboration with secondary care services but in so doing should be careful not to dominate the primary care level by outreaching in the secondary level.

Disease management requires collaboration and this fact makes health care more complex. It is therefore wise to limit disease management to those situations that require collaboration. The patient's situation should not be so complex that all sorts of comorbidity occurs which would mean that the programmatic approach of aiming at one specific disorder is no longer worthwhile.

The implementation of disease management should almost always be done by nurses. The advantage of using nurses is that these professionals can connect the two aspects of cure and care, can in general communicate with patients more easily and, are often used to working according to protocols. In addition they are cheaper than other professionals. There is however, a risk that medical knowledge may not reach the required depth whereby new symptoms will be insufficiently recognized and dealt with. Therefore, it is essential that the training for nurses who have a specific task in a disease management programme pays much attention to the medical aspects, that they can easily approach a medically-trained supervisor or consultant and that there is a question of good monitoring of the quality of the care.

Advantages of disease management

A clear description of the target population, standardization and protocollation of the treatment and feedback by means of relevant outcome parameters (benchmarks) are the necessary requirements for ensuring good working of a disease management programme. This requires the following:

- availability of sufficient data on the economical structure, the costs and benefits of the disorder in question

- availability of scientific data on which protocols and standards can be based
- availability of a system whereby caregivers who are involved in the provision of care can be steered and corrected
- a quality monitoring system which constantly measures and adjusts the results of the health care services
- harmonization of the business and process aspects and the actual content of the health care.

In particular, this last-mentioned aspect demands much from the managers of the programme.²⁵

In order to start up a disease management programme, experience is needed with the principles of working both target-oriented and with projects. In addition, starting up a disease management programme requires space for the essential aspects of money, time, and capacity. The Americans do not refer to return on investment for nothing.

1.5 Disease management in comparison to related activities

A number of activities are related to disease management. They show similarities regarding target or means although they can also be differentiated.

Managed care

Just as with disease management, many descriptions for the concept of managed care are in circulation. What the two have in common is that cost management plays a dominant role and that there is usually a third party involved such as an insurer or employer. In addition, control of the care process by means of protocols, control and feedback are common to both. The difference between the two is that managed care covers a whole range of care issues whilst disease management programmes are contained to one disorder. Furthermore, in the case of managed care, there is more emphasis put on cost control.

Transmural care

Transmural care is a typically Dutch concept that was described in 1995 by the former National Council for Public Health (NRV) as: forms of care that are tailor made for the needs of the patient, are provided on the basis of agreements on collaboration, harmony and direction between general and specialist caregivers and where, although responsibility is shared, it is also divided up into sub-segments.²⁶ Disease management not only regulates the collaboration between caregivers, it also usually accounts for a stronger central steering point. In transmural care, the patient is at the centre, in disease management, while this significance is evident it is also implicit. Although quality and efficiency were important parts of the aims of the NRV advice, these items are more explicitly present in disease management. In other words: nearly all aspects of disease management have bearing on transmural care but not all aspects of transmural care have bearing on the characteristics of disease management.

Shared care

Shared care is a term used in the United Kingdom and Australia for the coordination of the activities of caregivers who have diverse disciplinary backgrounds in order *to ensure comprehensive and consistent treatment whilst avoiding unnecessary duplication*.²⁷ While transmural care explicitly covers the aspect of collaboration between intramural and extramural, shared care can also cover collaboration that takes place extramurally.²⁸ The concept of shared care strongly resembles transmural care although transmural care concerns explicit agreements and the care is specifically tailor-made to meet the needs of the patient.

Integrated care

The World Health Organization (WHO) has described integrated care as follows: ‘the bringing together of inputs, delivery, management and organization related to diagnosis, treatment, care, rehabilitation and health promotion’. Integrated care is seen as a method ‘to improve services in relation to access, user satisfaction and efficiency’.²⁹ Integrated care and disease management are often intended for patients with a chronic disorder. In disease management, the main focus is on the steering mechanisms whilst integrated care concerns

the harmonization between the various care facilities and care elements. In other words: disease management is always integrated care, but integrated care is not always disease management. This means that urgent chain care, which is aimed at a wide range of acute care demands, does fall under integrated care but not under disease management. The same applies to wide-range occupational curative collaboration.

Care chains

The term care chains has not yet been clearly defined. Sometimes the term is used to describe the harmonization of the care content of the various elements of the care process (see figure 1). Others use the term to emphasize the fact that chain care concerns linking up with various elements in the care process for which individual caregivers are responsible. A care chain therefore, does not have to cover explicit collaboration between caregivers from various elements of the care chain itself.³⁰ The term care chain is an essentially descriptive term even though there are some connections with a number of concepts also discussed in this chapter. In English, the term clinical pathway is comparable.

Chain care

The meaning of the term chain care relates to health care whereby agreements are made on the harmonization between the various separate elements that make up the care chains. When all is well, transmural care is a form of chain care. Because transmural care is more clearly formulated, not all chain care satisfies the criteria of transmural care.

1.6 Evaluation of disease management

The American background of disease management programmes and the conditions set by especially the commercial third parties involved in disease management there, mean that up until now little scientific evaluation on the effectivity and appropriateness of disease management has been carried out.³¹ Although two prominent characteristics of disease management programmes are the systematic collation of data and the measurement of results, these two aspects are meant to act as support to the management and as feedback to the caregivers. They are not meant to act as a means of scientifically evaluating programmes or comparing them to other concepts. At the scientific level, the appropriateness and effectivity of disease management has only been slightly demonstrated. Due especially to the conjectures that the benefits of disease management programmes have been estimated too highly, the need has arisen for a universally accepted set of methods and standards in order to measure outcomes both in valid and reliable ways.³² The background to this has extremely diverse roots: rashly set up programmes, selection bias, too much attention paid to the content of the programme and not enough to a thorough evaluation. Only too often conclusions are drawn from measurements taken on a before/after basis without taking the aspect of regression to the mean into account. The American health care policy-makers now have to face the negative consequences for designing a short-term health care policy. As well as the methodological problems for measuring the effects of DM satisfactorily, it is important to remember that the efficacy of interventions for the chronically ill, certainly where preventive activities are concerned, can only be evaluated in the long term.^{33,34} Therefore, an ill-considered intervention programme in which patients with asthma are traced at an early stage, could lead to these people being over treated. A superficial evaluation would then show that many of these people have no symptoms after some time. This result is then unjustly put down to the programme and not to the natural course of the disease of asthma.

On the initiative of the Johns Hopkins University and the disease management organization American Healthways, 150 care providers have brought out a manual with instructions and standards for scientifically evaluating and comparing programmes.³⁵ In the manual, a compromise has been sought between the strict methodological requirements of Health Technology Assessment (HTA) and what is actually achievable concerning usable results in daily practice. In fact, a new methodology should be found for the evaluation of large-scale innovations in the health care system. As a starter for this, a checklist has been developed for the evaluation of programmes that are already up and running.³⁶ As well as research on evaluation, it is also necessary, from the point of policy, to have instruments available in order to estimate and predict the costs and effects for the coming years. The development of such instruments would be best included in a programme for the development of HTA for disease management.

In the Netherlands, the Maastricht disease management programmes have been evaluated using new prognostic techniques based on data assembled before and after the introduction of the programmes. On a variety of dimensions, the quality of life increased, while expenses could be kept stable or have even been reduced. Nurses performed much better than physicians, either medical specialists or general practitioners.³⁷

The introduction of disease management is considered a change of paradigm because it is breaking tradition with the past on a number of issues: the emphasis on education and self-management instead of treatment, the patient population-targeted instead of the individual approach in the consulting room, the great extent of working with protocols, the substitution of care from physicians to nurses and the businesslike approach. The position of the physician as the one who has the final word regarding treatment that has been a matter of course for so long is now under threat. In disease management, the approach is businesslike where the professional who has the most to offer on the result of the treatment is sought out as well as the costs and benefits. Pharmacists, nurses, and paramedicals are allocated new tasks in the care process. The observation that the introduction of disease management will question the well-established positions of some professionals means that the reactions in the form of objections and resistance to the concept must be taken into account.

Disease management however, also offers new opportunities for physicians. The concept allows them to concentrate on those tasks for which they have been trained and in which they are truly experts. Above all: whilst the actual realization of the care may pass on to another professional, the new caregivers will still need the support, the advice and the expertise of the physician.

In the Netherlands, it is only recently and on a limited scale that some experience has been gained with forms of care renewal that sufficiently comply with the definition and characteristics of disease management. Other chapters of this book will report on the situation for a number of areas on this subject.

1.7 Disease management in relation to the following chapters

The following chapters will cover a number of areas of health care in order to discover the extent of their suitability for the concept of disease management. In order to do this, the authors have taken into account the description of disease management as described in this chapter: *the programmatical and systematic approach of specific diseases and health problems by using the management instruments that aim at the advancement of quality and efficacy.*

The authors will indicate the extent to which it is advisable for the care for their particular patient population to meet the needs of the patients concerned in the long term according to the following characteristics that have been stated in this chapter:

1. relating to one health problem and aiming at clearly-defined patient populations and sub-populations
2. harmonization between the various care parts including prevention
3. methodological education and the advancement of self-management
4. disease management protocols that are evidence-based regarding diagnostics and treatment
5. classification of patients in clinical pathways based on sub-characteristics
6. use of a whole range of management instruments for benchmarking and feedback
7. large degree of task reallocation/substitution
8. use of information and communication technology
9. robust and large-scale approach
10. direction and funding coming from a central point

These ten characteristics have been derived from the introductory literature study. The characteristics are thus classified according to patient care (characteristics 1 through 4) organization of the patient care (characteristics 5 through 7) and the management of patient care (characteristics 8 through 10).

The patient populations concern patients with: cystic fibrosis, diabetes, depression, heart failure, and palliative patients. Representatives of the Council for the Chronically Ill and Disabled (CG Raad) made the choice for these five patient populations. The idea was to cover a wide range of disorders affecting the young (cystic fibrosis) to the old (heart failure, palliative care) to psychiatric (depression) and somatic illnesses (CF, diabetes, heart failure, palliative) and on the common disorders (diabetes, heart failure) and less common disorders (cystic fibrosis, palliative care). For these patient populations, authors were sought with a wide range of expertise on the development of integrated care for their particular group. They used knowledge coming from three sources. Firstly, they used their own experience and expertise (please see appendix II) Secondly, the authors carried out additional and extensive literature studies in recent years. For this purpose, they received help from two medical students from the University of Utrecht: Nanne Frenkel and Bob Bloemendaal. From 1999 to 2004 they carried out a computer search on such terms as disease management and integrated care. Publications were selected on the basis of quantitative research. These publications are available to interested parties at the Julius Centre in Utrecht. The third source of knowledge is that of the individual's analytical and judgemental abilities. On the basis of this, the authors reach conclusions concerning whether or not they wish the ten characteristics of disease management to be applied to their patient population.

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2 A modern care centre for patients with cystic fibrosis

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Marianne Acampo and Nanne Frenkel

2.1 Introduction

This chapter was realized on the basis of:

- A visit to the Children's Hospital of Philadelphia, University of Pennsylvania by Marianne Acampo
- A brainstorm session on 29 March 2004 held by Dutch experts in the field of cystic fibrosis treatment
- Two Dutch policy documents, namely: *Van der Laag J., M. Sinaasappel and HGM Heijerman (ed.), Diagnostiek en behandeling van Cystic Fibrosis, (Diagnostics and treatment of cystic fibrosis), CBO, Utrecht, 1998 as well as, Nederlandse Cystic Fibrosis Stichting, (Dutch Cystic Fibrosis Foundation) CF Centralized Care, Baarn, 2002*
- A literature study through Pubmed covering the period from 1 January 2002 up until the middle of 2004 and searching on the following terms: *care programs Cystic Fibrosis, disease management cystic fibrosis, and transition programmes cystic fibrosis.*

For some time now, CF care in the Netherlands has been connected with the disorder itself and is centrally organized. This means that Dutch care providers work according to a number of principles of disease management. The results of the working visit to the CF Centre of the Children's Hospital of Philadelphia in Pennsylvania (CHOP) and the literature study into care programmes for CF patients as described above, are meant to serve as an introduction for the discussion on the further possibilities for improving quality and funding of CF care rather than supplying information on a totally new concept. Quotes taken from the travel report by Marianne Acampo are spread throughout the chapter.

The authors seriously considered writing about a CF programme and not about a CF centre. After all, disease management concerns a collection of integrated professional activities or, in other words, a programme. This concept does not actually require the activities to take place at just one location. However, seen from the viewpoint of organization and effectivity, it is preferable to concentrate as many aspects of the treatment as possible in one centre. Within the framework of international terminology, we refer here to CF centres. In this chapter, children are people under the age of 18 years and adults people above this age.

2.2 The disease cystic fibrosis and current treatment and care

Cystic fibrosis (CF) is a hereditary disease presenting with a varying degree of symptoms and seriousness. In the Netherlands, this disease is also known as sticky mucous syndrome. The sticky mucous that is formed in the different organs clogs the lungs, nose, pancreas, intestines, biliary tract, and reproductive organs. This process leads to progressive damage

to the affected organs. The most commonly occurring symptoms are recurrent respiratory infections and exocrine pancreatic insufficiency producing fatty diarrhoea and disturbance of growth. A patient may also present with a variety of other symptoms such as: liver function disturbance, intestinal problems, ear, nose and throat disorders and infertility.¹ In 1989 the CF gene was identified. Following this it became clear that many different mutations in the gene can cause the disease. Because there is still no known cure for the basic defect within the gene, the treatment is completely centred on fighting the symptoms. The most important aspects here are, on the one hand tackling against the growth disturbances and the fatty diarrhoea by using an optimal energy-enriched diet, digestive enzymes and multivitamins and, on the other hand, fighting the respiratory infections with physiotherapy, antibiotics and mucous thinners. There is a clear relationship between the nutritional state of the patient and the seriousness of the respiratory infections and therefore, also with life expectancy.

In the nineteen-sixties, Ten Kate calculated the birth prevalence for CF in the Netherlands at 1: 3,600. The fact that CF is an autosomal recessive hereditary disease means that for 1 in 900 sets of parents, both parents are carriers of a badly functioning CF gene and that each of their children has a 25% chance of being born with the disease. In the Netherlands one person in 30 is a carrier. The prevalence already mentioned for the Netherlands has recently been confirmed in a random sample survey for carriers amongst 11,513 blood donors (carrier rate 1: 32). Estimates show that 550,000 Dutch people are carriers which result in approximately 50 new CF patients per year. The number of patients in the Netherlands on January 1st 2001 amounted to 1 in 14,680 inhabitants with the highest prevalence in the South West (province of Zeeland 1 in 9,038) and the lowest in the North East (province of Friesland 1 in 28,235) people. For the Caucasian population in the Anglo-Saxon countries, especially the United States, there is an incidence of 1: 2,500 newborns.² For the black American population, the ratio is 1 in 15,000, and for the Asian population 1 in 31,000.

CF presents with a varying clinical picture due to the different mutations. Nevertheless, the median life expectancy has risen during the last decade and currently lies at approximately 35 years. The total number of patients with CF in the Netherlands was put at 1,200 on 1 January 2001. This number includes 660 children under the age of 18 and approximately 500 adults over this age. The expectation is that the number of children with CF will increase from 660 to 760³ by the year 2020. A number of factors influence this trend. On the one hand, it is reasonable to expect that the mortality will be reduced by 0.5% per year during the first 18 years of life as a result of improvements in the existing treatment. On the other hand, the introduction of genetic counselling and prenatal genetic diagnostics will mean a reduction in the number of births of children with CF by 10 to 15% by the year 2020. Moreover, the number of foreigners (for which CF shows a lower prevalence) has increased considerably in the Netherlands during the last decades, meaning that fewer children born with CF can be expected. The result of these three developments leads to an estimate of the number of children with CF in 2020 put at approximately 760. The number of adults with the disease will increase sharply to almost a doubling of the present number from 500 to 900 in the coming decades. This number will increase even more sharply if we consider the improvement in treatment as a factor influencing the growth. Up to now, this has not been included in estimates.⁴

If neonatal screening for CF is added to the current screening programmes in the Netherlands for phenylketonuria (PKU), congenital hypothyroidism (CHT) and adrenogenital syndrome (AGS), then the time for diagnosing the disease can be brought forward from 1-1½ years of age in 1998 to approximately 1-2 months in future. This would enable treatment to be started before any damage has occurred to the respiratory and digestive tracts. In Australia, New Zealand and a few states of the US, this screening has been carried out for over 20 years.⁴ As a result, the number of hospital admissions during the first few years of life has been reduced in these countries. One other advantage is that genetic counselling for family members can be carried out at a very early stage. This, in turn, leads to the possibility of limiting the number of CF births in families that are genetically high-risk.

Another possibility of limiting the potential number of CF births is preconceptional carrier screening. In a study consisting of 38,000 people in the Netherlands, Ten Kate and researchers showed that there was a lot of interest for preconceptional screening in couples wanting to have children.

Introducing and implementing both these forms of screening in the Netherlands, will have significant implications for effectively taking care of and treating those CF patients who have been diagnosed at an extremely early age and are, as yet, without symptoms. In addition, there will be a sharp increase in the number of identified CF gene carriers who will need equal care and attention.

The costs relating to CF care per patient are high. For example, in the Wilhelmina Children's Hospital in Utrecht, the costs in 2001 relating to the care per CF patient per year were 6,125 euros. In the Leyenburg Hospital in the Hague, the costs in 1999 for adult CF patients were 6,350 euros higher than the average costs for other hospital patients in the same hospital. The higher costs for the treatment of CF patients are caused by frequent hospital admissions, expensive drugs such as intravenous antibiotics and inhaled antibiotics (for example, TOBI) and specific mucous thinners (e.g. rhDNase) as well as by advanced diagnostics and treatment facilities. CF patients with advanced lung damage (gradually increasing with age) are admitted to hospital more frequently than those patients with only minimal lung damage. Patients are often admitted to a single hospital room both because of the danger of infection to others and the necessary required rest and privacy. This is even more the case than previously now that research has proved that the segregation of patients who are chronically infected with *Pseudomonas aeruginos* is necessary. It is expected that the costs per patient will further increase because treatment will become even more intensive and the accent towards an integrated and team approach is receiving more and more attention. Medication costs for antibiotics are increasing due to the fact that the regimes are becoming more aggressive and longer. However, ultimately, the costs for CF patients only cover 0.07% of the total costs incurred for the whole of the Dutch Health Care Services. The reason for this is that the disease is quite rare, occurring only in 1 in 14,680 inhabitants. It has been estimated that a CF patient consumes around 600,000 euros of health care funding during his lifetime.⁴

At the end of the nineteen-nineties the so-called centralized care approach for CF patients was introduced in the Netherlands. This approach means that every patient is known to a specialized centre that is mostly attached to a university hospital for adults or children. Patients can be treated either within the centre itself or in a smaller peripheral hospital where the medical specialists keep contact with the CF centre in the region. Such CF centres are situated in seven locations in the Netherlands: Groningen, Rotterdam, the Hague (Leyenburg Hospital/Juliana Children's Hospital), North-west Netherlands (Amsterdam AMC, Amsterdam VU, Alkmaar), Nijmegen/Groesbeek, Maastricht and Utrecht. Both the organization and content of the extent of the care differs between the centres as well as the size of the patient populations under treatment.

During the last ten years, the care given to CF patients has been more and more concentrated in these seven centres. Sometimes, these centres had to enforce a registration stop for new patients due to budgetary reasons. However, this is only the case for adult patients who have been kept too long in paediatric care, sometimes until their 22nd year. At the brainstorm session that was mentioned at the beginning of this chapter, it came to light that the centres for CF patients do not always work equally well together. Apparently, there is some competition concerning the drawing of funds for research and there are hardly any or no common registration systems and staff appointments in place.

2.3 Differences between CF care in the Netherlands and elsewhere

There are a few striking differences in the care for CF patients in the Netherlands compared with other countries.

1. In the Netherlands there is no neonatal screening for CF. As already mentioned, this is the case in some countries such as Australia, New Zealand, and a few states of the US. This form of secondary prevention has been turned down by the Netherlands because scientific research has not yet produced sufficient evidence to prove that neonatal screening increases the effectivity of treatment yet to be

given.⁵ Due to new evidence, however, the Health Council of the Netherlands advised the government by the end of 2005 to extend the neonatal screening programmes with 15 inherited diseases, among others CF. The government's decision is awaiting.

2. Dutch CF patients can receive home intravenous therapy under the supervision of a CF centre. In the United States, this service is hardly ever available because the risk of legal prosecution is considered too high should a calamity occur with the treatment in a home situation. Even the CF centre at the Children's Hospital of Philadelphia (CHOP) which we considered to be a large centre did not offer home care services to patients for treatment with medication at home.
3. The treatment centres abroad are in general larger than the seven centres in the Netherlands. The CF centre in Copenhagen treats approximately 1,000 patients. This centre, together with one other small centre, treats the whole Danish CF population. In England there are various centres that treat between 300 to 500 patients. The American centres for CF patients treat mostly between 400 to 600 patients. This information was relayed to the authors during a visit to the American Cystic Fibrosis Foundation. The Children's Hospital of Philadelphia that we visited treats 500 CF patients. In 2001, 340 patients were treated in the CF centre of the Johns Hopkins Hospital in Baltimore.

In our supplementary literature study, we found a probing debate on the wish to see a special adolescent programme which is positioned between those specially designed for children and those for adults.^{6, 7, 8, 9,10,11,12,13} These transferral or transition programmes teach the children about their condition over the years as they grow up. Furthermore, the young adults visit the clinic without their parents and receive information on all aspects of the disease including those of choice of career, sexuality and reproduction and life expectancy. The fact that such programmes are necessary is shown amongst other things by a study by Boyle et al.⁷ in which they argue that adolescents and parents worry about leaving the trusted environment and the familiar carers as well as being exposed to potential new infections. It appeared that a successful transition from paediatric to adult care depended on getting to know the adult CF team on time and paying special attention towards the prevention of infections. In the Netherlands, specific transition adolescent programmes such as those described above do not exist. However, in some centres a model has been developed that is intended to help guide adolescents between the ages of 16 and 18 years and their parents. This model intends to lead the young adults through the transitional phase as easily as possible.

4. Approximately 98% of CF patients in the Netherlands are members of the Dutch Cystic Fibrosis Foundation (NCFS). In contrast to its American sister organization (CFF), the Dutch Cystic Fibrosis Foundation does not accredit the CF centres and the smaller practices of paediatricians.

The Children's Hospital of Philadelphia (CHOP) CF centre: a highly specialized centre for cystic fibrosis

The CF centre of the children's hospital (CHOP) of the University of Pennsylvania in Philadelphia consists of a multidisciplinary team of specialists in the field of lung diseases in children and adults: gastroenterologists, advanced practice nurses (nurse practitioners), physiotherapists, respiratory therapists and technicians and social workers. The centre is accredited by the American Cystic Fibrosis Foundation (CFF) for its patient care, education and research. In addition, the CFF recommended this centre as the *best practice* location for CF care for this case study.

2.4 Quality criteria for a CF centre

In 2002, a working group from the Dutch Cystic Fibrosis Foundation brought out a report⁴ which laid out 20 quality requirements for the care provided by the seven CF centres in the Netherlands. The working party consisted of medical specialists from these seven centres as well as three NCFS staff members. The authors of this chapter have completely taken over these quality requirements when drawing up their care programme for the future. However, in some places, the requirements have been re-ordered or re-numbered and supplemented with other requirements that issued forth from the literature study, the visit to the CHOP and the brainstorm session mentioned earlier.

According to the working group of the NCFS, the most important criterion is that treatment in a CF centre is far more preferable than treatment in a hospital that does not have such a centre. A CF centre has all of the following components: expertise, skills, a multidisciplinary approach and good treatment facilities. With this in mind, the following points can be considered.

- Treatment at a centre gives a better prognosis and life expectancy as well as a better quality of life for patients with CF.^{14,15,16} A CF centre guarantees a continuous and consistent treatment policy.
- A CF centre contains expertise in all CF problem areas, even for the more complex cases.
- Because there is close contact between the paediatric and adult teams, transition can be carried out in a planned and structured way.

As soon as the diagnosis has been made, or if diagnostic problems occur, referral to a CF centre is necessary. From this time, the centre begins to work for and on behalf of a patient and his/her parents or carers.

1. Multidisciplinary approach

Considering that various organ systems are involved with the disease process and that the disease has drastic psychosocial and social consequences for the patient and his environment, care for these patients in a CF centre is multidisciplinary in its approach. The treating professionals together form a highly specialized team. Every patient is regularly discussed in the CF team, which means that the team can offer an integrated and multidisciplinary treatment approach.

a. The composition of the multidisciplinary team.

The CF team consists of the following specialists: a (paediatric or adult) pulmonologist (who is mostly the chief of treatment) a gastroenterologist, a physiotherapist, a dietician, a social worker and/or psychologist, a CF nurse or nurse specialist (who is also the contact person between the team and the patient/parents) and nurses from the hospital ward who have specific experience and expertise regarding CF. Social workers and/or psychologists fulfil an important role regarding the psychosocial and material aspects of CF care. In addition, they monitor any behavioural, developmental or perceptual problems that may result from the disease. Successful psychological interventions for CF in the areas of emotional and social adjustment, adherence to therapy, and behavioural therapy (e.g. feeding problems)^{17,18} are described in the international literature.

b. Other disciplines needed occasionally and easily available for consultation.

Expertise and advice from other disciplines that have not been named under 1a are available should the need arise. These concern the following areas: medical microbiology, hospital hygiene, diabetology, surgery, ENT, radiology, cardiology, transplant medicine, stoma nurse, clinical genetics, obstetrics, sexuology, and fertility.

c. Future shifts in health care responsibilities (appointments for nurse practitioner, physician's assistant).

Nurses are increasingly taking on a central and coordinating role in the supportive care for the chronically ill.^{19,20,21} These nurses are able to take over part of the contact between physician and patient/parents and possibly even take on the role of coordinator of the multidisciplinary treatment team. In the United States, these nurses are also authorized to prescribe drugs. Within this framework, it is questionable whether the classical categories of professionals such as pulmonologist, nurse, physiotherapist etc. will remain as they are or whether new professional groups will emerge. These groups such as specialized nurse practitioner or physician's assistant will bundle all of the expertise areas from the classical model and bring them together under one person. Therefore, from time to time, the CF team will have to consider the roles of each team member and shift tasks and responsibilities round as these become necessary.

2. The organization of a CF centre

a. Centres for children and centres for adults.

A CF centre should be made up of two parts: a centre for children and adolescents up to the age of 18 years and a centre for adults over the age of 18 years. At these centres the

treatment and guidance of the patients is fully focussed on CF. Moreover, the children's centre should concentrate on specific aspects relating to young patients such as growth and development and education. In the adult centre, more attention should be paid to specific aspects such as quality of life and the labour market.

b. Coordinator.

The CF teams for children and adults should both appoint a coordinator who is responsible for all team activities and for managing the members of the team. At the same time, he/she manages the funding. If a CF centre encompasses both a centre for children and for adults, then a central coordinator should be appointed in order to ensure optimal teamwork between the two teams. This is important both for the care given to the patients as well as for scientific research and educational purposes.

c. 24-hour availability.

The CF team is on call 24 hours a day for consultation both for patients as well as medical and paramedical staff mainly from other hospitals.

d. Home care.

Under certain conditions it is possible to transfer care from the hospital to the home situation. In particular, certain therapies such as those given through a nebulizer or extra nutrition through a nasal gastric tube are suitable for home care. Because most chronic patients suffer from frequent lung infections which do not always respond adequately to oral medication, very frequent administration of intravenous antibiotics is necessary. These iv drugs can be administered equally effectively in the home situation as in the clinical setting.^{22,23,24,25} This form of home care should, provided it is medically responsible, be encouraged and further stimulated through specialized nurses belonging to the CF team or through home care technology teams that are attached to a hospital or home care organization.

e. Possibilities for isolation/segregation.

A CF centre has facilities both in the outpatient and admission departments for adequately isolating patients should they be infected with methicillin-resistant *Staphylococcus aureus* (MRSA), multiresistant *Pseudomonas aeruginosa* and *Burkholderia cepacia*. Becoming infected with *Pseudomonas* and/or *Burkholderia* includes the potential danger of losing lung function more quickly. During the last few years, warnings have been given out regarding potential cross infections with multiresistant *Pseudomonas* strains.

f. Transition.

Both paediatric and adult teams in a CF centre need to work intensively with each other. This means that a CF centre has a programme in which the transition of care from paediatric to adult care is well organized.

The CHOP centre started to treat adult CF patients fifteen years ago and their programme is now one of the most extensive in the US. Most patients have been transferred from the CHOP's own paediatric treatment programme but some have been referred from other clinics in the region. This centre provides state-of-the-art treatment and guidance for CF patients (approximately 225) of 18 years of age and older in two locations: one third of the patients in the CHOP and two thirds in the HUP (Hospital of the University of Pennsylvania). The programme for adults is accredited by the CFF.

3. High standards of a CF centre

a. Minimum size.

The team members work with the patients daily in order to build up sufficient experience and expertise on all aspects of CF. For this purpose, up until now a minimum number of 100 patients (50 children and 50 adults) per location was called for.⁴ The question remains whether the minimum size of a CF centre should be more than 200 patients. This seems to be suggested both by data on the experiences of large centres abroad,^{15,16,17} and by the need to create enough operational activity. This means that medical specialists, in particular, paediatric and adult pulmonologists can fully concentrate on CF care and research and build up an extensive expertise in all areas including those less frequently occurring problems.

b. Quality control.

According to the guidelines that are drawn up, a CF centre should be regularly visited by independent organizations such as the CBO (Dutch Institute for Healthcare Improvement) and the NCFS. In the United States the CF Foundation has set up an accreditation system for the evaluation of CF centres. In the Netherlands, this could be attached to visitation guidelines drawn up by the Royal Dutch Medical Association (KNMG). CF centres also gain from periodically looking at their own quality. From a patient's viewpoint, they should look at such aspects as working methods, information to patients and guidance of patients and ensure that these conform to the expectations of both centre and patients.

c. Diagnostic and treatment guidelines.

The diagnostics and treatment of the various aspects pertaining to the disease and the guidance of the patients is carried out according to national and international guidelines (CBO, European Cystic Fibrosis Society).

4. Specific control measures for CF.

a. Outpatient department.

A CF centre has a separate outpatient multidisciplinary consultation surgery for patients with CF. All CF patients are seen at least once every three to six months, or as often as necessary. At these visits, medical and paramedical controls are carried out, condition and treatment are discussed and further consultation with the various disciplines takes place according to the needs.

b. Annual check-up.

All CF patients undergo a thorough check-up at least once a year. These check-ups take place in the CF centre and all members of the multidisciplinary team participate.

c. Collaboration with local specialists.

Outpatient controls can be partly carried out by a local specialist although they fall under the responsibility of the centre.

d. Consultations for potential CF patients and carriers coming from neonatal screening.

Should neonatal screening for CF be introduced in the Netherlands, then a CF centre is responsible for providing enough care, additional diagnostic procedures for confirmation of the diagnosis and treatment for these babies who are asymptomatic when diagnosed. They should be admitted to the existing programme of care and treatment of the centre. Neonatal screening will also lead to a number of carriers of the CF gene being discovered. These babies are basically healthy although the parents may have many questions regarding the genetic burden and on how to best deal with the news. This process should be supported by the CF centre in consultation with the clinical genetic centre.

Early detection by the CHOP

The centre carries out general screening for CF in newborn babies. This means that treatment can be started at a very early stage of the disease before any (potential) organ damage has occurred. Moreover, families become aware of the risks before deciding to have more children.

e. Care and guidance for potential CF carriers coming from preconceptional screening.

The care and guidance of adult potential carriers of the CF gene primarily belongs to the general health care services and not directly to the CF centres. However, it is essential that these centres also have time and attention available for this group of people.

f. Clear communication.

The members of the CF team are responsible for clearly communicating with the patient, family and any other people involved in the treatment during the outpatient visits or clinical treatment. This communication regards all aspects of CF such as, for example, how the centre functions, also in relation to locally treating professionals, the diagnostics, the treatment, scientific research, and the mutual expectations and collaboration agreements between patients and carers.

g. Social development.

One of the special attention areas of the CF centre is that of the social development of patients, especially regarding such issues as daily functioning, education and work, as well as the welfare of parents and siblings, or partner and the general functioning of the family.

5. Specific diagnostic testing for CF.

A CF centre should have access to proper and advanced facilities for carrying out the various clinical investigations necessary. These facilities may or not be within the centre itself. Within this category are the following:

a. a microbiological laboratory.

A lab for extensive diagnostic testing for potential infections.

b. a department of hospital hygiene.

One that provides good advice and protocols concerning the isolation of CF patients if they are infected with *Pseudomonas* and/or *Burkholderia*.

c. a clinical chemical laboratory.

For example for sweat tests and fat excretion tests. As long as the quantitative sweat test remains the gold standard for diagnosing CF, every CF centre should follow procedures effectively and according to protocol for confirming any suspected diagnosis. The CF Foundation in the United States recommends that this test should be carried out in one of the 117 centres accredited by them. This is due to the guarantee that the centres in question work according to protocol.

Diagnostics at the CHOP

As a recognized care centre, the CHOP follows CFF guidelines when carrying out CF diagnostic tests.

d. a clinical genetic centre for DNA mutation analysis.

These centres are used for diagnostic testing of CF as well as for genetic counselling. As far as testing for CF is concerned, three centres in the Netherlands are used, Amsterdam, Groningen and Rotterdam. With increasing possibilities for molecular and diagnostic testing, it is expected that DNA mutation analysis for patients will be carried out by clinical chemical laboratories situated in the CF centres. In order to make sure that CF patients receive adequate genetic counselling, this task should be performed by the clinical genetic centres.

e. electrophysiological tests.

If, in spite of extensive and effective diagnostic testing, there are any doubts regarding the diagnosis of CF, then a nasal potential difference test and/or intestinal current measurement of rectal mucous membranes may be decisive. This test is carried out in one centre only in the Netherlands (Erasmus Medical Centre, Rotterdam) due to the highly-specialized nature and the required performance expertise.

f. a lung function laboratory.

For diagnostic purposes and for establishing the seriousness of lung disease and damage, a CF centre should have an advanced lung function laboratory that is also suitably equipped for testing young children between the ages of 0-6 years.

g. X-ray facilities including equipment for echo diagnostics and CT-scan.

A CF centre should have good and easy access to diagnostic x-ray facilities especially with regard to the occurrence of complications of the disease.

6. Specific treatment for CF.

a. Interventional radiology.

Interventional radiology may be necessary when complications of the disease occur. In a few CF centres extra specific expertise in this area of therapy needs to be developed and maintained.

b. Transplantation.

Patients who suffer from an extremely bad lung function and for whom the life expectancy is less than two years, may be eligible for lung transplantation if all other forms of

treatment have failed. The five year survival rate following lung transplantation is approximately 60% and will possibly increase as treatment methods for dealing with acute and chronic rejection improve.²⁶ In the Netherlands, transplant surgery is carried out in the University Medical Centre at Groningen (UMCG), in the combined lung transplant centre of the University Medical Centre at Utrecht (UMCU) and the Erasmus Medical Centre of Rotterdam (EMCR). For children, any liver transplants that are necessary are performed in the UMCG (possibly in combination with lung transplantation), for adults, liver transplants are performed in the EMCR. Transplant patients receive special care that has been developed by multidisciplinary transplant teams who work intensively with the CF professionals who have referred the patient. The transplantation of other organs, such as the pancreas, does not yet take place in the Netherlands although this has been carried out a few times abroad for CF patients.

The multidisciplinary team is the core of the CHOP CF centre offering integrated care from the time of diagnosis and start of treatment until final evaluation. In addition to this highly specialized team, the centre also holds expertise concerning genetic testing and research, radiotherapy, and transplant medicine. Patients eligible for lung or liver transplants can be treated in the centre itself.

7. Scientific research

a. Scientific research.

Demonstrable interest for scientific research forms an essential part of the total care package of a CF centre. This research should cover at least the regular evaluation of any centre's patient population. In addition, scientific research is of paramount importance for treatment areas such as the effects of clinical care and treatment as well as the more fundamental question regarding the causes and effects of the disease and the treatment for both medical and paramedical domains. In order to achieve optimum results, collaborative efforts should be set up between national and international centres. From the medical point of view, scientific research should be carried out not only for the area that covers all medical disciplines involved but also for the area covering the cause of the disease, the possibilities for cure of the fundamental genetic defect and the implications and effects of diagnosing CF at the earliest possibility. More examples are, of course possible in this research area.

The various paramedical disciplines, including psychosocial care professionals, should translate any questions they have regarding their own field into scientific data in order to evaluate and optimize their treatment methods. Examples of the above are as follows: the effect of physiotherapy, the effects of nutritional intervention, the quality of life, the transition from paediatric to adult care, education and schooling and social development.

Research at the CHOP

The CF centre of the CHOP conducts both clinical and fundamental research. There are two clinical researchers working at the centre. The centre is also taking part in the 5-yearly patient satisfaction study that is being conducted in all departments of the hospital. The CF centre is accredited by the CFF.

b. Database.

A CF centre should have access to its own database containing information on its patient population in order to carry out both basic scientific research as well as performing clinical evaluations effectively. In order to exchange data and apply it to scientific research, databases from the various centres should ideally be interrelated.

c. Multicentre research.

In a small country such as the Netherlands, scientific research for CF should ideally be conducted as much as possible by using data from the various CF centres. This promotes the stimulation of uniformity of approach and treatment as well as attaining results of evidence with larger groups of patients. In order to achieve this goal, databases from the centres need to be interrelated.

8. Education.

a. Continuing education, medical/paramedical.

A CF centre has responsibility for providing continuing education on CF in the broadest sense of the word for paediatricians, pulmonologists, other medical specialists, nurses and other health professionals including paramedical staff and students. In addition, the CF centre is responsible for continuing education for the members of its own CF team.

b. Patients, parents and family.

Education appears to be a prominently effective part of disease management for CF.^{27,28} The disease manifests itself in various organ systems that brings with it many different care aspects. The systematic and didactic informing of patients and parents/carers on the disease, the treatment and how to live with it is essential in order to reach maximum results in the care. In the Netherlands, specific educational material for children and adults exists for this purpose. An information book on CF is used in Groningen, educational material for adults in Utrecht, a website in Rotterdam and the Dutch Cystic Fibrosis Foundation has a lot of folder material as well as its own website.

Patient education at the CHOP

The centre mainly offers individual education sessions for patients. Group education has been discontinued due to dangers of cross infection. Education is seen as a continuous task and is tailor-made for each patient. Much written material is used such as books and folders and reference is given to the CFF website. The centre has developed a reference manual with patient information that is handed out to the families of recently diagnosed patients. This enables patients and their parents to look up information at home that they have already received from the centre during a visit. Material is available for various age groups so that children can read it for themselves.

9. Support and funding.

a. Secretarial support.

A CF centre has enough administrative support in order to carry out its tasks effectively.

b. Funding.

A CF centre has sufficient financial means to expand and render permanent its CF care.

10. The Dutch Cystic Fibrosis Foundation.

In 1969 the Dutch Cystic Fibrosis Foundation (NCFS) was set up by a few parents of CF patients in order to represent the best interests of CF patients. This aim of the Foundation remains unchanged today. In addition, the NCFS does the following: acts as a platform for contacts between fellow-sufferers, distributes information on CF to patients, parents and professionals, makes a stand for sufficient facilities and good treatment of CF, maintains contacts with all health professionals specialized in CF and stimulates scientific research.²⁹ These aims illustrate the considerable extent of the NCFS. The care of CF patients in the Netherlands is for patients, parents and other interested parties who are members of the Foundation, optimally organized through CF centres.

2.5 Diagnosis and Treatment Combinations (DTC) and the Centres for CF care

Although financial incentives are named as an important characteristic of disease management programmes for promoting efficiency in the review by Weingarten³⁰, they hardly exist in the daily practice of CF care. From our tour of the United States and the Netherlands, it was clear that financial issues do not hold a significant place in the care of CF patients. The various parts that make up the total care are remunerated through regular health care insurance.

During the next few years, financing through the use of DTCs will be introduced in the Netherlands. This system means that hospitals will receive a fixed amount for the total care package delivered for the treatment of a specific diagnosis within a particular period. We will now look into this system of financing more closely because it will have considerable consequences for CF patients. Firstly, some theory on the nature of DTCs.

The DTCs are derived from the American financing system and based on Diagnosis Related Groups (DRGs) which are being used in Medicare, the American health care insurance fund for people over the age of 65 years. A DRG contains patients with the same diagnosis and similar treatment costs. Because there are no cystic fibrosis patients over the age of 65 years, we cannot import any information from the United States that could be used with the DTCs in the Netherlands.

DTCs distinguish three parts known as *length*, *breadth* and *height* that together make up the total DTC.

The *length* concerns the duration of time for which a DTC applies. On one end of the scale is the duration of a single hospital admission, for example for an intravenous antibiotic course for an admitted CF patient. On the other end of the scale is the total lifespan of the CF patient. The treatment will last for the span of the patient's life following the diagnosis of CF. For practical reasons, a rational proposal would be for a DTC for CF patients to last for a period of one year. This means that treating professionals and management will have the necessary financial incentives to deliver the care within the time period of one year in the cheapest and most effective way.

The *breadth* or broad aspect of a DTC covers the question concerning how wide the group of patients is that fall under the same DTC. For example, for a seemingly simple procedure such as a total hip replacement due to chronic pain, it would be advisable to distinguish between two groups of treatment, one for patients undergoing surgery for the first time and one for patients undergoing repeated surgery. The surgery time and rehabilitation period is longer for this second group of patients. In CF care, two groups of patients are currently distinguished: those of children and adults. Therefore, it would be advisable to adhere to two DTCs: one DTC for the usual care given to children and one DTC for the usual care given to adults. The costs attached to large interventions such as lung transplants fall outside the concept of customary or usual care. Separate DTCs should be developed for these items. Also falling outside the customary care for CF are those activities that work towards prevention and for which separate financing methods are necessary. These points, as well as that of the financing of lung transplantations will not be taken into consideration in our arguments.

The third aspect of a DTC is that of *height*. This aspect concerns the price belonging to a DTC. In the case of CF care, this covers the price that the treating hospital receives during the period of one year for all of the customary care given to either a child or an adult with cystic fibrosis. The hospital is obliged to pay all of the care from this amount. Encompassed in this package of total care are outpatient care, admission costs, the salaries of hospital staff as well as the fees for the specialists involved. It is expected that this price will be established from discussions and agreements between the individual health care insurer who buys in the care and the individual hospital that provides the care. Further to be expected is that the health care insurers will be influenced and led by the price that is offered per CF patient, the quality of care and the terms of delivery. One point regarding the above is whether or not there will be a policy for not taking on new CF patients.

The question to ask at this point is whether the seven Dutch CF centres can expect to encounter advantages or disadvantages with the introduction of financing through DTCs. The answer to this question is clear if the new system means that the centres can provide both better care and at lower costs. In this instance, the health care insurers will buy in the care from the hospitals that have a CF centre. Paediatricians from other hospitals will be able to continue to treat CF patients but only through collaboration with the centres for CF care. They will thus receive remuneration for their services from these centres. If it turns out that the specialized centres offer higher quality but with higher costs compared to paediatricians in peripheral hospitals, then it is not clear at the moment where the health care insurers will buy in their CF care. The centres would then have to defend the higher costs against the better quality of care that they can provide.

Financial incentives and the use of feedback/reminders at the CHOP

Health professionals in the United States do not receive financial incentives for achieving certain outcomes. There are also no direct financial incentives for patients. Patients from other states who visit the centre actually lose out financially and are encouraged to use the services of hospitals in their own region. This also saves them the travelling time.

The interviewees did not indicate any financial problems. CF care is reimbursed through Medicare, Medicaid and most of the private health insurers. However, each organization

applies its own special regulations and differs in the extent of the amount reimbursed. If patients have difficulty obtaining reimbursement for their care, then social workers will help them in their contacts with the insurance companies.

The CHOP also has sufficient funds to carry out research. In addition, the CF centre receives subsidies from the state of Pennsylvania as well as from the CFF for paying nurses and social workers and for collecting data and maintaining their databases. When the programme was initiated, a development grant was received from the CFF and from the State, which was essential for setting up and developing an excellent programme.

Other components of disease management are far less recognizable, such as e.g. for feedback. Feedback to care professionals on the outcomes of the treatment does occur during patient discussion meetings but is geared more to individual cases than to the patient population. Health care providers do not receive reminders or incentives to use guidelines although a lot of value is attached to the accreditation given to organizations by the CFF, which does require the use of guidelines. In addition, there is no use of electronic patient files, which would enable the feedback of outcomes.

Patients are informally stimulated to cooperate with the treatment by looking at and discussing care plans during visits to the clinic. Nurse practitioners and social workers are actively involved in contacting those patients who have not attended the clinic for a long time. They try to motivate the patients to still take part in the programme. The introduction of genetic screening and therapy has meant that asymptomatic patients are currently being treated. This group of patients is difficult to educate because often they still have to face the fact that they are patients. Nurse practitioners and social workers are also actively involved with this group of patients and chase up those who have not been seen for a while or who do not adhere to treatment advice.

2.6 Do the Dutch CF centres comply with the ten characteristics of disease management?

The CF centres described in this book have been included in order to illustrate disease management programmes for people with a disorder that occurs infrequently. Although we chose to take cystic fibrosis patients as the example group, the choice could have been made equally well for a disorder such as multiple sclerosis or Huntington's disease. Can the ten characteristics for disease management as described in chapter 1 be applied to such a patient population? This question will now be addressed.

There is unmistakably a question of a health care problem and of a clearly described subpopulation of patients (characteristic 1). Late on in this chapter, the aspects of methodological education and the advancement of self-care are clearly seen to play a crucial role in how the patients and their parents cope with the disease (characteristic 2). The integration of the care process and preventive interventions are also highlighted (characteristic 3). Further, this chapter pleads for further screening such as preconceptional screening and neonatal screening to take place. National and international protocols for the treatment of CF patients are currently being implemented (characteristic 4). The classification of patients in treatment circuits according to sub-characteristics, for example, a group under the age of 18 years and a group over the age of 18 years is logical, especially now that the number of adult patients has increased (characteristic 5). In addition, within the area of patient care, nurses have taken on more tasks that relate not only to coordination but also to education. Although the role of the physician remains stable, there will be a reshuffling of duties/responsibilities from doctors to nurses (characteristic 6). Modern Web-based technology and electronic patient files (characteristic 7) hardly exist in the Netherlands. Therefore, CF care does not comply with this characteristic. The other remaining three characteristics that set up conditions for disease management (8, 9, 10) are also missing in the Netherlands. Benchmarking between the seven CF centres is difficult to get off the ground (characteristic 8). In comparison with centres abroad, the Dutch centres are on the small side (characteristic 9). A certain degree of centralization has been achieved thanks to the choices made by patients in recent years to be treated at the CF centres. Although this move meant that travelling times were increased, patients and their families were not deterred by this factor. A centrally funded system for the centres based on transmural DTCs would be a natural conclusion to make and fit in with the centralization of care. If confidential cost information becomes available, then the sector for providing care for children and adults with cystic fibrosis will be ready to further concentrate the care in high-quality centres that receive payment per year per registered patient (characteristic 10).

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3 Care Programmes for people with Type 2 diabetes

Guy Rutten

3.1 The disease, the patient population, care demands and costs

What is diabetes?

Diabetes mellitus can be divided into two types.

The onset of type 1 diabetes is normally before the age of thirty and is due to an autoimmune process that destroys the β -cells in the pancreas resulting in a life-threatening condition caused by the shortage of insulin. This condition is treated in hospital and the patients play a vital role in their own treatment by injecting themselves with the necessary insulin and monitoring their blood glucose levels. Type 1 diabetes will not be discussed here but the much more frequently occurring form type 2 diabetes.

Type 2 diabetes is a chronic condition which results from inadequate secretion of insulin by the β -cells in the pancreas and reduced sensitivity to the effect of insulin in the relevant organs i.e. liver, muscle tissue and fatty tissue. This is called insulin resistance. Insulin resistance is associated with the accumulation of fat in various organs, particularly the liver but also in the heart and muscles. This accumulation of fat in non-fatty tissue leads to functional and structural abnormalities in these organs and then to a disorder in the metabolism of fat which forms part of and can lead to the *insulin resistance syndrome* or *metabolic syndrome*.

Of all the people with diabetes in the Netherlands around 85% have type 2 diabetes mellitus. More than 80% of those with diabetes type 2 also have metabolic syndrome. Diabetes mellitus type 2 can therefore in no way be regarded as a disease that is characterized only by raised blood sugar levels.

Prevalence and incidence

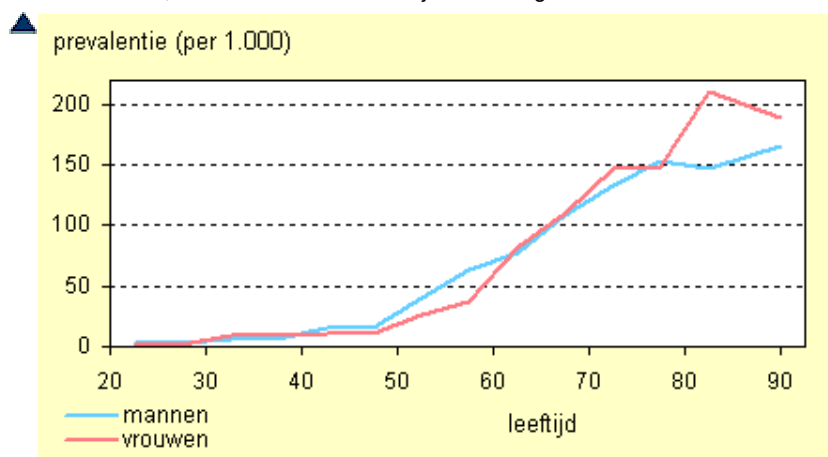
By combining the results from five GP registries of the yearly prevalence of diabetes, it is possible to estimate the number of diabetes patients in the Netherlands. Standardized to the population in 2000, the yearly prevalence is 27.4 per 1,000 men and 32.1 per 1,000 women (absolute 216,000 men and 258,300 women). In the elderly population prevalence is higher among women than among men (Fig.3.1). The incidence of diabetes mellitus based on figures from GP registries (standardized to the population of the Netherlands in 2000) is estimated at 3.5 per 1 000 men and 3.7 per 1,000 women (absolute 27,900 men and 30,200 women). There are no significant age-specific differences between men and women in incidence.² Due to an increasingly ageing population and the rise in the number of people who are overweight (overweight is the main determinant of the onset of diabetes type 2) the number of people with diabetes type 2 will undoubtedly continue to increase.

A recent American study shows that diabetes type 2 occurs more frequently in the lower socio-economic classes.³ Although American research cannot always be extrapolated to the situation in the Netherlands due to the different organization of diabetes care, this finding also appears to be applicable to the Netherlands.

Combining these statistics leads to the conclusion that in the year 2004, an estimated half million people in the Netherlands were known to have diabetes. Furthermore, there is also a group of people who have diabetes but in whom it has not yet been diagnosed. The exact size of this group of undiagnosed people with diabetes is unknown. Estimates made in the second half of the 1990s concluded that for every known diabetes patient there is another person with diabetes undiagnosed. Since that time however, known prevalence has increased from 1.7% to 3.2 % of the population. A big national campaign and increased alertness to case-finding among doctors has increased diabetes-awareness. We do not know how many unknown diabetes patients there are at present but it is certain that the percentage of unknown diabetes patients is below 50% of the total.

Figure 3.1: Average prevalence (per 1,000) of diabetes mellitus to age and sex in a number of epidemiological population studies.

Blue line = men; red line = women.. Leeftijd means age.



Care demand

The GP is the main care provider for around 75% of people with diabetes type 2. Of this group about 10 to 15% use insulin. Patients with type 2 diabetes who use insulin are often treated by a specialist. The role played by the GP in diabetes care is changing. More and more GPs are initiating insulin therapy themselves instead of referring the patient to a specialist in internal medicine. Over the past few years several initiatives to improve the structure of diabetes care within GP practices have been launched. In a growing number of regions specialized Diabetes Services are becoming increasingly important in carrying out diabetes care. There is little quantitative information on the uptake of care by diabetes patients. A recently published study (Table 1) reports findings on the utilization of care amongst diabetes patients.⁴

Table 3.1 Percentage of diabetes patients who have had contact with a care provider during the past year.

Care provider	Percentage
General Practitioner	95
Diabetes nurse specialist	23
Medical specialist	80
Nutritionist	30
Physiotherapist	20
Podiatrist	10

Data from a country-wide GP organization show that in 22% of contacts concerning diabetes the patient was referred to a medical specialist, nutritionist, chiroprapist/podiatrist, or diabetes nurse specialist.¹⁵

Costs

There are a number of methods of estimating the costs of an illness. Usually calculations are made using cost of illness studies which involve calculating the costs of an illness over one calendar year related to the prevalence of that illness. The incidence costing approach is another method. A further distinction is the source of the costs; costs incurred by the health services, costs incurred by the patient and loss of productivity. According to the CODE-2-study (an international study into the costs of type 2 diabetes) which was carried out in eight European countries, the total cost of care for type 2 diabetes and its complications in 1998 in the Netherlands was an estimated € 260 million, which is 1.7% of the total health care budget. In 1998 the total cost per patient per year was € 1,666. When broken down, 26% of costs were incurred by the ambulant care services, 34% for clinical care and 39% for medication. Factors influencing higher costs are the age of the patient, insulin use and diabetes-related complications.⁵

Co-morbidity

Diabetes type 2 is often associated with complications. At the time of diagnosis, around a quarter of patients have a history of myocardial infarction, CVA, angina pectoris, peripheral vascular disease or heart failure.⁶ Of 2,40 patients with type 2 diabetes in 52 GP practices, 1,640 were treated by their GP. In this group 44% had one or two diabetes-related complications, and another 7% had three or more complications.⁷ Micro- and macrovascular complications negatively influence quality of life.⁸

As well as these diabetes-related complications, people with type 2 diabetes often have other diseases e.g. COPD, arthritis, hypothyroidism and gastro-intestinal conditions. This is more or less logical taking into account that around half of the people with type 2 diabetes are over the age of 70.

In summary

In 2005 between 400,00 and 500,000 people were suffering from type 2 diabetes and this number is continuing to rise. Around half of them have cardiovascular complications as well as other co-morbidities. Many people with type 2 diabetes are over the age of 70. When calculating the costs of diabetes care (estimated at 2% of the total health care budget) not only are the direct medical costs important but also the costs incurred by the people with diabetes themselves. This is particularly true as type 2 diabetes occurs more frequently in the lower socio-economic classes.

3.2 Prevention and care

Primary prevention

Overweight and obesity are the main risk factors for diabetes. Depending on its extent, people who are overweight or obese (Body Mass Index > 30) have a 2 to 27 times higher chance of developing diabetes. Overweight and obesity are a danger to the health of the public and the problem is expected to increase over the coming years.⁹

Primary prevention of diabetes means an attempt to stop the onset of the disease e.g. by stimulating weight loss and exercise. According to the Dutch guidelines for diabetes (Zorgstandaard) issued by the Dutch Diabetes Federation (NDF) intervention should begin at an early age and target not only individuals but also the family and society itself.¹⁰ Guidelines on preventing overweight and stimulating physical activity are not yet available. However, general recommendations can be given in which the government can play a leading role. Examples include: healthy eating at home, at school and in public institutions (reduce the sales of high density food and drink) and stimulating exercise and sports activities. The Guidelines also recommend that care providers should be aware of their patients' risk factors and should give wide-ranging health care advice.

Secondary prevention

Recently a Health Council Commission issued recommendations concerning screening for Type 2 diabetes.⁹ A prerequisite for employing screening (secondary prevention) is that early treatment is more effective than late treatment. The aim of treatment is after all to detect diabetes as soon as possible in order to minimize any resulting morbidity and mortality. No research has been done into the use of *general* screening for diabetes in order to reduce complications and death resulting from this disease. Based on research into early treatment of the disease process, it can however be assumed that general screening for diabetes will bring about improvement in health. Taking these findings into account, it is theoretically possible that screening of the general population will lead to an improvement in health. The extent of this improvement cannot be determined exactly as there has been no comparative research in this area.

A further potential use for screening is to select *high-risk groups*. Overweight people often have a clustering of risk factors for cardiovascular diseases. As well as a very high chance of developing diabetes they also have elevated blood pressure and unfavourable levels of fat distribution in the blood. The Commission sees this clustering as reason to screen overweight people as there are potentially many benefits to health to be obtained. These benefits can be achieved if not only the diabetes but also the accompanying risk factors for cardiovascular diseases can be treated.

The 1999 Recommendation of the Dutch College of General Practitioners (NHG) on case finding is in complete accordance with the above. It advises GPs to do a three-yearly blood sugar test on everyone over the age of 45:

- with parents or siblings with diabetes mellitus type 2
- with hypertension
- with manifest cardiovascular disease
- with a fat metabolism disorder
- with an ethnic predisposition such as for example Hindustanis
- with an BMI > 27
- with a history of gestational diabetes or who has had a baby weighing over 4000 gram.¹¹

Naturally lifestyle advice on exercise, healthy eating and stopping smoking should be part of the treatment. However, it has not yet been scientifically established that screening this high-risk group really would infer health benefits and how big these benefits would be.

Treatment

In 2003 the Dutch Diabetes Federation (NDF) published recommendations, which are based on existing Dutch guidelines on diabetes care. All these guidelines are, as far as possible, evidence-based. Following diagnosis, treatment is as follows:

- Seek to positively influence the lifestyle of the patient in the areas of nutrition, exercise habits, smoking behaviour and use of alcohol.
- The treatment of hypertension, hyperglycaemia, and dyslipidaemia.

Three important, closely connected yet distinct processes are set in motion. First targets are set, aspired to and assessed. Second is the process of education – learning to cope with diabetes. In this process people with diabetes acquire knowledge, attitudes and skills which enable them to recognise how they can learn to cope with their condition. They learn self-control and self-regulation and become able to estimate the effects of exercise, diet and stress and use this knowledge accordingly. The aim of this education is that people acquire the knowledge and skills necessary for them to be able to take care of themselves properly. Third is the process in which people with diabetes recognise, fight for and improve their position in society. After being told “you have diabetes” it becomes clear to them, often unexpectedly, that this may have a negative impact on their position in the community and in social relationships. They want to learn to cope with this and if necessary, are willing to fight for their rightful position and a fair deal.

In summary

Table 3.2 summarizes the interventions in the field of type 2 diabetes.

Table 3.2 Interventions necessary to avoid and to treat diabetes

PHASE OF DISEASE PROCESS	INTERVENTION
Before the onset of diabetes	Education and policy measures in the public domain
If the chance of developing diabetes is high (the 'high-risk group')	Case-finding by GP according to the NHG-Recommendations Possibly targeted screening
When the diagnosis is suspected	Meticulous diagnostics in accordance with the NHG-Recommendations/NDF Dutch guidelines for diabetes
When the diagnosis has been made	Education including lifestyle advice/recommendations Multifactorial treatment targeting risk reduction in accordance with the NHG-Recommendations/NDF Dutch guidelines for diabetes

3.3 Diabetes care: care chain

Diabetes care is so-called chain care.¹⁴ The term 'care chain' (freely translated from the Dutch 'ketenzorg') describes precisely what every person with diabetes can expect to encounter – a number of care providers who should ideally be in contact with one another. The term care chain implies cooperation between each of the links of the chain and emphasizes the responsibilities of each individual care provider.

The chain begins with the patient. All the links in the chain have their own particular area of expertise and are expected to be accountable in a well-defined area. The length of the chain is dependent on the specific needs of the patient but can consist of eight or nine caregivers. An example of an organized care chain (and incidentally also an example of disease management) is the diabetes care model in the Gorinchem area of the Netherlands, into which the following vision is formulated:

- Optimal care according to accepted guidelines for everyone with diabetes
- Tailored to the individual needs of the patient
- Accessible and unambiguous information and education of a high standard
- Cooperation and accord between primary and secondary care providers
- patient data easily accessible to every care provider
- structured financing.¹⁶

Figure 3.2: The chain which includes all disciplines generally involved in the care of people with Type 2 diabetes. Please note that many other specialists may also form part of the chain e.g. nephrologist, vascular surgeon or psychologist.

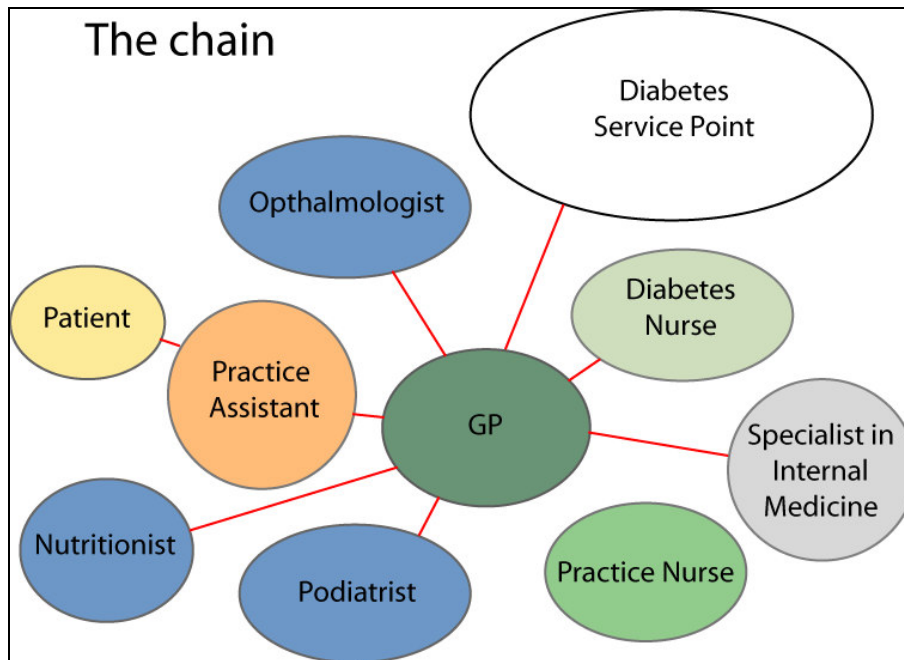


Figure 2 illustrates that diabetes care is not only complex in its content but also in its organizational aspect. The more people that become involved the more complex it becomes. How do the advantages inferred by task differentiation weigh against the disadvantages of the resulting more complex organization? In order to answer this question adequately it is necessary to examine a number of the links in the 'main chain' in greater detail.

The patient

Patients, quite rightly, demand qualitatively good diabetes care. The results of the care on offer however, depend on how the patient deals with the recommendations on lifestyle, medication use and a regular monitoring scheme over a period of often decades. Doctors whose patient population with diabetes type 2 consists mainly of well-educated people in middle-age are more likely to be successful in achieving good results in lowering blood pressure and hyperglycaemia than doctors whose patients are mainly younger diabetics from a lower socio-economic group. A striking illustration of this can be found in a recent American study in which at first sight one group of doctors appeared to be delivering better diabetes care than another group. When the differences for age, sex, socio-economic status and the health behaviour of the patients were adjusted, these differences disappeared.¹⁷

In recent Dutch and British studies on diabetics treated by general practitioners, poor regulation was shown to be most closely related to level of education and relative youth.^{18,19} The 'typical' patient does not exist. Treatment and support will have to be adapted to the mentality and manner of living of the individual patient.

Practice assistants

As a good re-call system is important in structured care, the employment of a practice assistant in diabetes care is to be recommended. Some GPs have delegated the larger part of diabetes care to a practice assistant. It should be noted (and here we are talking about the specific situation in the Netherlands) that practice assistants have been trained to the level of intermediate vocational education and their pathophysiological knowledge is limited. They also receive no training in giving advice on lifestyle changes in anything other than

acute conditions.²⁰ In other words, practice assistants who take 'independent diabetes clinics' are not geared up for this job unless they have received extensive further education.

The General Practitioner

The extent to which general practitioners are successful in providing good diabetes care varies greatly. Some GPs have good insight into the important parameters regarding the care that they give; others however, are unable to summarize the data concerning the care that their diabetes patients receive. Even so, in 2004 the average GP in the Netherlands was able to provide good diabetes care. Table 3.3 shows the results of the management of diabetes care in ordinary general practices, none of which uses the specialist Diabetes Services. In all these practices the three-monthly and annual check-ups are carried out at the practice itself. These data were gathered before an innovative intervention had been introduced.

Table 3.3: Results of diabetes management in patients treated by general practitioners. Patients, 2000-2004 (Averages)

Ref.	Location	Practice. (n)	Pat. (n)	Remarks	HbA1c (average)	Blood Pressure (average)	Cholesterol (average)
1	Utrecht area (2000)	52	1641	Baseline measurements scientific research. Patients treated by GPs. Half of the practices participating in the Utrecht Diabetes Project	7.1	148 / 84	5.8
2	Nijmegen area (2000) (2004)	10	870	Nijmegen Monitoring Project. All patients treated by the GP for > 1 year. Regular feedback, but no special support.	7.2	146 / 81	5.1
3	Apeldoorn area (2003)	40	1721	Baseline measurements scientific research. No selection. All patients treated by GP	7.1	141 / 80	5.2
4	Eastern Netherlands (2003)	41	1432	Baseline measurements scientific research. All patients < 80years treated by the GP. No extra support. No selection	7.1	146 / 83	5.3
5	Whole country (2003-4)	53	2701	Baseline measurements on participation in Diabetes Care/management Protocol. All patients treated by GP.	7.0	148 / 83	5.2

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- | | |
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| 5. Cleveringa F. et al. | f.cleveringa@umcutrecht.nl |

We may assume that these data are representative of the average Dutch general practice. It is true to say that these were practices actively seeking to improve their level of care but at the same time they were practices that had not previously taken part in any other diabetes study. Some practices proved to have poor registration systems and the degree of assistance varied widely. In each case, the prevalence of diabetes corresponded to the known national prevalence. Viewed in this light, the improvement in the results of diabetes care has been remarkable: the average HbA1c in the Netherlands in 1998 was 7.5%. The average total cholesterol was 6.0 mmol/l and the average blood pressure 154/87.²¹

Although Dutch general practitioners have clearly been successful in improving the quality of diabetes care, there are still thousands of diabetics who are not getting the care they need. Why is this? There are guidelines after all? Bouldin et al. produced the following summary of the causes of qualitatively inadequate diabetes care, a problem much more prevalent in the United States than in the Netherlands.

1. Doctors overestimate the quality of the care they provide;
2. Doctors do not follow guidelines because they know the patient will not stick to the recommendations;
3. It takes time for new knowledge and guidelines to become completely disseminated throughout the medical community;
4. Rapid changes and modernization of treatment strategies only increase the problems in following guidelines;
5. The increased complexity of the disease is not accompanied by an increase of the time allocated to it in the doctor's surgery.

The authors conclude that a systematic approach to diabetes care is necessary in every practice and that more time and manpower is necessary to improve the quality of diabetes care. "Modern diabetes care is expensive, but the old adage remains true - we can pay for it now or pay for it later."²³

One of the solutions is the delegation of tasks to nurses i.e. to practice nurses and to specialist diabetes nurses.

The Practice Nurse

In 2005 there are about 1,000 practice nurses employed by 2,000 of the more than 7,000 Dutch general practitioners. The majority of them are actively involved in the care of people with Type 2 diabetes. All practice nurses have been educated to higher vocational level and work at this level. Final attainment levels with medical content have been formulated.

Where delegation is concerned, the duties and responsibilities of the practice nurse should be clearly defined and enough time set aside for consultation with the treating GP. Neither practice nurses nor diabetes nurses are licensed to prescribe medications. If the general practitioner is not readily available for consultation there is a danger that high blood pressure, an abnormal fat spectrum or inadequately regulated hyperglycaemia may not be followed through by a medication adjustment. In the most extreme case, a patient may be seen regularly but not really treated. A Canadian experiment in which at the end of each appointment five minutes were set aside for a communal consultation between patient, practice nurse and general practitioner led to significantly better adjustment of medication than in a situation in which this 'mini consultation' did not systematically take place (lecture EASD, München 2004). An additional benefit of this system of working is that the general practitioner is obliged to keep his/her knowledge of diabetes up to date and perhaps even improve it. The opposite can also be true: general practitioners have the idea that they have delegated diabetes care to a highly-trained professional, they see most of the diabetes patients perhaps only once or twice a year and little by little they lose their knowledge and skills in the area of diabetes. In the long run this can lead to a diffuse distribution of responsibilities and transparency remains a long way off.

The diabetes nurse

In the Netherlands at the end of 2004, a group known as the First Association of Diabetes Nurses (EADV) published a brochure containing a summary of the core activities of the

EADV- registered diabetes nurse. The EADV see themselves as playing five different roles: those of expert, educator, consultant, innovator and initiator.

According to the EADV, expert diabetes nurses are able to carry out certain tasks such as: they are able to adjust blood glucose lowering therapy in accordance with a protocol, transfer people to insulin therapy independently, choose the correct insulin regimen, are able to recognize vascular damage (such as TIA, stroke, angina pectoris, myocardial infarction and peripheral neuropathy) know about body fat spectrum disorders and blood pressure disorders and the treatment of these conditions as well as being able to adjust medication according to protocol in all these areas.²³ This job description combined with the other four roles corresponds with the role of the 'specialist diabetes nurse', which will be discussed later in this chapter.

From 1997-1998 a pilot study was carried out with the diabetes nurse at five practices. This involved the diabetes nurse instead of the general practitioner doing the three-monthly diabetes check-ups. One of the outcomes (the HbA1c%) improved. Although the design of the study precludes the drawing of any robust conclusions, it is certainly an indication that diabetes nurses are able to take over part of the care from the general practitioner and maintain if not improve the quality of that care.²⁴ It has recently been shown that when nurses in the role of facilitator visit GP practices regularly, it is possible to improve diabetes regulation considerably in a short space of time.²⁵

As well as the practice nurse and the diabetes nurse, there are a number of other members of the nursing profession involved in diabetes management.

Firstly, there is the case manager. Bringing in a case manager to coordinate diabetes care in a general practice or at an outpatient clinic, seems at first sight to hold many advantages. Over the last few years, bringing case managers into diabetes care has become popular not only the Netherlands but also in many other Western countries.

Secondly, there are nurse specialists. These are registered nurses with long experience in a specific field of nursing and extra specialist training which qualifies them to work as a specialist in a specific clinical area and deal with matters such as patient care, consultation, education and research. The nurse specialist is primarily concerned with education (including the responsibility of coordinating the advice given by other care providers which may sometimes be contradictory) as well as supporting the patients, coordination of care, advice of the use of medication and advice on how to deal with intercurrent diseases.

A third function covers that of diabetes education. In the United States this is interpreted in the broadest sense of the word and is given by a whole spectrum of care providers including nurses, dieticians, pharmacists, physiotherapists, doctors and social workers under the collective title 'Certified Diabetes Educator'. Their job description is more limited than that of the nurse specialist, notably they do not give advice on medication. Some of them act as a nurse case manager. The table below shows how this type of education is organized in the Naomi Berrie Diabetes Centre, which Marianne Acampo visited for purposes of this book.

Diabetes care and diabetes education in New York

The Naomi Berrie Diabetes Centre (NBDC) is one of the three Diabetes Centres of Excellence in New York State. The centre was established in 1998 and provides multidisciplinary, integrated family-orientated diabetes care for 4000 adults and 800 children with diabetes mellitus in Manhattan and surrounding areas. About a third of the patients have diabetes type 1 and two-thirds have Type 2 diabetes. The centre is housed within the Russ Berrie Medical Science Pavilion. The centre is staffed by four endocrinologists, three paediatric endocrinologists, three education officers, three nutritionists, a social worker, two podiatrists, an ophthalmologist and five nurses. The centre is spacious and has treatment and investigation rooms, classrooms, offices and its own laboratory where glucose tolerance tests, meal tolerance tests and insulin tolerance tests can be carried out. The diabetes education programme is recognized by the American Diabetes Association (ADA) and therefore costs are reimbursed by Medicare and Medicaid. The aim of the programme is the optimal integration of diabetes care into the daily life of the patient. The programme places great emphasis on self-care and is targeted at achieving optimal health-related outcomes. In order to become recognized by the ADA, an institution must have a multidisciplinary instruction team with at least one registered nutritionist and nurse. The staff must meet certain educational requirements and have demonstrable skills in education and diabetes management.

The NBDC offers a number of education programmes to patients and their families, including group and individual classes for children and adults, instruction on using insulin pumps and sessions on specific themes such as eating out, exercise, weight loss, research update and support following transplantation. The centre also organizes courses for schools and summer camp counsellors about how to cope with people with diabetes. The Becky Dickinson Family Learning Centre is situated within the centre. Here with the help of interactive multimedia, patients can get help and information best suited to them.

Fourthly we come to the registered diabetes nurse. This is a nurse specialist who works only in the field of diabetes care, either intra- or extramurally. In Britain, in 1991, the British Diabetes Association recommended that there should be four registered nurse specialists per 250,000 inhabitants. However, in 2000 this number had been achieved in only two of the nine districts being studied.

The role and effectiveness of nurses in diabetes care has been systematically researched by the Cochrane Review. This unusually thorough form of research guarantees that all research on the role of nurse case managers has been included in its conclusions. The following is derived entirely from this review.

Although in general patients are satisfied by the care delivered by the nurses and often consult them before their treating physician, at the time a Cochrane Review was published, the effects of nurse-led and coordinated care were as yet unknown. Based on six trials, five of which were randomized with a follow-up period of 12-18 months, the reviewers concluded that there is still insufficient proof of the suggestion that diabetes care is improved by the appointment of nurse specialists or nurse case managers. They concluded that the first and most urgent need is to make a detailed inventory of the many and widely differing tasks of the nurse specialists and case managers throughout various care systems. An extensive inventory of the advantages and disadvantages of the allocation of tasks is necessary e.g. to examine if the role of educator should be combined with a management or medical role? Only then should new randomized trials be set up. Included in these should be the cost of appointing a case manager.²⁶

Other innovations in the treatment of diabetes at the NBDC

The social work department is active in tracing patients who are unable to take care of themselves adequately and also helps patients to obtain care facilities at home. Patients who are not well-controlled are e-mailed or telephoned weekly. They are assigned to a case manager who coordinates their care. If it is at all possible the patients see all their caregivers on the same day. As they often spend a long time at the centre there is also a cafeteria where snacks suitable for diabetics are available and where they can get information about healthy eating. The waiting areas are laid out in such a way that while patients are waiting they can make phone calls or do their homework.

What distinguishes the NBDC from other institutions offering treatment is their emphasis on involving members of the patient's family in the treatment. Parents, husbands and wives, children and other family members are asked to attend consultations with the specialists, the aim being to avoid the complications that so often accompany diabetes.

The Specialist in Internal Medicine

The Dutch health system is organized in such a way that only those people with the most complicated and difficult to treat conditions are seen at a hospital outpatient clinic. International comparative research has shown that in a system with a strongly developed primary care structure, the care on offer is more effective and efficient.²⁷ Since the nineteen-eighties, diabetes care has been moved out of the hospital outpatient clinic and into general practice. Regional specialists in internal medicine played a prominent role in these developments. As early as 1989, the NHG guidelines were giving concrete recommendations concerning which diabetes patient should be treated by the GP or referred to a specialist in internal medicine. The Dutch guidelines for diabetes make the same recommendations.¹⁰ Now in 2005, almost 20 years after this structure was put in place, the majority of people with Type 2 diabetes who are being treated by a specialist in internal medicine have had diabetes for many years: they are being treated with insulin and often have diabetes that is difficult to control. This group also has a relatively high complication rate.²⁸ In other words, the diabetes population of a specialist in internal medicine is a

different one to that being treated in primary care. We can also see this reflected in the diabetes control with HbA1c-percentages of an average of 8.2% and 7.6%.^{29, 30}

While the objectives of diabetes care should be realistic, there are some groups of patients who require a more intensive type of care than routine three-monthly check-ups. In this respect, the current development of guidelines for special categories of diabetes patients e.g. those with renal failure or with a diabetic foot is to be applauded.

In summary

Diabetes care is chain care (bearing in mind the Dutch term).

The division of diabetes care between primary health care and hospital as it is advised in the guidelines is both logical and efficient

The introduction of diabetes nurses (or specially trained practice nurses) into the care of people with Type 2 diabetes is both desirable and necessary. The appointment of nurses will facilitate the integration of education into the diabetes services.

The often-heard statement that the introduction of diabetes nurses will improve the quality of diabetes care, is not evidence-based. There is no indication that the creation of new posts alongside those shown in Figure 3.2 would be cost-effective or improve diabetes care. At the very least, the differences between the functions of each of the currently existing posts must be clearly defined.

3.4 The diabetes care programme: a form of disease management

The framework of a care programme for people with diabetes type 2 is made up of the following elements:

- Early tracing of people with diabetes
- The accurate establishment of diagnosis
- Soon after diagnosis: education on the disease itself and the related importance of lifestyle
- Soon after diagnosis: support from a nutritionist
- A structured recall system in order to permanently monitor which people fall outside the care system.
- Differentiation in treatment between the three-monthly (if necessary at more frequent or less frequent intervals) 'minor' check-ups and a yearly 'major' check-up. The major check-up is aimed at the early detection of risk factors which could lead to new and disabling complications: cardiovascular complications, disorders of renal function, foot problems
- Early eye check-up
- Early, and, if necessary, repeated adjustment of the medical treatment of hyperglycaemia, hypertension and dyslipidaemia following the principles of evidence-based medicine
- Early and individually tailored instruction on self-monitoring of blood glucose levels
- Treatment of the complications that accompany diabetes following the principles of evidence-based medicine
- A continuous process of education tailored to the individual
- Coordination of appointment times of all the care providers directly involved: doctors, diabetes nurses, practice nurses
- Clear written descriptions of the tasks and responsibilities of all directly involved care providers
- Clear arrangements concerning who handles which complications
- Working with a laboratory that satisfies NDF-quality requirements
- Registration of all data from the above-mentioned elements and agreements as to who has access to the data.
- An integrated quality system with an annual review at which all the process- and outcome parameters arising within the care programme during the preceding year are discussed. These discussions are then taken as a starting point from which plans for improvement of quality are made and implemented.

- This summary paraphrases the NDF Dutch guidelines for good diabetes care. There are guidelines available, some of them evidence-based, on many of these elements. They are produced by the NDF, the CBO and various specialist organizations of general practitioners, specialists in internal medicine, diabetes nurses, nutritionists, podiatrists, psychologists, pharmacists and clinical chemists.

It is common knowledge that good quality diabetes care requires a good organizational structure. Norris et al.³¹ conducted systematic review into the effectiveness of disease management in diabetes. They describe disease management as a structured means of providing care, as proactive, as being made up of multiple elements and targeted at all members of the population with a certain disease. Feedback and benchmarking are an integral part of this.

Basing their findings on dozens of studies, they drew the conclusion that disease management leads to a better form of diabetes management, more retinopathy screening and foot abnormalities and focuses more attention to dyslipidaemia.³¹

Although there are indications that providing Dutch GPs with benchmarks and feedback on the quality of diabetes care is improving the quality of the results of diabetes care in the long-term,³² three points should be made:

- Randomized studies have not been carried out in this field; it is therefore by no means certain that giving feedback contributes to a significant degree to the improvement of the care outcomes;
- As far as is known, feedback is only given to GPs; the degree to which specialists in internal medicine and nurses value feedback and adjust their care on the basis of this feedback is totally unknown;
- Ensuring reliable benchmarks is a time-consuming and expensive activity.

Randomized trials in the Netherlands add a postscript to the above that emphasizes that attention to the organizational aspects and processes of diabetes care is necessary but in itself not enough. The results of diabetes care, which in the end is what it is all about (reducing diabetes-related complications, maintaining quality of life etc.) are determined by the institution of effective therapy in response to abnormal findings. Statistics are important but not an end in themselves.^{33, 34, 35}

In order to tackle the problem of non-committance, the Dutch guidelines propose that everyone who has Type 2 diabetes should be treated within the framework of a care programme. This means that every health professional providing diabetes care should be part of such a programme. We would like to start by making the following basic assumptions:

- the distinction between primary care and specialist diabetes care each with their particular areas of competence and cooperation has proved to be worthwhile, from the point of view of both quality and cost
- Care for people with diabetes type 2 should be available as near to their homes as possible. Transport costs are often considerable, even for short distances. This is all the more important as mobility declines with age; half the people with Type 2 diabetes are over 70 years of age and the lower socio-economic classes are over-represented.
- A diabetes care programme should ideally include care providers from both primary and secondary care levels. It is probably most efficient to organize primary and secondary care equally well but separately (there remains much to be done in both sectors) while ensuring there are clear agreements on the integration of care.
- There is no reason to introduce categorized diabetes care. Not a single study has been able to demonstrate that this would improve the results of diabetes care. In addition, its cost effectiveness has never been established.

The USA³⁶⁻³⁹

In 2002 it was estimated that 6.3% of the population of the USA had diabetes. That is more than 18 million people.

Although the American Diabetes Association guidelines are stricter than the European or Dutch guidelines, the results of diabetes care in the USA are in general worse, although the situation is now clearly improving.

Around 15% of the population of the USA do not have health insurance and most of the studies on the quality of diabetes care do not include this group. Many of them, principally from the lowest socio-economic classes only feature in the healthcare statistics if they develop complications such as blindness or have a foot amputated. Serious diabetes-related complications occur more frequently in the USA than in the Netherlands. The cost of the health services in the USA is around

14% of the Gross National Product. Costs associated with diabetes in the USA are many times those of the Netherlands.

The Health Maintenance Organizations (HMOs) who guarantee their members various forms of disease management and continuity of care are reporting progress in care outcomes. De HMOs generally distinguish between uncomplicated forms of diabetes which are treated by 'generalists' and the more complex forms which are treated by endocrinologists. It is probably true to say that Americans have more to learn from the way in which the Dutch organize diabetes care than the other way round.

In summary

In the Netherlands there is general agreement about the necessary elements that make up a diabetes care programme. Such a programme is by definition a form of disease management. Disease management leads to a higher level of diabetes care. However, it is not enough only to look at the managerial aspects of diabetes care: the institution of effective therapy in response to abnormal findings is of overriding importance. Benchmarking is an integral part of any diabetes care programme, although its cost and cost-effectiveness are not supported by much evidence. The simplest way to organize a regional diabetes care programme is from within both primary and secondary care. There is still room for improvement and it goes without saying that close cooperation between both sectors is indispensable.

There is no scientific evidence whatsoever to support the introduction of categorial diabetes care. Indeed, this in itself would be a fundamental break with the current organization of the health care services in the Netherlands.

3.5 Continuity of care

The continuity of care for people with diabetes type 2 is important for a number of reasons.

1. Diabetes itself is a disease of many and varying aspects.
2. People with Type 2 diabetes take more medication than any other category of patients.
3. People with Type 2 diabetes often have co-morbidities.

Although diabetes patients often have a 'main treating specialist' many of them under the care of a general practitioner still often consult a specialist in internal medicine, cardiologist or ophthalmologist. They are often referred to a specialist team e.g. a diabetes patient with a foot problem is referred to a hospital Foot Care Service which means a specialist in internal medicine delivers part of the treatment. Each patient has personal experience with blood glucose regulation, blood pressure, and quality of life 'So to whom (which caregiver) do we attribute these quality markers?' is the question posed by Pringle.⁴⁰ The so-called communally carried responsibility with explicit areas of shared responsibility which fits into the definition of transmurial care has not so far offered any consolation. Pringle's answer is that continuity of care must be followed by continuity of data collection as the basis of continued quality assurance. This implies a linked system of data information technology both within and outside the hospital setting. Although in Britain primary care is to a large extent automated, automation in hospitals was introduced initially with a view to providing management information and not to supporting the clinical process or quality assurance. There is a long way to go before patients have access to an electronic dossier that will track their medical history both in and out of hospital. However, this is the only way forward and the government in the Netherlands also holds this opinion. Diabetes care will be a spearhead of the advancement of information technology in the health services.⁴¹

In summary

The Ministry of Health, Welfare and Sports (VWS) has quite rightly chosen diabetes to spearhead innovation in the area of electronic data collection. Continuity of care is particularly important for people with diabetes. This can be made considerably easier if the patient dossier to which multiple care providers contribute is easily accessible to all of them.

3.6 Financing diabetes care

Without dwelling too long on all the various ways that good diabetes care can be financed, it is useful to look at some of the considerations that care purchasers and care providers have to take into account.

- In comparison with other countries, diabetes care in the Netherlands has been relatively cheap up until now.
- Both general practitioners and specialists in internal medicine indicate that a lack of time and support staff are reasons why care in some branches is substandard. It is therefore only logical that optimally-functioning diabetes care programmes will be considerably more expensive in the short and middle-terms. For many people, the profit in terms of improved quality of life will show itself only in the long term. Cost-effectiveness is therefore also a long-term question. Care purchasers want to know which 'product' they are buying. Diabetes care should, for this reason, be open and transparent and quite correctly so. However, this does not mean to say that the purchaser should check minutely on everything the care provider does. Firstly, this would not only frustrate the care providers but and more importantly, this would lead to a huge bureaucracy that would cost a great deal of money. It would be a disaster if diabetes care programmes fell prey to bureaucracy.
- Quality measurement and benchmarking take time, manpower and therefore money. Diabetes care programmes ought to be so structurally financed so as to enable integrated quality assurance.
- In the funding of every part of a diabetes care programme the organizational costs should be carefully weighed against the expected improvement in quality that is reasonably to be expected from the organization.

In summary

In the short term the introduction of diabetes care programmes will mean that diabetes care will be more expensive. Cost-effectiveness will become apparent only in the long term.

An integrated policy of quality costs a great deal of money. Money for a specific aim should be structurally available within a diabetes care programme.

A too-detailed quality control system is self-defeating and not only from the financial point of view.

3.7 Conclusions

Diabetes care calls for a form of disease management. The definition of Norris et al.³¹ and the further development of a care programme for diabetes largely corresponds with what Spreeuwenberg has written on the subject. Spreeuwenberg ascertains that differentiation between patients with the same disease is unavoidable. This is entirely in keeping with my plea for the parallel development of care programmes for diabetes both inside and outside hospital.

However, Spreeuwenberg does not include active tracing in his definition of disease management given in Chapter 1. In this sense, diabetes care programmes as they are described here go one step further and follow on from the growing practice of case finding.

Disease management should promote cooperation between care providers. As Spreeuwenberg wrote, this was not the case in the United States. Over the last 20 years there has been large scale successful cooperation between general practitioners, specialists in internal medicine and nurses in the area of diabetes care, even though some of the

arrangements are still fairly informal. Real transparency within a diabetes care programme will only come into being when every person with type 2 diabetes is involved in a care programme. This demands health informatics computer systems both in and outside the hospital setting which are aimed at and tailored to quality parameters and contain verifiable agreements on e.g. referral procedures, back referrals, and agreements concerning medication prescription practices. This should preferably be done in stages beginning with both primary and secondary care putting their houses in order. This will take time; there remains much work to be done within groups of general practitioners, specialists in internal medicine, practices and in hospitals in general. Then agreement must be reached about the binding character of arrangements between the various parties. Only in the third stage will regional achievable, verifiable arrangements be made which will raise the quality of diabetes care and promote regional agreement on working practices. Only in this way will a diabetes care programme that really works, take root. This view corresponds with what Spreeuwenberg has written about the Health Management Forum (STG) and the organization representing Dutch healthcare insurance companies (ZN). Both organizations see disease management as efforts aimed particularly at the advancement of chain formation in the care process in which separate trajectories and parts are coordinated with one another.

Central steering of both process and content is a characteristic of a disease management programme. Central steering is indeed necessary but the essential question is in how far central steering will lead to an improvement in quality. And it really does all concern quality - fewer non-compliers, fewer complications, better treatment results and not just more charts with records of blood pressure, weight etc. The quality of registration (a 'process-parameter') is actually only a very limited indicator of quality.³³ It is far more effective if doctors prescribe medication properly than if they only concentrate on the improvement of the process of diabetes care without implementing it effectively.²²

It will require the commitment, wisdom and skill of all those involved in diabetes care to find the balance between guidance and organizational fanaticism. This is also true for the management information that is used for benchmarking. Spreeuwenberg states that benchmarking and culture shock go hand-in-hand. Benchmarking should give a valid and current picture of the provision of care. And importantly: '...the further an observer may be from the clinical situation, the more difficulty there is in interpreting the data. For data to be turned into information they require context.'⁴⁰ Over the coming years many randomized trials will take place in order to provide information on the real effects of benchmarking.

One characteristic of disease management mentioned by Spreeuwenberg merits further explanation. One very recent health report on European Primary Care talked of a potential regional separate umbrella agency to support primary health care in management tasks.²⁷ A regional organization could, for example, deal with health insurance companies, employ diabetes nurses and coordinate feedback and benchmarking. This type of set up would combine the advantages of personal, small-scale care available near home with the advantages of a large-scale administrative organization. In 2004, in a number of places throughout the Netherlands, similar Diabetes Service Points have been set up within the primary care setting (www.dihag.nl).

The development of diabetes care models and large-scale forms of disease management in which third parties take over the responsibility of the current care providers has as yet hardly taken root in the Netherlands, according to Spreeuwenberg. If this means that non-affiliated care for a group of people with a chronic condition and a high level of comorbidity is not introduced into the Dutch health services then this is a good thing – all the more so when set against the background of a doubling in the greying of the population. It looks as if within both primary care and the hospital setting, the challenge of providing transparent diabetes care is being adopted on a large scale. The implementation of the Diagnosis and Treatment Combinations (DBC) in primary and secondary care is expected to stimulate the development of diabetes care programmes.

Quite correctly Spreeuwenberg proposes that the functionalism and effectiveness (including cost-effectiveness) of disease management have, as yet, scarcely been demonstrated. In this chapter, with respect to diabetes care programmes, conclusions have been drawn on the

introduction of case managers, the emphasis on education and self-regulation, and the provision of benchmarking. Spreeuwenberg argues 'Changing the organization and financing of diabetes care into that of a large-scale disease management model requires a considered strategy from government, health insurance companies, patient organizations and organizations of care providers'. This chapter is an attempt to deliver as much spiritual ammunition to this end as possible.

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4 Care Programmes for patients with depression

Guido Nabarro, Aart Schene

4.1 The patient population

Depressive disorders, or in short depression, belong to the most important and most frequently occurring conditions covered in our present health care services. The term covers disorders that are extremely varied both in manifestation, seriousness and course. For example, a disorder can be a brief and self-limiting episode that lasts for a few weeks or an extremely serious recurring disorder that has major consequences for the person's daily functioning and quality of life. In this chapter, we take the definition as stated in the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV classification system) in order to describe the disorder adequately. This system¹ is worldwide the most commonly used for the classification of psychiatric disorders. The starting point for the classification of a depressive disorder is that one or more episode has occurred. The core symptoms relating to such an episode are a depressive mood and/or a decrease in the amount of interest or pleasure in life. The relative criteria in relation to the above are shown in Diagram 4.1.

Diagram 4.1: Characteristics of a depressive episode

<p>Five or more of the following symptoms have been present during the same 2-week period; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure in life.</p> <ol style="list-style-type: none">1. Depressed mood for most of the day, nearly every day as indicated by subjective report or observations made by others.2. Markedly diminished interest or pleasure in all, or almost all activities most of the day, nearly every day (as indicated by either subjective account or observation made by others)3. Significant weight loss when not dieting or weight gain (e.g., a change of more than 5 % of body weight per month) or decrease or increase in appetite.4. Insomnia or hypersomnia nearly every day.5. Psychomotor agitation or retardation nearly every day as indicated by subjective account or observation made by others.6. Fatigue or loss of energy nearly every day.7. Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being ill).8. Diminished ability to think or concentrate, or indecisiveness, nearly every day as indicated by subjective account or observations made by others.9. Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide plan or attempt. <p>In addition, the following applies:</p> <ul style="list-style-type: none">- The symptoms are not due to the direct physiological effects of a substance (medication, drugs) or a medical condition.- The symptoms cause clinically significant distress or impairment in occupational or other important areas of functioning.- The symptoms are not better accounted for by bereavement i.e. after the loss of a loved one.

According to this classification system, the group of mood disorders contains various depressive disorders as shown below in diagram 4.2. In order to differentiate between these

disorders, attention must be paid to whether or not there are clinically relevant mood changes from depressive disorders to bipolar disorders that contain euphoria, whether or not there are psychotic symptoms (psychotic depression) or if there is a question of a minor yet prolonged depressive disorder (dysthymic disorder). In addition, depressive disorders exist that are related to somatic disorders or to the use of certain substances such as prescribed medication or addictive drugs. Symptoms added to the diagnosis indicate not only the seriousness of the condition but also whether or not (partial) recovery is taking place. This chapter will deal especially with depressive disorders.

Diagram 4.2: Summary of mood disorders

-	Depressive disorder
-	Dysthymic disorder
-	Psychotic depression
-	Bipolar disorder
-	Mood disorder resulting from a physical illness
-	Mood disorder resulting from a psychoactive substance

Depressive disorders are common. On a worldwide level, the lifetime prevalence of the bipolar disorders and the dysthymic disorders is put at 6.3% and 1.8 % respectively. For depression, these figures are 12-15% for men and 20-26% for women. The annual prevalence for depression in the Netherlands is in the region of 6%.² In the US, 20% of patients in primary care are suffering from a psychiatric disorder, of which approximately one third is due to depression.³ At the same time, depression often occurs in combination with a number of other psychiatric disorders, especially anxiety, obsessive-compulsive, eating, and addictive disorders. In a number of cases, depression is the first symptom to appear, whilst in others there is clearly a question of comorbidity where the depression can also be secondary to the other disorder.

The morbidity and mortality for these disorders is high. In spite of the fact that treatment possibilities have improved, the death rate resulting from suicide has not decreased during the last decade. Depressive disorders account for a considerable portion of the use of medical services in the first two care levels of primary and secondary care. This is due not only to the direct treatment costs of the depression itself but also to the many physical symptoms that accompany depression and may or may not prompt somatic diagnosis and treatment. In addition, depressions also very much account for a person's marked functional impairment at work which inevitably leads to absence in the form of sick leave. By now, the European Economic Community has come to recognize depression as a problem that needs to be addressed by all its members. It is expected that by the year 2020, depression will be the second most important cause of disease worldwide.⁴

As is the case for most psychiatric disorders, the exact cause of the depressive disorder is not known. Biological factors, many of which are present in the person from birth as well as those that sometimes develop during a person's life are known to play a significant role. In addition, psychological and environmental factors are also of great importance. These factors may explain why depression manifests itself in one person but not in another. Moreover, it appears that the two factors known as *nature and nurture* can influence each other significantly. This means that traumatic experiences can result in permanent changes to neurobiological processes in the brain. These can then influence the behaviour of the person. This process of multiple causality is summarized in the popular bio-psychosocial explanatory model in the etiology of psychiatric disorders.²

From the Dutch Nemesis study,⁵ it appears that a large number of people suffering from depression do not seek help but that in spite of this fact, the recovery rate of these people is 85%. This group, in general, suffers from a light to average form of minor depression that is not prolonged. By this we understand that only a minimum or slightly more than the minimum number of symptoms are present in order to diagnose the disorder and that there is only a slight degree of functional impairment. From the same Nemesis study, the data shows that out of the 900,000 people per year who are known to suffer from depression and the 350,000 people who suffer from the dysthymic disorders, approximately two-thirds i.e. 750,000 people seek help. The factors that account for whether or not people seek out help

are amongst others, the nature and seriousness of the depressive symptoms, the duration of the depressive episode and the frequency with which depressive episodes occur. For approximately 500,000 or two thirds of these patients, the disorder is recognized and diagnosed as such by the person's general practitioner. The majority of these people remain (with or without treatment) in primary care. Only 6% of these people are referred to the mental health care services (GGZ) at the first visit to the GP. A further 2% of these people are referred for a similar episode at a later time. Of those people referred to the GGZ, a small number, approximately 15,000 people will be admitted to a psychiatric unit for treatment of the depression or will be admitted for partial treatment. Depression can therefore be described as a disorder of primary care.

The rate of recurrence in patients treated for depression depends on the setting. A rate of 40 percent was found in patients who were treated in Dutch general practice settings over a period of 10 years.⁶ Van London et al. followed a group of outpatient patients with a depressive disorder and found a recidivity rate of 41 percent over a period of five years.⁷ British researchers found a recurrence rate of 30 percent within one year for a group of intramural patients, a percentage that increases to 75 percent when measured over a period of more than 10 years.⁸

It appears that a large number of patients does not recover sufficiently meaning both that the chance of recidivity is greater⁹ and that the disorder turns into chronic depression for 10 to 15% of the patients.¹⁰⁻¹³ Chronic depression is in this instance defined as a depression that lasts continuously for two years or more. This means that we can conclude that for some patients with depression (approximately half) the disorder can be seen as one which runs its course as a recurring and/or chronic disorder and can therefore be compared with such diseases as diabetes, hypertension, COPD and back problems. The functional impairment that results from depression is however greater than with these other diseases.¹⁴

In the Netherlands almost 10 % of the national income is spent on health care and in the US this amount is 15 %. In 1999 the Netherlands spent 7.8 billion euro on care for the benefit of psychiatric disorders. This amounts to 21.6% of the total of 360 billion for the whole of the Dutch health care services. From this amount of 7.8 billion, 497 million euro was spent on care for people with depression. These costs were 339 million euro for the female population and 158 million euro for the male population. It is expected that these percentages will increase in the coming years and that the treatment of depression will represent an even greater part of the whole.

This chapter will focus in particular on the approach towards and treatment of depressive disorders, paying particular attention to the concept of care programmes.¹⁶⁻¹⁹ As previously mentioned, there may often be a case of some patients presenting with more than one psychiatric disorder. For these cases, the choice will have to be made whether or not to treat the disorders and in which order. Taking the city of Amsterdam as an example, there are three large GGZ institutions that are each responsible for mental health care in a specific part of the city. Ideally, the three care programmes for mood disorders would be placed behind the primary care services. By using multidisciplinary cooperation programmes, the expertise in the programmes is made available through the primary care level. The following paragraphs will go into more detail on this point. In order to do this we will draw exhaustively on our own experiences with the care programmes for mood disorders that have been running for ten years in the AMC and The Meren locations.

4.2 The coherence between prevention, cure and care

Since its recognition, prevention has always been divided into primary prevention (the prevention of the disorder) secondary prevention (early recognition and treatment) and tertiary prevention (the prevention of the recurrence of an existing disorder). Nowadays, the differentiation between universal, selective, and indicated prevention is also used. These terms refer to a whole general population, populations at risk and groups with symptoms of the disorder respectively.

Little is known on the subject of primary prevention for depression. However, there are preventive interventions that are aimed at the risk factors of depression. For example, the effect of preventive interventions aimed at the prevention of child abuse has been proven. In addition, preventive interventions have shown reductions in long-term effects such as problems with alcohol and drugs, criminal arrests and convictions, and the number of sexual partners.²⁰ In schools, anti-bullying programmes have also shown to be effective. This last-mentioned factor is important because prolonged bullying can lead to psychic symptoms including that of depression.²¹

The meta-analysis made by Jane-Llopis et al.²⁰ shows that prevention programmes aimed at depression appear to be effective for various age groups and risk levels. The most effective programmes consisted of different components and were mainly comprised of training in skills. They took up more than 8 sessions lasting between 60 to 90 minutes each. Older people were particularly helped by the social support they experienced and less by the behavioural approach. It appeared that programmes that were not primarily aimed at depression could also be effective.

Considering the scientific limitations that have been named, it would be a good idea to develop methods whereby it is possible to anticipate which people are likely to develop depression. The primary care setting would be the most suitable place to do this. For the time being, there are no good instruments available that could be used quickly and easily, for example, questionnaires that could be filled out by the people involved themselves. Therefore, we face the problem of detecting who might be at risk: the vulnerable, for whom difficult situations or life-events may increase the chance of depression. For this last group, information and education on how best to deal with problems in life, self-help groups, life style advice, and Internet can be beneficial.

Because depression can occur early on in life (or at least a basis laid for it) e.g., in childhood or adolescence, some attention should be paid to the subject in schools. For example, what is the difference between an incident of 'feeling down' and what is an incident of depression? A general practitioner would be able to carry out such a programme providing that he/she had enough time and personal interest in the subject. A social psychiatric nurse from an organization working on behalf of the GGZ could also play a role in such a programme. In fact, this is already taking place in some places in the Netherlands. In such a situation referrals to the second care level can take place more quickly and with more consideration.

As far as secondary or selective prevention is concerned, the prevention of depression occurs through cognitive behavioural training towards positive thinking, learning to cope with thoughts and feelings of depression and training of social skills that are applied to adolescents who are considered high risk. In this last group of people, the actual occurrence of a real depressive episode was reduced from 26.7% in the control group to 14.5% in the intervention group.²² In addition, another study in the Netherlands by Allart et al.²³ amongst young adults who did have symptoms of depression but who had not yet been diagnosed as having a depressive disorder, showed that the probability of depression following the intervention (a score greater than 25 on the Beck Depression Inventory) could be reduced from 10% in the control group to 1.5% in the course group.

More is known from the studies on the prevention of recurring episodes by indicated prevention in people who have suffered from previous depression episodes. For these people, long-term use of antidepressants is effective.²⁴ It is interesting to note here that the application of cognitive therapy (CT) in the acute phase has a longer lasting preventive effect than antidepressants (AD) in the acute phase.²⁵ The continuation of CT in patients who reacted well to CT in the acute phase is more effective than when treatment is not continued.²⁶ Applying a psychological intervention after patients have been treated and ended treatment with an AD in the acute phase is more effective than when no follow-up treatment is given.^{27, 28, 29} The latest studies show that the effect is particularly visible in those patients who have had at least three previous episodes. One limitation of many of these studies into the long-term effect of psychological interventions, is that there is still too little attention paid to the effect on social functioning. With regard to this, the following

parameters should be remembered: work, daily activities, generating income, relationships and giving meaning to life.

The findings of Bockting et al.³⁰ in a Dutch population were similar. They also found that a preventive cognitive group module consisting of eight sessions proved to work preventively for relapse and/or recurrent episodes. Moreover, there was no difference either in the kind of treatment patients had had during the acute phase or whether or not they used an AD during the two year follow-up period. In these cases the intervention was more effective when a patient had suffered more frequently from previous depression episodes and also depended on the age at which the first episode had occurred. It appears therefore that these forms of prevention can be beneficial for treating depression meaning that preventive measures for relapse and recurrence should be part of the standard treatment package for recurrent depression.

Many epidemiological studies show (as we have mentioned) that many patients with psychiatric disorders are seen especially in the primary care services. This group of patients has a far greater consumption of health services than others, for example, because they are treated for undiagnosed physical symptoms. One interesting point to note here is that these physical symptoms that accompany depression have been given a relatively small place in the DSM-IV classification system of depression. Some important obstacles that are faced in treating these patients in primary care are the time pressure, the tendency to focus especially on acute symptoms, and the limited possibilities as far as consultation is concerned.³ This has led in the first place to a system of collaborative care (CC) or shared care. Collaborative care systems use multidisciplinary consultation and teamwork, training for GPs and other primary care professionals in the recognition and treatment of depression, and education, advice and stimulation of the patient population.³¹ Unfortunately, this collaborative care did not work as well as expected due to the fact that the results were limited, the labour intensive and the related costs high.

The second generation of the approach to depression³² came from the disease management (DM) model. In this approach, disease management means a programme that is specifically designed for a target group and in which there is a question of screening, where evidence-based guidelines are applied and where there is intensive and structured teamwork between doctors and other supporting disciplines. At the same time, the patient receives both extensive education/advice and encouragement for self-management. Normally, most studies look at the effect of just one treatment mode, for example, psycho-education or psychotherapy. Research on the effect of multi-modal interventions is limited and good descriptions of multi-modal programmes are largely missing. A recent systematic review³³ reaches a positive evaluation of the DM programmes with regard to the seriousness of the depression, the adherence to therapy, satisfaction and cost-effectiveness. Limitations of the review were firstly that the ten RCTs covered were all in the US whereby the question of application with other health care systems remains, and secondly that the follow-up, in general was not longer than 12 months. Finally, the question remains on how well and consistently these experimental programmes can be implemented and maintained within a regular health care system.

In the meantime, this has led to a third generation of studies. Most of the recent forms of DM use standard evaluations of outcomes and periodic follow-ups with monitoring of the depressive symptoms. In addition, experiments are taking place with the use of Internet in which contact between the patient/doctor or patient/therapist is maintained electronically. Inasmuch as various components of a DM programme have been researched, there is still no completely worked out DM programme for depression operating in the US. However, there are a number of interventions operating that have been proved to be successful in DM programmes. These include, enhanced education for patients and staff, informing patients and actively maintaining contact as a follow-up with patients by telephone. One learning curve for the Netherlands is that the matter is not over and finished with once the findings have been published. The intention is to apply the DM programmes to the regular care services and convert them into guidelines that can be used in daily practice.

Partly due to the aforementioned, the use of a *collaborative care programme* (CCP) is recommended in order to improve care and treatment results for patients with depression. One example of this is the teamwork between the general practitioner, a psychologist and where necessary a psychiatrist³, but professionals from other disciplines can certainly also be involved in this process. In most of these programmes, an important role is played by psychoeducation, the allocation of a 'depression case manager' as well as long-term follow-up. When giving patient education, certain points should be remembered such as environmental and behavioural factors and treatment protocols should be tailor-made to fit the needs of each individual patient whereby the age, culture, and social-economical status is taken into account. One American study from 2001 showed that a CCP for patients with a chronic depressive disorder in which the stepped care approach was used, led to an increase in the number of depression-free days with only a small increase in costs.³⁴ The success of the CCP is influenced by such factors as co-morbidity and the initial seriousness of the depression.³⁵

In particular, older patients with a depressive disorder could benefit from a CCP. In this group of patients, the chance of recurrence and/or chronicity is after all, much greater as well as the risk of dying, suicide or illness. Contributing factors here are deterioration of health, loss of social support and diminished abilities. Unutzer et al.³⁶ studied a group of 1,801 older patients who followed either care as usual (CAU) or a specific treatment plan that had been specially made for them. Moreover, they used Care Managers who had followed special training to become a Depression Clinical Specialist (DCS). Patients were followed for a period of twelve months and when the results were successful offered a prevention plan for relapse of the disorder.

In the Netherlands, an outreach programme has been developed for older people with depressive symptoms that takes the form of a course *How to cope with depression*. With this, the participants learn by means of self-observation and making appropriate changes at an early stage how to prevent a downward spiral of depression from occurring. From a meta-analysis of similar studies it appears that good effectivity that can be maintained over a long-term period is possible.³⁷ This shows that not only in other countries, but also in the Netherlands prevention has once more been put on the map: curative care does not reach the aims of national health policy so that attention is being paid towards prevention.

The psychiatric department of the University of Arkansas for Medical Sciences (UAMS) was recommended by the American Psychiatric Institute for Research and Education as the *best practice* location and suitable for use as case study material on integrated care for patients with depression. Researcher Marianne Acampo visited this centre for a number of days. In this centre, four different divisions take part in the patient care and research: the adult department and the department of paediatric psychiatry of the academic hospital, the mental health department of the health department for veteran affairs and the division of psychiatry of the Arkansas State Hospital. The main goal of the centre is to be the leader in integrated and cost-effective care.

4.3 The triage, front door and gatekeeper functions

Three steps can be differentiated in the treatment of depression: 1. waiting, supporting and monitoring, 2. treatment in a primary care setting, and 3. referral to the specialized GGZ. The new multidisciplinary guidelines indicate that in the first instance, treatment of minor depression in the primary care setting should not be too active but focus instead on monitoring, explanation, and *problem solving* as well as offering the patient support.

If, after a period of time the clinical picture is the same or has even worsened, then step two, that of active treatment in the primary care setting should be given. With this, the following should be considered in accordance with the protocols, problem solving therapy, counselling, supportive discussion sessions and if necessary medication. This second step often depends on the primary care setting itself and the possibilities and motivation of the GP or the presence or absence in the practice of other mental health professionals such as primary care psychologists.³⁸ One recent American study shows that the results of this second step can be improved by offering specific training to primary care professionals even if there are no GGZ professionals present. Such training can, for example, be aimed at

improving medication control and supporting patients who start to use an antidepressant for the first time.³⁹ In most cases, the training does not need to be too labour or time-intensive for the GP. One Canadian study describes a training session of three hours with a possibility for weekly consultation with a psychiatrist.⁴⁰

Such training can be supported by using interventions in primary care that are aimed at the prevention of relapse, for example in the form of a maintenance treatment with antidepressants. In a study dating from 2001⁴¹ such intervention with primary care patients is described. The intervention consisted of psychoeducation by means of video and written material, two meetings with a depression specialist who maintained contact with the general practitioner and monitoring and follow-up by telephone. The intervention group showed significant improvement in adherence to therapy as well as a significant reduction in depressive symptoms. No difference was seen however, regarding relapse. The programme was ideally suitable for primary care settings but was probably not intensive enough. A similar study in 2002,⁴² that compared a relapse-prevention group with a care-as-usual-group, showed a slight increase in the number of depression-free days in the prevention group against a slight increase in costs.

In the Netherlands various models are currently being tried out that give primary care settings a gatekeeper function. One model embraces the improvement of the diagnostic and treatment-related qualities of the general practitioner by using good continuing education, training and the use of standardized protocols. In a second model, the *consultation model*, the general practitioner is offered knowledge and skills in various ways from the GGZ. This includes, for example, telephone consultation with a psychiatrist, the opportunity for GP and psychiatrist to discuss a case together whereby the GP is advised on diagnostics and treatment. This can be taken one step further by a consultation between GP, psychiatrist and patient and as a final step, the model allows the GP to send the patient to the GGZ for a single consultation. The GP retains the responsibility for the realization of the treatment. This is not the case for the model known as the *replacement model*, where the treatment is realized in the primary care setting by social workers, first-level psychologists, social psychiatric nurses or psychiatrists. In particular, collaborative work between GPs and primary care psychologists is common in the Netherlands. Finally, there is the model of transferred *care*, in which the GP is not replaced but second-level GGZ treatments are carried out within the primary care setting by a social psychiatric nurse or psychiatrist.⁴³

It is generally known that the transferral of guidelines to the clinical setting goes at a slow pace, all the more so because these guidelines are generally founded on material coming from experimental studies where it is not always known whether the outcomes are suitable for application in a daily, non-academic setting. A large multi-centre study by Charbonneau,³⁹ for which nearly 13,000 patients were eligible, showed that in particular regarding the duration of treatment with medication, the guidelines were not adhered to. This was also the case although to a lesser degree for the dosage of antidepressants. Another influencing factor was the stage at which the depression was in. Certain indicators such as age, race and primary care setting, predicted this.

One recent study from 2004 by Dietrich et al. showed that a quality improving programme for depression management can be suitably used in the primary care setting in order to implement evidence-based medicine techniques.⁴⁴ Repeated and long-term follow-up by telephone by a care manager played an important role in this. Comparison between intervention and control groups, showed that the response and the remission rate was better in the intervention patients. The intervention patients were seen more often and also contacted by telephone. They were asked more frequently about suicidal thoughts, received educational and information material more often and were helped more in their efforts to make self-management aims.

At what point should the third step, the referral be considered? Some indications can be given for this on a global level although much depends on local settings and conditions such as the quality of available professionals, the patient's wishes, and the organization of the care.

The decision for referral is considered at an earlier stage in the event of the following:

- in the seriousness of the symptoms (number and nature) increases,
- the duration of the symptoms increases and with it the accompanying dysfunctioning (expressed in nature and number of social roles) increases,
- the reaction to treatment already started (depending on the effectivity of those treatments and the way in which they have been implemented) was not so good,
- the course of the depressive symptoms over time (degree of relapse and inter-episodic recovery) is less favourable,
- other pathology (fear, addiction and somatic disorder) is present,
- there is a question of less favourable personality traits and negative social factors (poor family relationships, low social status, a bad relationship, lack of social support) reducing the prognosis.

A proposal could be made for the Dutch situation in which the general practitioner receives education and training so that the timing and the momentum for taking the three steps described above can be more well-reasoned. The first two steps could then take place within the GP practice where other disciplines could be used if necessary for the satisfactory implementation of the treatment. For example, depression specialists or care managers whose professional expertise in treating patients with depression is more important than the discipline from which they come.

4.4 Working with *evidence-based medicine* guidelines for the treatment

In general, the treatment of depression is divided into various treatment areas as follows:

- treating symptoms and complaints
- improving daily functioning
- providing information on the disorder
- explaining possible causes, luxury factors
- paying attention to work, study, daily activities
- involving the patient's environment in the treatment.

We now know, from existing evidence that treatment for a minor depression which is short-lasting should be approached very carefully. In general, medication is not necessary in these cases and can even sometimes be contra-indicated. An improvement in daily functioning can be expected when the symptoms and complaints are reduced. Criteria used for objectively determining for example, the degree of severity and duration of the disorder may provide insight into the point at which a following step should be taken. Most of the treatment measures available (apart from that of medication) can be given by non-medical professionals. Therapies should be offered that have already been proved through EBM to be effective. From the Dutch guidelines^{2,46,47} it appears that the following therapies are effective:

- Anti-depressant medication (AD)
- Electro Convulsive Therapy (ECT)
- Cognitive Behavioural Therapy (CBT)
- Interpersonal Psychotherapy (IPT)
- Problem Solving Therapy (PST)
- Running and Psychomotor Therapy
- Psychoeducation and family support
- Ergotherapy

The UAMS is a centre of excellence for the registration and use of patient data in determining and adjusting the treatment of patients. Central to their system is that of giving feedback on outcomes that have been reached. Moreover, they are striving to have and use the most up-to-date and at the same time evidence-based knowledge and to work according to guidelines. In this way, an important role is played by translating scientific knowledge into knowledge that can be applied in non-academic practice.

4.5 Patient education and the support of informal carers

On the subjects of psychoeducation and family support, we make the following observations. Within our own Mood Disorder Programme, one specific module on psychoeducation was developed during the past few years. This psychoeducation is part of the standard treatment and covers in 12 sessions the most important aspects of depression for the patient. The module is made up of various parts: an introduction, a follow-up and a training module available on CD with additional course material.⁵⁴

Psychiatric disorders can have serious consequences for the families of the patients and in general are seriously underestimated. In a previous study we studied what the consequences of depression can be for family members and loved ones of the patients.⁵⁵ In particular, the following points are relevant: worrying about the patient (for example, his/her health and future) one's own future, the treatment and the safety of the patient) feeling responsible for the patient, feeling irritated by the person's behaviour, taking over certain tasks in the home, the continual stimulation of the patient needed and the tense atmosphere in the family. In addition, it appeared that small children in particular were troubled when a parent had a long-lasting depression. Predicting the consequences for the family and loved ones on the basis of other factors was however, possible: the consequences appeared to be worse in cases of an acute episode, by a depression duration of less than three years, by lack of support for the family members, by the feeling that the relationship between the patient and the family member had actually changed, and with less effective coping mechanisms.

In our own programme, we have turned such findings into (amongst other things) a family-supporting module. This is based on the fact that during an active depression, the first priority is to offer support and education to family members. Only in the recovery stages of the disorder should any and which systematic therapeutic interventions be considered. By now new and shorter modules have been developed for outpatients and their families that are based on the principle of 'no, unless' and will be offered to all outpatient clients.

Most care programmes for the treatment of depression work on a system of stepped care. This means that the treatment starts with the least radical intervention that, based on the nature and the course of the disease, should bring results. If the expected result is not reached, then the treatment is moved along the care programme or the care line where there are, for example, indications for the use of more therapies at the same time and with an integrated approach. This multi-modal approach is clearly visible in our own Care Programme for Mood Disorders developed at the AMC/The Meren.^{48 - 52} From the clinical evidence gained so far, it appears that such an integrated approach for the treatment of serious depression is preferable. However, it is important to remember that the effect of these multi-modal interventions has only been scantily researched and good descriptions of multi-modal programmes are largely missing.³⁴ Moreover, the long-term effects of interventions and the degree to which they contribute to the prevention of relapses are often insufficiently researched. Diagram 5.3 illustrates this point by means of a case study on a multi-modal approach in a patient with serious depression.

Diagram 4.3 Case study 60-year old man with serious depression who received multi-modal intervention

A single, divorced man of 60 years of age, unemployed, who has little contact with his adult daughters and lives an isolated life is being treated for depressive symptoms at a psychiatric outpatient clinic. The symptoms have been present for a year and the treatment was started six months ago. The patient has already tried two types of effectively-dosed antidepressants. The latest antidepressant has led to the patient sleeping better and feeling less anxious. However, the other symptoms including physical complaints have not improved.

The treating psychiatrist has proposed a more intensive treatment programme. The programme will last for three months and consists of a number of therapy parts offered in groups and given on three set weekdays. The treatment parts are as follows: interpersonal psychotherapy in a group (IPTG), psychomotor therapy (PMT) and a course 'coping with depression'. The patient agrees with the time investment of 7 hours per week excluding travelling time.

In the IPTG he chooses as the main treatment focus his interpersonal shortcomings and works on his lack of social skills that have partly caused the depression and are sustained by the depression. The group format gives him the possibility of practicing these skills both within and outside the group. During the course he learns, amongst other things, how to look for pleasurable activities and the PMT teaches him how to approach others more and more easily as well as to realise that he is physically capable of more than he thought. The antidepressant medication stays the same. After three months, the patient shows clear improvement as far as his symptoms go and has also decided to take up voluntary work. Following the treatment he receives follow-up care at intervals of three and six months for a year. The improvements remain visible and in spite of a few unexpected setbacks, no depressive episode returns. The patient revealed in the follow-up that the fact that the treatment⁵⁰ consisted of various parts given weekly worked well for him. Although the patient was initially against the idea of group therapy, he admitted that this turned out to be the most positive aspect of the treatment.

Offering the various programme parts together increases the chance of success of the treatment. The therapies offered capitalize on the heterogenous character of the diagnosis of depression, as well as on the differences between the patients themselves which may mean that they are more susceptible to one form of therapy or another. The efficacy of the treatment as a whole is equally increased due to the multi-modal interventions.

A good proposal for the Dutch situation could be to use only treatment for depression which has been proved by evidence-based medicine to be highly effective. The treatment should be offered in care chains or lines. The further the patient moves along the care chain, the more therapies will be offered at the same time through the care programme. The aim of this system is to treat the diverse symptoms of depression and to sort out the desired effects according to long-term effects.¹⁸

4.6 The relation/connection with primary care for patients who are following a care programme

One point that becomes clear from the previous paragraphs is that depression can probably be treated better and for longer in the primary care setting with relatively simple methods than is currently the case.

An advancement of expertise and the possibilities of consultation are elements that also contribute to this process. The placement of professional depression experts in primary care such as in the US, for example with CC and CM, is one aspect that could be further developed in the Netherlands.

These professionals could be compared to the case-managers who work for example, with chronic psychiatric patients and are by now a familiar part of the care services in the Netherlands. Professional depression experts could play a role in the treatment of patients with chronic and/or recurrent depression by maintaining contact with the primary care services regardless of where the patient is in the care chain.

It is interesting to note that in the Netherlands the development of care programmes for mood disorders in the second and third care levels is developing quickly.⁵³ These programmes should, more than is currently the case, add to the large network of primary care facilities and be able to function in its midst. This would enable on the one hand, quick and easy contact to be made with the primary care services where, although most patients are not treated there, advice is given and the patient is returned. On the other hand, such a programme could offer a form of primary responsibility for a genuine GGZ population or in other words, a population with frequent recurrent episodes and high co-morbidity etc. From such a GGZ programme, patients would be able to return to primary care for certain treatment periods and in the event of any problems occurring, have direct access to the care programme. The treating professional keeps those who are in the care programme for the duration of their life in a treatment contract although this could be with a very low frequency.

If it becomes possible to treat patients with depression for longer in primary care and if more non-medical specialized professionals are involved with the treatment, then this could

lead to a decrease in costs. The previously-mentioned study by Katon³ describes how it is possible to work with other professionals by using a system of collaborative care (CC). Apart from cost-effectivity, this system certainly has advantages when other professionals are added to the services because patients often indicate a preference for these professionals.

It is interesting to compare the outcomes of the CC approach with the consultation model that is by now a familiar concept in the Netherlands and was described in the previous paragraph. In a study conducted in 2003⁴⁵ a treatment plan was drawn up by a GGZ team for the primary care services. The plan included interim coaching and modifications for the benefit of this primary care setting and the patients. The study contained many 'difficult' patients. Nevertheless, the study showed that by using this method it was possible to treat more patients in primary care without an increase in costs. In addition it appeared that for the telephone assessment and triage no psychotherapists or physicians were necessary but that this function could be learnt and taken on by others.

In a further study³¹ the researchers looked at the positioning of CC within the health care sector. This study concentrated on older patients. These patients accepted CC better in the primary care setting than in the secondary care setting and the treatment results were better than with the customary care. In this setting, a case manager (CM) is an essential professional who assists the physician on educational aspects and for monitoring of the treatment. In more complex situations the help of the specialist can be called upon, for example in the form of consultation between the physician and the CM. Also described is how more expensive forms of collaborative care can be implemented step by step. When the patient shows a sufficient amount of recovery, he/she can then be returned to less expensive collaborative care services. The interesting point to note here is that this model proposes using the same CM for various chronic disorders whereby the CM is supervised by the various specialists involved. This could lead to treatment which takes place 'during the life-span', which is accordance with the starting point that depression is a disorder that often runs a chronic course. In particular, for older patients who present with multipathology this model holds advantages as the GP remains the central figure in the treatment.

The primary care setting has always concentrated more on the treatment of acute and less on the chronic presentations of the disorder. For those really serious cases, and those patients who do not react to treatment in the primary care setting, further treatment is necessary. Nowadays, this usually means that the third step is referral to a secondary care programme, if one is available and otherwise to the specialized GGZ. One proposal for the situation in the Netherlands could be to implement the first two steps as described in the previous paragraph in the primary care setting more often and for a longer period. This would enable the system of CC to be used and case managers could be appointed. If further steps (that are usually more costly) are needed, then these should of course be taken. When the patient recovers sufficiently so that these are no longer necessary, the patient returns to primary care. The GP or the CM then becomes the central person in the treatment.

Just as with other chronic and recurrent disorders, the treatment result may depend on the working relationship between the patient and those professionals treating him. There seems to be an indication that patients with depression benefit the most from a treatment relationship where the contact is both repeated and varied over time, according to the situation.³⁴

Continuity of care can take place at different levels. There is a strong preference for example, not to change the treating professionals if at all possible and never with ambulatory patients. But equally important is that there is continuity within the care programme itself. This continuity can be seen, for example in the Mood Disorder Care Programme from the Amsterdam location AMC/The Meren. Moreover, the programme should be structured on a system of building up where each new outpatient, day-treatment or clinical treatment segment is a natural, logical and necessary successor to the previous step.

Some links in this chain are accompanied by a discontinuity of treating professional but in some cases it can be desirable to have a certain kind of break in the treatment. A case

manager could then be given the task of putting a large number of patients with the more serious, recurring and only partially treatable depressions on the care programme. This would mean that if the patients are temporarily under the care of the general practitioner the case manager is a stable factor for both parties. It goes without saying that it is essential to reach good agreements with all primary care health centres in the region when setting up care programmes. Providing continuity through the use of patient files is of course an obvious necessity, especially as the care chain grows longer. Electronic patient data files are the most suitable option for this.

4.7 Feedback on the achieved accomplishments

The most important standard measurements for the outcomes of the delivered care are as follows:

- decrease in the depressive symptomatology
- decrease in the number of physical symptoms and complaints and improvement of physical functioning
- improvement of social functioning
- patient satisfaction regarding the treatment
- less use of medical facilities
- fewer hospital admissions
- fewer medical costs
- the degree to which guidelines are followed by treating professionals and patients

The most important measurements for the process of the delivered care are as follows:

- the comprehensiveness of the screening instruments used
- the number of referrals to a psychiatrist
- the degree to which the most effective treatment was established
- treatment adherence of the patient
- patient satisfaction.

From a systematic review on the efficacy of disease management programmes for the treatment of depression it appeared that these programmes led to an improvement in both the outcomes and the process of the delivered care. The biggest effect was found in a programme that used an extensive screening instrument for detecting depression. Such screening instruments can also be used to set the threshold for establishing treatment.³⁴

One of the most important measurements is the final opinion of the patient himself on the treatment or that of the whole patient population. In order to measure this, the following points should be considered:

- exit interviews per patient
- team evaluation of complex cases
- satisfaction research in individual or groups of patients
- mirroring sessions between patients and their treating professionals.

One important aspect of treating a disease such as depression that recurs frequently is long term monitoring of the patients irrespective of where they are being treated. In the United States, telephone interviews are frequently used to do this. Within our own AMC care programme, a system has been developed in which patients are followed by using measuring instruments and interviews for the period of one year following completion of treatment. One important aspect of this follow-up is to always address any faults or failures that have been indicated in the treatment.⁵⁰

The Centre for Outcomes Research and Effectiveness of the university of Arkansas is an outcomes management system on the Internet that is designed to be used in the patient care of psychiatric patients. This Net Outcomes System registers patient characteristics, (mental) health parameters according to validated instruments, process and cost parameters

and the use of guidelines and reports each quarter to all of the care providers. There is a specific module for depression: the Depression Outcomes Module (DOM). The scored outcomes are corrected for case mix and seriousness of the disorder and compared with benchmarks. The aggregated outcomes form the subject matter of three-monthly reviews which look at the discrepancies between the scored outcomes and those that were expected and then makes comparisons with standards found in evidence-based medicine.

4.8 Unity of policy and funding for the whole programme

Our experience¹⁸ shows that it is extremely important for all those involved with the care programme to work according to a well thought out and solid vision. Such a vision should encompass the starting points regarding etiology, pathogenesis, and treatment of the disorder in question. In the case of depression, for example, this will mean that there must be a protocol for treating with a medication regime. Subsequently, it must be clear what the treatment policy is for a patient if he/she does not or insufficiently respond to medication. Any consideration for the option of Electroconvulsive Therapy should be recognized by all professionals and be relayed to the patient as an unequivocal message.

Alongside this biological treatment method, it is advisable to make a clear and well-founded choice for certain psychotherapy forms. This treatment choice should be conveyed to the patient in such a way that he/she knows at all times how and why the psychotherapy is being given. Here the preferences of the patient play an important role. This is certainly the case for patients with mildly severe depression where the effect of a psychotherapeutic treatment is not inferior to a biological treatment.⁴⁶ Finally, the points named above are certainly true for the other therapy forms such as: system therapy, psychomotor therapy, ergotherapy, social psychiatric therapy, rehabilitative therapy as well as psychiatric policy.

In those care programmes where there is a collaboration of professionals from diverse disciplines, it is of great importance that there is a central management point where the manager ensures that the common formulated vision is shared and conveyed to the patient in a convincing manner. It is also important to monitor this vision and adjust it accordingly. All collaborators must speak the same language and work together from out the same conceptual framework. Holding multidisciplinary assessment consultations for patients with difficult clinical pictures or patients who are difficult to transfer along the care chain is an excellent way to help this process along.

One basic condition for all of the above is that the same protocols and guidelines are used by all those involved. This is tricky however, due to the fact that it costs time to create such a situation at a time in which the GGZ is undergoing permanent change in its organizational form and working methods. These changes bring difficulties with them as it is difficult for staff on the work floor to keep up with all the changes. Mergers and organizational changes can lead to a situation where treating teams who are not aware of each others working methods are suddenly required to work together. This means that the ideas already gathered over time and with difficulty regarding mission and vision will have to be melted together to form one whole again.

A consultation system that is easily accessible for the benefit of GPs or other health professionals in primary care that holds active search possibilities for feedback back and forth, is an ideal that is often far from reality. This is due sometimes to practical problems such as bad telephone reachability and sometimes just due to unwillingness on the part of the professionals to involve themselves in the further treatment of a patient who has been referred on. It is exactly in the case of depression that information on the long-term course of the treatment is essential in order to be able to say something useful on the successes of the treatment or a referral. Patients are making more and more use of Internet sources to gain information on diseases, health and treatments. The health care sector is apparently lagging behind in this regard as well as for the internal communication between professionals.

Finally, safeguards should be given for maintaining and renewing the knowledge that has been collected for a care programme. This task will be easier for those institutions such as academic medical centres with obligations for research, education and training than for

those that do not carry out these tasks. The most important aspect here is that a culture is created in which questions are allowed to be asked. As previously mentioned, in our care programme we have a weekly assessment meeting in which the long-term situation of patients is followed at all points in the care programme. This meeting provides senior and junior staff members alike with the opportunity to ask each other critical questions within a safe environment.

As far as the process of renewing is concerned, our programme meets regularly with project and steering groups which are made up of staff from various disciplines. In this way, results can be presented to the plenary treatment and/or management teams after which any implementation can be carried out if wished. This covers all the various aspects of the programme including possible reorganization of treatment meetings or the formulation or changing of one of the treatment protocols.⁴⁸⁻⁵² This method of working increases the involvement of the professionals involved in the programme and helps to keep their vision sharp.

The funding of the Dutch GGZ has been in a worrying position for a long time. Moreover, it is striking that the care (for what it achieves) given by the GGZ is neither cheap nor expensive compared to other countries. The worrying point is that the funding system does not contain enough incentives to make it work more efficiently, powerfully, innovatively or market-oriented. Furthermore, the so-called product elements that are at the base of the funding system hold little relationship with the efforts put in by the professionals concerned. Finally, there is no information whatsoever on the relationship between the invested euros and the achieved healing or care.

Within the foreseeable future, the GGZ will also go over to the system of Diagnosis Treatment Combination (DTC). At present it is not clear exactly which and therefore how many DTCs will be available. Because of this, it is also impossible to tell which positive or negative effects will result from the DTCs. We are taking part in the pilot project for the development of DTCs for the GGZ with our AMC care programme. Our expectation is that as far as our programme is concerned, we could manage with approximately 10 DTCs that each show a clear relationship with a number of Clinical Pathways that patients go through in large numbers in our programme.

4.9 Considerations

Depression is a common disorder that is recurrent in half of the cases and in one tenth of cases runs a chronic course. Considering these facts, it is hardly surprising that depression is named as the perfect example of a psychiatric disorder suitable for disease management in the ongoing discussions on the matter. This chapter demonstrates that at present a DM approach according to the description given by Epstein, “a systematic, population-based approach to identify persons at risk, intervene with specific programs of care, and measure clinical and other outcomes”⁵⁶ can only be found in the US in the form of research-driven innovation projects.

The concept of care programmes is the closest to the idea of DM. Care programmes can be described as the total whole of all necessary, linked, and integrated care and treatment for a specific and described patient population. A programme describes which patients are being treated, why they are being treated (EBM) when and where the treatment takes place, by whom and how long it lasts. In addition, the treatment sequence and the combinations of various treatments are described.¹⁶⁻¹⁹ This concept is currently drawing wide attention in the Dutch GGZ and there is almost no region in the country left where people are not involved either with the formulation of or the implementation of such a programme. A care programme for Mood Disorders is a regular part of the package of approximately seven programmes for adults.

If we compare the components of a care programme with the criteria that are adhered to by Spreeuwenberg in the first chapter of this book, then it is clear that the GGZ also has the following points: identification of a clearly-defined target group (patient population), adherence of evidence-based guidelines and encouragement of collaboration between

physicians and other professionals and care providers who can provide support to the treatment. That differences exist is an indisputable fact. Firstly, for the time being, the Dutch care programmes are secondary care initiatives that only move minimally towards the primary care level let alone recognizing as a patient population and in an epidemiological manner all people from a given area with the same disorder. Screening for a particular disorder in general or primary care populations does not take place in care programmes.

Secondly, there is a clear difference concerning the accent put on the final treatment objectives. With DM the focus is partly to be found on such concepts as cost management/control and suitability by adhering to a strict central steering point focussed on process and content. In the case of care programmes, the focus is on quality improvement and demand-oriented care.

This brings us to a third difference in the two concepts. The DM approach requires much stricter demands on information and communication technology due to the fact that computerization is the only way to compare input and output with each other. The Dutch care programmes are almost without exception not equipped with information technology and in those cases where they are in place, it is only with regards to a system of invoicing to the health care insurer. The feedback of treatment results and client satisfaction to professionals and managers as well as the principles of benchmarking are still non-existent in the Dutch GGZ.

In the future, the characteristics of disease management and care programmes in the GGZ will be connected by the following concept. The approach towards the patient should be a holistic one whereby the patient receives sufficient stimuli, and helped by his own competences as well as through multi-modal, multidisciplinary and continuous patient care, is able to live his life as he wishes.

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5 Chronic heart failure: care centred in specialized outpatient clinics

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5.1 The disorder and the extent of the problems

Chronic heart failure occurs when the pump function of the heart is insufficient. A heart affected by diseased coronary arteries, high blood pressure or by other frequently unknown causes, is no longer capable of adequately pumping enough blood round the body. This causes symptoms such as fatigue, shortness of breath and oedema in legs and lungs. In most cases, the classification system of the New York Heart Association (NYHA) is applied in order to measure the gravity of the symptoms. The system ranges from class I, no symptoms, to class IV, symptoms during rest or slight exertion.¹

Although the estimates of the number of heart failure patients in the Netherlands range from 165,000 (National Institute for Public Health and Environment (RIVM)² to 200,000 cases (Dutch heart foundation)³ it is clear that chronic heart failure is a common disorder that occurs especially in people over 75 years of age. Estimates show this number rising by 37,000 new cases each year. Annually, approximately 6,000 people die of heart failure in the Netherlands.

Based on demographic developments alone (increase of the ageing population) the RIVM expects the number of people with heart failure to rise by 47% by the year 2020. This number will increase further because the survival rate in the acute stage of a coronary has improved and the period of chronicity has been prolonged as a result of early detection, more adequate adjustment of medication and improved therapy compliance. However, the prognosis of patients with heart failure is poor with a survival rate of 35% five years after the initial diagnosis.

Generally speaking, the treatment of heart failure is not geared towards curing but towards optimizing the pump function and preventing exacerbations that require hospitalization. Annually, approximately 25,000 patients are admitted into hospital with heart failure as the discharge diagnosis. Medication and life-style changes (smoking cessation, losing weight) are the most important interventions.

In the Netherlands three important guidelines exist: the NHG standard (Dutch College of General Practitioners) for heart failure, the CBO (Dutch Institute for Healthcare Improvement) multidisciplinary guideline for chronic heart failure and the protocol multidisciplinary information on heart failure issued by the Dutch Heart Foundation.^{3,4,5} These guidelines describe the most important components of care, but they do not indicate how this care should be organized.

Increasingly, care is centred in specialized outpatient clinics, the so-called heart failure clinics. These are characterized by an approach in which many of the principles of disease management can be recognized: multidisciplinary teams, working with guidelines with a central role appointed to specialized nurses. In 2002 it was shown that 75% of Dutch hospitals had outpatient clinics for heart failure or were designing programmes for these clinics.⁷ In 2000, 35 of these clinics were operating in the Netherlands.⁸ Cooperation between the various hospital disciplines was a central characteristic for most of them. Transmural cooperation with primary health care services takes place in 25% of these clinics.

In 2003, the inspectorate for public health performed a study on care chains for heart failure.⁹ They concluded that in most cases, the general practitioner is the primary care giver in the early and final stages of chronic heart failure and that in the intervening period

the cardiologist is responsible for the care. In many hospitals, although certainly not in all, there are heart failure clinics which mainly treat the more severe forms of heart failure. Therefore there is some degree of intramural integrated care. Cooperation or integration with primary health care, is far less common. The inspectorate concluded that the care for heart failure patients in the Netherlands shows great variation in quality, coherence and availability, and that is mainly due to the limited capacity of heart failure clinics. The inspectorate also pointed out differences in the quality of the information given, the use of integrated care protocols and lack of clarity concerning tasks, competence and expertise of various caregivers as well as a lack of uniform data registration such as the number of complications and patient satisfaction.

In as far as it is known, patients who are treated in heart failure clinics, are satisfied with the care that these clinics offer. Although there are good examples of high-quality care for heart failure patients in the Netherlands, unfortunately this is not available to everyone everywhere.

This chapter deals with the various components of care that are considered necessary for heart failure patients and is based on good examples from the Netherlands and expertise from abroad, both from the literature quoted and from the Baylor Heart Clinic that we visited. The American Heart Association recommended this centre as one of the best University centres for cardiology in the south of the United States. Following the analysis of the literature and a visit to the site, a brainstorming session was organized with Dutch heart failure experts. In addition, a meeting was held to discuss these issues with the patient association Hartzorg (project group for heart failure). Based on these sources, we list a number of recommendations for improvements that could help to further increase the level of care for heart failure patients in the Netherlands. In addition, we indicate the current barriers to the realization of this level of care.

Baylor Heart Clinic, Houston Texas

The Baylor College of Medicine is situated in Houston Texas and houses a cardiology department. This department combines education, research and patient care and strives to be one of the best University centres in the south of the US. The Baylor Clinic aims for excellence and where much emphasis is put on top clinical and laboratory research as well as applying the ensuing results to daily practice. Both patient care and training are based on an evidence-based philosophy.

The basic assumption of the training institute is that physicians are best trained in an environment where scientific research is also carried out. At Baylor both fundamental and clinical research is performed and there is a separate research institute for heart failure: the Winters Center for Heart Failure Research. Patient care takes place within the Baylor Heart Clinic. More and more specialized treatment courses have been adopted here, such as cholesterol management, congenital heart defects and for women with cardiac diseases. Presently a separate clinic for heart failure is being founded in the centre.

5.2 Prevention, care and follow-up care

Either a collective strategy (public health) or an individual (medical) strategy can be adopted for the prevention of heart failure. Collective (primary) prevention is targeted at large sections of the population and comprises information campaigns about wholesome food, giving up smoking and taking up exercise. Although this information reaches a vast audience, it is not usually very specific, so that the success of these campaigns is limited. Individual prevention is targeted at people with risk factors such as hypertension and at detecting the disease in an early stage. In the Netherlands, the Dutch Heart Foundation is especially active in the area of collective information concerning cardiovascular diseases. In 2002-2003 it launched a public awareness campaign 'Heart failure. Recognise the symptoms'; this campaign provided information through TV ads about the concept of heart failure and its symptoms. The Dutch Heart Foundation also maintains a website where patients can find information about heart failure and its treatment (www.hartstichting.nl). Primary prevention is virtually separate from curative care, both in America and the Netherlands, and there is no systematic approach to prevention either in the Netherlands or at the Baylor Clinic. In primary health care and in the heart failure clinics at home and abroad, care is initiated at the moment in time when patients have symptoms and the diagnosis has to be made or has already been made.

Campbell from Australia¹⁰ advises a multi-layered, integrated approach for successful prevention. Programmes ought to deal with environmental factors, adjust legislation (such as that concerning advertising tobacco and food) and educate the population from childhood on issues for a healthy lifestyle. In addition, aggressive check-ups by general practitioners should be part of the approach in high-risk patients. This requires drawing up individual targets and guiding patients in realising them.

When heart failure is suspected, diagnostics consist of taking a medical history of the patient (including questions about previous heart disease and co-morbidity such as COPD, hypertension and diabetes mellitus) and a physical examination.^{4,5} This is followed by additional examinations such as laboratory measurements, ECG, echocardiography and a chest X-ray. The objective is to map out the cause and the extent of the symptoms as well as to assess the prognosis. The patient is classified according to the NYHA guidelines and then prescribed medication.

Medication is usually first prescribed for patients from NYHA II (mild symptoms) and initially consists of diuretics and ACE inhibitors. If the disease becomes more serious, β -blockers, digoxin and nitrates are added to this regime. The general practitioner initiates the treatment and will refer the patient to the cardiologist if the medication does not provide sufficient improvement according to the stepped approach of the NHG standard. Sometimes general practitioners can use a regional rapid-access outpatient department for prompt diagnostics in cases of suspected heart failure.¹¹ In these cases, patients return to their general practitioners once the diagnosis has been confirmed. General practitioners will have had chest X-rays and blood tests performed in advance, the results of which are brought in by the patients during their visits to the cardiologist.

According to the CBO guideline, patients who are classified with a class NYHA II or higher should be advised a low sodium and fluid-restricted diet, with or without supervision by a dietician. In addition, advice should be given on starting follow-up care quickly after a hospital admission and continuing this for an extended period, depending on the patient's physical condition, autonomy and needs. During a stable phase, patients are encouraged to follow a physical exercise programme (cardiac rehabilitation) that may be supervised by a physiotherapist.

In some cases, surgical interventions such as bypasses, balloon angioplasty or heart valve surgery may be performed in order to try to eliminate the causes of heart failure. However, often the expected benefit of such treatment does not outweigh the risks these interventions may entail. Heart transplants can be performed in patients with severe chronic heart failure who cannot be treated otherwise. For most patients, heart failure is a chronic disease that is treated conservatively over a long period of time.

Jaarsma et al.¹¹ indicate that proper counselling and training of patients, as well as extensive self-management are important elements of follow-up care, in combination with counselling for psychosocial consequences. In addition, it is important to pay attention to the coordination of the care, for example, appropriate planning of discharge after hospitalization and arranging home care.

As treatment of heart failure is aimed towards preventing a deterioration of the condition, informing and educating patients play an important role. Patients should be informed on such aspects as diet (salt and fluid restrictions) obesity, smoking, alcohol use and the part of physical exercise. They should learn to adjust their lifestyle according to their situation.

Patient education at Baylor

At the Baylor Clinic, oral as well as written information is provided both to individual patients and to groups. All patients are offered education programmes. Physicians mainly provide oral information and invest a lot of time in it. In addition they refer patients to a nurse practitioner, who practices and repeats what the physician has already explained. In addition they provide training on diets, exercise and the use of salt. Group education allows patients to get in touch with fellow-sufferers. The objective of education is make patients aware that they should adopt a different lifestyle permanently and that they should be careful with their diets and medication. Patients are frequently referred to the American Heart Association's website.

In the long term, care mainly consists of monitoring and checking the medical situation and the timely adjustment of treatment. Frequent checks are done by physicians and/or nurses. In addition, patients learn to recognise a deterioration in their condition in order to contact

their caregivers in time. In addition to planned check-up visits to the treating physician, home visits by nurses or extended and easily accessible telephone surgery hours are available.

Various successful projects have been described in the literature that involve patients who monitor themselves at home and send in their data to the treating clinic. Goldberg¹² described an electronic system where patients send in their body weight and the presence of other symptoms each day via the computer. This has resulted in a decrease in mortality in the intervention group. La Framboise¹³ and others experimented with a Health Buddy for heart failure patients. This is a simple communication device that allows patients to transmit data. This buddy turned out to produce equally good results as telephone contacts or house calls by nurses. In Canada, the use of an interactive Internet site has improved the communication between doctors and patients as well as resulting in high patient satisfaction and improving the quality of life.

5.3 Organizing patient care: heart failure clinics

Nowadays the treatment of heart failure is often centred in specialized outpatient clinics. These result in fewer admissions and re-admissions, a smaller number of in-hospital days and a higher degree of self-care than traditional care. Some studies show a lower mortality rate whilst in others this has not been proven.^{15,16,17,18} In some studies, the quality of life is shown to be significantly improved due to heart failure care programmes.^{19,20,21,22} One study showed that the results were even better when a pharmacist was included in the multidisciplinary team.²³

In the Netherlands, the added value of heart failure clinics has not yet been proved. It is hoped that the large-scale COACH study²⁴ will provide a comparison of results obtained with traditional care, basic additional support and intensive guidance by nurses who specialize in heart failure. The parameters included are the mortality rate, the number of admissions and quality of life. The results of this study are expected in 2006.

In the Baylor Clinic good-quality care is high on the agenda but this clinic is still in the process of setting up and developing a specialized heart failure clinic. Generally speaking, patient care that is on offer at Baylor strongly resembles the care that is offered in good specialized heart failure clinics in the Netherlands. However, this care is not available throughout the whole of the Netherlands. As previously stated, appropriate medical guidelines are available, which means there is consensus as to what appropriate care should entail, but these guidelines are not being observed to the same extent everywhere.^{9,27}

In addition, the content of care varies per region. Just how the care is locally provided is left up to each individual setting. Sometimes the emphasis is on offering prompt diagnostics (rapid access clinics) and in most of these clinics cardiologists and nurses carry out check-ups collectively. In the Netherlands, most heart failure clinics are organized within hospitals, although there are some transmural forms where (homecare) nurses make house calls, supervise patients and report back to the general practitioners.¹¹ Both the inspectorate for public health as well as some patient groups^{9,27} have expressed the wish for heart failure clinics to be set up on a larger scale, for example, in each hospital.

As yet there is no uniform definition of a heart failure clinic. However, a number of features can be summed up that are generally recognized as essential to the philosophy of heart failure clinics. Working with guidelines in which the various elements of care are carried out in a coordinated way by specialized nurses is a central feature.^{15,16,25,26}

The exact job responsibilities of these nurses vary, however. At the very least they are responsible for educating patients, supervising and monitoring patient parameters such as circulatory volume, weight, blood pressure etc. during their own surgery hours. In some cases, their responsibility even extends to adjusting and/or prescribing medication.

Optimizing a medication regime is considered to be the joint task of physicians, nurses and patients. In most cases, a protocol is adhered to that describes the tasks of the nurses and clearly defines at which point they should involve the cardiologist.^{24,26}

Other tasks that fall under responsibility of the nurses could include maintaining (frequent) contact through telephone calls with patients and updating databases. In addition, the coordination of the care, especially around discharge as well as arranging adequate homecare are important elements of care programmes for heart failure patients.

Although many institutions in the Netherlands employ nurses specialized in heart failure, there is as yet no official definition of the function 'heart failure nurse' or the training

requirements for such a function. At present, the level of training of most heart failure nurses is that of niveau 4 - 5. These nurses may fall into any of the following categories: specialized nurses, nurse specialists or nurse practitioners. Characteristic for these nurses is in-depth expertise concerning the symptoms in combination with enhanced autonomy and responsibilities.¹¹

Gorski and Johnson²⁸ describe a transmural programme where a homecare organization performs house calls and a disease management organization maintains telephone contact with patients. Jaarsma¹¹ describes some forms of extramural heart failure care where nurses, either working in homecare or in the general practitioner's surgery, provide additional care for heart failure patients. In addition there are transmural cooperative initiatives where primary and secondary health care professionals share responsibility for the care. In most cases these programmes are aimed at providing information/education and follow-up care, but there are some examples of cooperation in the areas of diagnostics, treatment and follow-up care by physicians and nurses from both primary and secondary health care services.

Heart failure clinic being founded at Baylor Clinic

Baylor Clinic hopes to found a complete heart failure clinic in the near future. Physicians and nurses expect a great deal from such a clinic and want to focus on high quality heart failure care. Multidisciplinary guidelines are already being observed and nurse practitioners play a central role in the treatment and education of patients. The treating physician refers patients to the nurse practitioners. They are the ones who read the files and check whether patients are receiving the best possible and the most appropriate care and medication. They give advice concerning these issues but the physician holds end responsibility and is the one who takes treatment decisions. Two days prior to a planned visit, all patients receive a phone call to remind them of their appointment. The AHA guidelines are observed to the greatest possible extent. The clinic uses existing instruments when they are available.

In practice, other important elements of disease management, such as working with feedback of data and financial incentives are not found as often as the components that have been described here previously. Jaarsma¹¹ mentions having access to databases with patient information as being absolutely necessary for managing the care of the individual patient and keeping track of the number of patients in the outpatient clinic. Working with aggregated data and managing in accordance with the outcomes that were realized or linking this method of management to financial incentives have not been described. Because of this as well as the fact that prevention is nearly always carried out independent from treatment, these care programmes cannot in fact be regarded as complete disease management programmes. At the Baylor Clinic we saw some elements that utilised feedback as well as education for professionals.

Different disease management components at the Baylor Clinic

At Baylor feedback to treating professionals is given in the form of feedback of results from patient satisfaction studies on a four monthly basis. These studies compare scores concerning treatment, procedures, attitudes towards patients, nursing care, interaction among physicians and waiting times against other scores gained. This is expected to have a self-regulatory effect. No specific sanctions are applied if the results are negative. In addition, a feedback system was recently introduced that monitors the quality of medication use at the CCU.

At present no use is being made of aggregated data and target values, although there are hopes that files will be maintained electronically in the future which will make this possible.

Financial incitements to reach certain treatment targets are not being applied in the Clinic, neither with patients nor with professionals.

The Baylor Heart Clinic offers a wide range of educational forms, especially for fellows (trainee doctors of medicine who want to acquire more expertise in cardiology). Education includes programmes on interventional cardiology, cardiac electrophysiology, echocardiography, research methods and heart transplant techniques. The fellows rotate among various clinical and outpatient clinic settings and are obliged to carry out a follow-up of patients on outcomes spanning a period of 36 months.

Weekly seminars are also organised, for example, on nuclear cardiology, catheterisation and recent research results. National congresses are held each year as well as two regional congresses and a symposium on molecular cardiology. Both fellows and members of staff participate in journal clubs where recent publications are discussed. The integration of clinical training, clinical research and basic research are indicated as strong points of the training. One of the interviewees commented on the importance of individual or small-group education and informed us that a lot of attention was paid to communication with and respect for patients.

In addition to several clinical trials that are being carried out in general cardiology, the Winters Center for Heart Failure Research has been specifically founded for basic and clinical research on heart failure. The institute has received the status of 'specialized centre for heart failure research' (NIH). The implementation of research in practice is important and should be seen as a focus point in educational activities for professionals.

5.4 Areas for learning for the Netherlands

Chronic heart failure is a serious, life-threatening disease that frequently occurs at an older age. It is expected that the future will see a considerable increase in the number of patients with heart failure as a direct result of the ageing population. There is reasonable consensus on the desired content of good care for heart failure patients. The most important elements of the care comprise adequate establishment of medication regimes, good information and counselling regarding patients' lifestyle and timely observation and management of problems. During the last few years, it has become clear that concentrating the necessary expertise in specialized clinics offers the most chance of achieving optimal treatment results. Heart failure clinics are on the rise but by far not incorporated everywhere.

In their book 'Zorg Rndom Hartfalen'¹¹ (Care concerning heart failure) Jaarsma et al. provide instructions on working procedures when setting up a heart failure clinic. In the stepped plan that is described the following choices are outlined:

- the objectives to be aimed for and the target groups
- the location: intramural, extramural or transmurial
- the disciplines involved and the allocation of tasks and responsibilities
- the cooperating partners and agreements.

When staffing heart failure clinics care and attention should be paid to the expertise, qualification requirements and a guarantee for the quality of the care. According to the patient association,²⁷ cardiologists should also have good communication skills and be respectful and friendly towards patients.

The most important barrier encountered when starting up a heart failure clinic is probably the financial investment that is needed, while the benefit due to a decrease in the number of hospital admissions and visits to cardiologists in clinics is not always visible immediately.

During our brainstorming session with experts it was pointed out that certain locations that started a heart failure clinic have stopped the service. Various reasons were given such as a lack of continual financial stimulus and little direct gain in the way of fewer admissions and cardiology outpatient clinic visits. This could be due not only to the highly intensive investment in the cooperation with nurses but also to the fact that patients were drawn from places where these facilities were not present. In addition, there is no unanimous proof for the effectiveness at patient level. Until this happens and until the time when health insurance companies start programmes for purchasing the care for heart failure patients, or the health inspectorate sanctions poor performance, the question of whether or not heart failure clinics will be set up is mainly left to the providers themselves. The CBO is currently running a breakthrough series in which eight hospitals receive support so that the care procedures for heart failure patients can be implemented according to the guidelines.²⁹ This also includes attention paid to geriatric patients and patients from nursing homes who often have multi pathology requiring coordination of the care between several specialists. We found that when a hospital plans to set up and run a heart failure clinic, there should be sufficient expertise present concerning content and change management. Setting up heart failure clinics also fits in with national quality collaboratives such as Sneller Beter (Better Faster) which aim at rapid implementation of the introduction of innovations that have been proven successful (best practices).³⁰

One of the most striking features noticed at the Baylor Clinic is the strong focus on the integration of research and care within one location. In both areas of education and patient care the main emphasis is on participating in research and being informed about research results and subsequently applying these results in practice, especially regarding the education of professionals. This link between research and practical application is not seen to such a significant extent in the Netherlands. Much of the research that is carried out in university hospitals in the Netherlands is not perceived by professionals in regional hospitals as being relevant for their daily practice.

5.5 Heart failure programmes and the characteristics of disease management

Outpatient clinics for heart failure and heart failure clinics meet most but not all of the characteristics of disease management that are covered in this book. We will subsequently describe the ten characteristics listed by Spreeuwenberg in Chapter 1 and discuss whether or not they are present in the heart failure programmes.

The heart failure programmes described relate to a well-defined and circumscribed health problem and are aimed at clearly-defined patient populations and sub-populations (categories NYHA I-IV) (characteristic 1). However, one problematic area is that of the group of patients who have several disorders. Patients with heart failure often have other diseases as well, e.g., diabetes and therefore often have to take different medications that may interact. If care is increasingly being organized by diseases, these patients may not receive an optimum level of care. In these cases, coordination covering the different disorders is essential.

Patient education and self-management are central components of the heart failure programmes described (characteristic 2). Up until now, most programmes promote coherence between the components of specialized care and do not extend to primary health care or prevention (characteristic 3). The area of prevention and early detection, for example by means of information campaigns and by screening at risk patients (especially those with lifestyle factors) is still separately organized from curative care both in America and the Netherlands. This is seen in the Dutch heart failure clinics as well as in the Baylor Clinic where the programme commences after diagnosis has been determined.

Working with evidence-based protocols and clinical pathways based on sub-groups (characteristics 4 and 5) is common practice in these programmes, as is the large role that specialized nurses play in the implementation of the care (characteristic 6).

The use of information and communication technology (characteristic 7) with heart failure patients is still in its infancy. This also holds true for management instruments based on benchmarking and feedback (characteristic 8). Both the Baylor Clinic and the Netherlands do not have adequate electronic systems for patient monitoring and follow-up. This, in spite of the fact that some benefit can be had from such systems, for example, when patients

monitor themselves at home. With self-monitoring patients could (in part) determine when it is time to visit the clinic. A disadvantage however, could be that because of less face-to-face feedback patients no longer feel they have a listening ear.

Characteristic 9, large-scale and a solid organizational structure, is by no means being met everywhere. Firstly, heart failure clinics are not yet available everywhere. Secondly it appears that clinics that have been set up may falter due to a lack of structural funding and the fact that 'the profit' does not flow back into the programme itself.

Care for heart failure patients is not being purchased and funded from a central point (characteristic 10). Both at the Baylor Clinic and in the Netherlands no financial incentives are applied in order to realize certain treatment objectives. However, the patient association does not consider this point to be a deficiency. Nevertheless, a systematic central approach towards funding is regarded as a stimulus for the continuation of this form of care.

We conclude that providing systematic care in the form of programmes for heart failure patients is feasible and that it should be encouraged. The existing outpatient clinics would gain from using systematically collected data as well as with the feedback of aggregated information. The screening of risk groups could be organized on the basis of the infrastructure that is available in heart failure clinics.

Funding according to a DTC (disease treatment combination) would encourage the setting up of and maintenance of new heart failure clinics. There is sufficient expertise available in the Netherlands to initiate this process. Every hospital could, in principal take the initiative to do this. However, the dissemination of this kind of care would be enhanced if it were to be included in a national quality collaborative such as those commissioned by the Ministry of Health in numerous other sectors.

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6 The programming of palliative care during the last phase of life

Cor Spreeuwenberg

Since the beginning of medicine, care and support for people who are suffering has been considered the most important task for the health care services. This statement considered, palliative care should therefore be a self-evident part of the health care sector. Unfortunately, the way that medicine has developed (especially during the twentieth century) has contributed to the fact that the self-evidence of this need has been lost and that palliative care even has to be rediscovered. This rediscovery is being stimulated by the hospice movement as well as dedicated physicians, nurses, and psychologists working in the Anglo-Saxon countries. The most important aspect of their activities has been not what they said, but the fact that they dedicated themselves to the recognition of palliative care. The Swiss-American psychiatrist Elisabeth Kübler-Ross was not completely correct with her staged model, but her book 'On death and dying' enabled dying and care for the dying to be a subject for discussion.^{1,2,3} Dame Cecily Saunders managed to ensure that the philosophy of care surrounding St. Christopher's Hospice would be sufficiently brought out into the open. In the nineteen-seventies and eighties, the London hospices and centres abroad such as the Mount Sinai Royal Victoria Hospital in Montreal and the St. Luke's of Yale University not only carried out a philosophy on palliative care but also especially developed practical and scientifically founded knowledge on the subject.

In the Netherlands, palliative care is a late phenomenon, only being really developed during the nineteen-nineties. This late development could be seen by some as a compliment to the Dutch Health Care Sector. In the Anglo-Saxon countries, many people did not have access to non-medical facilities in the areas of nursing and care. In Great Britain, although the care facilities of the National Health Service were available to everyone, these mainly covered medical facilities and not those for pure care. Palliative care had for some time been a matter for institutions associated with religious parties. In the nineteen-seventies and eighties, the level of care facilities in the Netherlands was considerably higher than in Great Britain. Criticism from abroad that euthanasia in the Netherlands was on the agenda because of a backlog in the area of palliative care as well as the experiences that were slowly being built up with hospices and other kinds of palliative care homes the 'almost-home homes' led to the Minister of Health, Wealth and Sport Affairs taking action. She placed palliative care on the policy-making agenda and the Ministry stimulated palliative care in three directions:

- the stimulation of research and innovative projects from within the programme Palliative Care in the Terminal Phase of Life developed by (ZonMW) the Netherlands Organization for Health Research and Development.³
- the stimulation and steering of palliative care from six academic Centres for the Development of Palliative Care (COPZ-en).⁴
- the stimulation of the integration of hospice facilities into the regular health care services by the (PIH) Project Group for the Integration of Hospice Care.⁵

The Ministry took a generalized perspective as its point of departure with the opinion that palliative care should be part of the regular health care services. With this, it resisted the tendency to develop an independent circuit for palliative care.

In order to offer high-quality palliative care, much attention must be paid to the enhancement of expertise for the care providers working in general care and to the possibilities for providing them with support and consultation services. Bearing this in mind, the Comprehensive Cancer Centres (IKC) have been commissioned to set up

networks in their separate regions for consultation and the enhancement of expertise in the area of palliative care.

This book covers the concepts of disease management, care management and care programmes.

These concepts offer a new approach to care for which a number of aspects can hardly be applied to palliative care. For example, cost limitation is one aspect that simply cannot be taken up in the aims for palliative care. Other aspects, however, can be applied to palliative care. For example, multi and interdisciplinary collaboration is almost always an indispensable aspect of palliative care, both within and outside the various sectors. This requires making agreements on the following: direction, task allocation, structure, quality monitoring, collective file creation and the exchange of information. All these aspects belong to the new forms of health care.

This chapter focuses on the organizational aspects as opposed to the actual content of palliative care for which various manuals are available.^{6,7}

6.1 Definition

The term 'palliative care' is derived from the Latin 'pallium' which denotes a coat, for example, of love and warmth. The World Health Organization (WHO) defined palliative care in 1990 as: *the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount.*⁸ The words 'curative treatment' found in this definition do not refer to those operations that aim at actually curing the disease, but to those activities that delay death as a direct result of the disease. Palliative care can go very well together with such curative operations. In this respect, this form of care differs from terminal care, which is the care given during the last phase of the palliative phase in which death is visible and unavoidable. Therefore, we can refer to palliative care during the terminal phase. A working party (see ref. 3) from the ZonMW, proposed that palliative care encompasses all care that is directed at reducing suffering during the last phase of life. The editors of the Manual for Palliative Care from the COPZ review committee described palliative care as follows: *all measures that are taken in order to reduce the suffering of people for whom death must be seen as a reality. Suffering is seen in a broad context and therefore constitutes physical and functional aspects as well as social and existential or spiritual aspects*.⁴ When we refer to palliative care in this chapter, we mean the palliative care that is given during the last phase of life.

The WHO describes the aim of palliative care as the achievement of the best possible quality of life for both the patient and his/her loved ones. The working party of the ZonMW, sees the aim as follows: *the achievement that the last phase of life reaches as far as possible the realistic wishes and needs of the patient*. In order to achieve this, the patient's loved ones are involved in the care and the care will reach out to them. Palliative care in this respect, becomes a continuous, active, integral and personal phenomenon.

6.2 Palliative care, oncological care and palliative medicine

Now that palliative care has been defined in its broader sense, it is natural to assume that a whole scale of care providers are involved in the process. These include not only: general practitioners, anaesthetists, nursing home physicians, professionals treating the primary disease, and sometimes psychiatrists, as well as nurses (both in home care and institutions) pharmacists, paramedicals, pastoral staff and sometimes psychologists and social workers. It is not correct to associate palliative care with oncological care during the last phase of life. Whilst, on the one hand, palliative care is about more than just focussing on a tumour, on the other hand, it is about the care for patients during the last phase of life who are suffering from any disease whatsoever. Sometimes, it is not even relevant from which disease someone is suffering.

Palliative care should be differentiated from palliative medicine. This is the area of study concerned with the medical aspects of the last phase of life. It is not correct to place palliative care side-by-side with palliative medicine. The knowledge that stems from the discipline of palliative medicine is widely used in palliative care. The classical contradistinction between 'cure and care' does not apply to palliative care. On the contrary,

palliative care is explicitly concerned with integrating the care given by care providers with different backgrounds and from various disciplines. For example, in the case of pain, nurses play an important role in the diagnostics of the pain whilst the physician has the task of prescribing and adjusting medication on the grounds of the findings. The two professionals therefore, need to be in close consultation with each other.

6.3 The demand for palliative care

In the Netherlands, 141,000 people died in 2003. From this total, 54,000 people of 20 years of age or older died as a consequence of cancer or a chronic disorder.⁹ From the 36,000 people who died of cancer, approximately two-thirds died at home and one third in a hospital or nursing home. In the UK, approximately 65% of people with cancer want to die at home although only approximately 30% actually manage this.¹⁰ On this point, large regional differences can be observed.¹¹ Many of these patients present with frequently occurring symptoms such as pain (84%) fatigue (69%) weakness and anorexia (66%) lack of energy (61%) dry mouth (57%) constipation (52%) weight loss (50%) breathlessness (50%) cough (49%) anxiety (48%) sleeping problems (47%) and a sombre mood (40%).¹² Whilst the symptoms of the disease that is the cause of death differ strongly, these differences are not as strong during the dying phase. This means that people with all kinds of diseases have a great deal in common as far as their symptoms and care needs are concerned.¹³

In addition to medical problems, existential and spiritual problems also exist. Problems with the nursing care, the approaching death and dealing with relatives and loved ones who will be left behind also need to be addressed. Often the people closest to the patient have their own problems to deal with. In one published article, half of the women interviewed who were in the terminal phase related that they had anxiety concerning death.¹⁴ Most of the women interviewed would have liked to discuss their approaching death with their treating physician. In one study in the United States, 77% of the patients indicated that they wanted to talk to their physician about religious aspects.¹⁵ Incidentally, in another study 7% explicitly stated that they did not want this.¹⁶

Whilst a large part of the problems observed could be referred to as 'medical', these are mainly multidisciplinary in nature and show a strong interrelationship between the various aspects of suffering of people in the palliative phase.

Due to the ageing of the population, more and more problems are occurring during the dying phase that are related to age. These problems are both physical and social in nature. Often, in these cases, the partner is no longer mobile. It is also not uncommon that the children of the patient have reached such an age that they are themselves suffering from a chronic disease.¹⁷ The physical and social problems of the elderly however, do not imply that they have a bad quality of life. Kutner et al. refers to this as the 'disability paradox'. In spite of their bad state of health, many elderly and terminally ill people indicated in one large study that they considered their quality of life to be good or average and upheld a certain optimism.¹⁸ These people reported that their dignity was preserved. However, some people consider dignity to be a completely obsolete term in combination with palliative care. Macklin sees 'dignity as a useless concept in medical ethics that can be eliminated without any loss of content'.¹⁹ Others report that many terminal patients refer to dignity and that it is related to the degree in which patients suffer from depression or anxiety. Whether or not their primary physical functions remain intact, such as being able to care for themselves, going to the toilet independently, washing etc. are factors that also play a role.²⁰ Particular attention should be paid to those people in the direct environment of the patient and who are directly involved in the care. From all kinds of studies, it appears that these people suffer considerably more from anxiety and depression during the period that they are giving care to their loved one. Moreover, they are more vulnerable for a long time following the death.^{21, 22} On the one hand, informal care considerably adds to the total care for these patients. Without this care, the quality would certainly come under pressure and the costs be increased. On the other hand, informal caregivers from the patient's direct environment can only continue their work if they are supported by the professional services. In addition, in relation to their increased physical and emotional vulnerability both during and following the final phase, they need to receive help and support for their own problems that have been caused by the death of their loved one. Volunteers working in the area of terminal care also need to receive professional support.

6.4 The supply of palliative care

In 2002, Teunissen and Witteveen surveyed the organization of palliative care in the Netherlands.²³ They describe many aspects of care programming, such as, the demand for and the supply of palliative care, transmurals support teams, consultation, coordination, and quality, the monitoring of expertise, the technological support and the funding. From their summary, it appears that although much is currently in a state of development, the final picture is not completely clear.

The supply side of the care amounts to a whole hotchpotch of the following: institutions (hospitals, nursing and care homes, home care organizations, volunteer organizations etc.) locations, (intramural, extramural) and practising professionals (general practitioners, medical specialists, pharmacists, nurses, homecare carers, social workers, physiotherapists, ergotherapists, dieticians, psychologists, pastoral workers etc.). The structure of the Dutch health care sector is such that no one holds final responsibility for the total care. The most obvious choice for this role would probably be the general practitioner because of his position but there are other health care professionals who could claim this responsibility such as the specialist who has been treating the patient.²⁴ Lack of clarity in the situation is only encouraged by the fact that the transfer from curative to exclusively palliative treatment is not always noted and there is equally no explicit study of the consequences.

When the home care sector still worked with district nurses who cared for their own group of patients, these professionals took on an increasing prominent place during the palliative care phase. The general practitioner and the district nurses often made mutual agreements on who would take on which responsibility in the care for those patients staying at home. At present, the home care sector is organized in such a way that patients being cared for at home encounter a large number of different nurses and homecare carers, a situation that does not encourage coordination and harmonization.

In Britain as well, the following statement has been made: 'until, recently, apart from Macmillan general practitioners and nurse facilitators, few comprehensive workforce initiatives have been undertaken in primary care that focus on end of life care'.²⁵ Macmillan general practitioners and nurse facilitators are general practitioners and nurses who have undergone special training in palliative care. They are funded outside the regular health care system, often by registered charities.

6.5 Hospice care

Since the nineteen-nineties, new palliative care providers have arrived on the scene including the special care homes known as the almost-home homes and the hospices. The almost-home home is particularly intended to serve as a substitute for the home situation where care at home is no longer possible for practical reasons. An almost-home home does not form part of the regular care services. Care is offered by volunteers and is supported by both the general practitioner and the home care services. Hospices originate in the Anglo-Saxon countries. In the Netherlands the number of hospices has sharply increased in recent years. In February 2004, there were 58 hospices in the Netherlands with the number of total beds at 304.²⁶ The hospices differ both in their size and supply of care. Most hospices work on a small-scale, are based on a certain philosophy of life and rely strongly on volunteers. Much attention is paid to how the patient and his/her loved ones experience the phase. A few hospices are large-scale and concentrate on the consultation aspect for the region in which they are located. These hospices are often linked to a nursing home and employ one or more physicians.

In the ongoing discussions on hospices, a differentiation is made between low-complex care versus high-complex care and small-scale versus large-scale care. Although, in principle the complexity of care should be completely separate from the size of a facility, most hospices are small-scale facilities for low complex care and only in a few instances does a hospice provide highly complex care. Partly due to efficiency reasons, such a hospice is usually of considerable size.

Larger hospices are run either by a physician or a nursing home physician who is specialized in palliative care. The small-scale facilities by no means always have a permanent physician in house. Sometimes agreements have been made between a nursing home or a hospital or sometimes with a general practitioner who lives in the vicinity. The

problem is that the founders of small-scale hospices usually assume that the patient's general practitioner will continue to look after the patient during the last phase of life. This however, is not always practical for the general practitioner in question, for example, if the hospice is located outside the catchment area of the GP practice. The problems surrounding the medical support can usually be solved although the situation is not ideal and remains somewhat messy. The small-scale hospices are often largely dependent on volunteers.

This situation does present some problems such as: how responsibilities and tasks are allocated, how to cope with sudden absence due to illness, the extent of the authority of these volunteers, how to train them and whether they should receive certificates and lastly how to maintain their level of knowledge. The discussion surrounding the small-scale facilities includes the fact the initiative for them is nearly always taken by citizens themselves and that maintaining a homely atmosphere is important. Another significant factor is that people do not always realise which complications can occur during the palliative phase and that with this in mind, reliable medical facilities need to be available whenever necessary.

Ideally, there should be a charter outlining which requirements are absolutely necessary for small hospices. However, this should not work against the individual identity of a small-scale facility. Any such charter should in any case indicate where the medical and nursing responsibilities lie. For example, the allocation of a permanent general practitioner or nursing home physician should be compulsory.

6.6 Collaboration

Teamwork between professional care providers coming from various disciplines should be seen as a cornerstone of palliative care.²⁷ Various forms of collaboration are in place for palliative care: collaboration within the various sectors of palliative teams, such as hospitals, nursing homes and hospices and collaboration between various sectors in the form of transmurial collaboration.

For the palliative teams within the various sectors, the relative backlog of the formation of palliative teams within the hospitals is striking.²⁸ This is caused by the fact that also in the Netherlands, the added value of such teams is not recognized and that many specialists consider themselves to be expert in this area and therefore consider guiding the dying patient as a natural part of their duties. This last-named point should only be alluded to as positive and not be disregarded too lightly. The question, however, is whether or not the expertise of the specialists and nurses is at the required level and whether or not the curative aspect of the specialization does not have a hampering effect on early recognition of the special needs of patients during the palliative phase. The fact that there are hardly any specialists for palliative care in the Netherlands certainly does not increase either the recognition of or the experience with possible added value. One strategy that could be used to improve this situation would be to provide extra training for medical specialists and nurses in hospitals for palliative care. These professionals would then be called upon as a consultant for patients during the palliative or terminal phase instead of as exclusive treating professional. Furthermore, systematic meetings on the care for people during the palliative or terminal phase could be encouraged. A palliative team can then be built up around these physicians and nurses.

Many palliative teams work transmurally, often with a hospital, nursing home, or hospice as home base. If a region already has an organization geared towards transmurial collaboration, then linking up with existing services should be sought. The unusual aspect of transmurial collaboration is that there is a question of collaboration concerning organization, structure of authority, scale size, and financing of the various providers. In addition, what is even more important than just collaboration within sectors is the absolute necessity to structure the transmurial collaboration and explicitly allocate the responsibilities and tasks. A systematic collaboration whereby for all those patients eligible for care the collaboration and allocation of tasks actually takes place, hardly ever occurs.

In the case of collaboration, it should be taken into account that crisis situations can occur during the palliative care phase for which it may be necessary to deviate from the original planning. Therefore, the protocols should contain not only agreements on the working methods within the team, but also on how to handle if unexpected situations occur and, for example, a patient has to be admitted suddenly.

In the Anglo-Saxon countries, the teams are often led by a medical specialist who is expert in the area of palliative care. In the Netherlands, this medical specialism is not recognized as such; palliative medicine is practised by a number of medical specialists who have received training abroad. In most cases a palliative team is led, for example, by a physician, an oncologist, an anaesthetist, a nursing home physician, or a general practitioner. The nurses who are either trained or not trained in palliative care have the main task of carrying out the work involved in the care. Apart from the nurses, other professionals such as social workers, psychologists, psychotherapists, and pastoral workers, make up the team in varying degrees. In a number of cases, there is a core team of care providers who together discuss the cases and plan the treatment strategy. This core team can often, in specific cases, call on the expertise of a number of other professional care providers such as pharmacists or physiotherapists who make up the outer layer of the team.

One thing that is absolutely essential here is that all members of interdisciplinary teams in palliative care strive to meet the same goal. However, the fact that there is a common goal does not mean that the task for each professional involved is the same. The character of palliative care, in which there is often a 'common clinical pathway' involves a large area which extends beyond the individual discipline and has been described by Groffen as the subdisciplinary area.²⁹ In addition, each professional care provider has a specific area for which he/she is specialized; this is known as the profession-specific area. Collaboration within this profession-specific area is particularly rewarding. On this point, agreements have to be made concerning task distribution and allocation. Here, the individual's specific expertise should be taken into account. The combination of the expertise in both areas, i.e. the so-called 'cross-functionality', ultimately determines the potential of the team for the achievement of attaining one whole result that is more than the sum of the separate parts.³⁰ Special attention should be paid to the formation of such a team even if the team has been in operation for some time. This includes the aspects of organization, leadership, the distribution of tasks and authority and enabling any friction or conflicts to be discussed and solved.

6.7 Substitution

Palliative care is one area of health care in which general practitioners and nurses collaborate extensively. Both categories of care providers have, in addition to their own area of expertise, a considerable shared subdisciplinary area. Although it is true that nurses are only involved in the care process at a later stage, following this, there is a certain amount of transferral of the patient's psychosocial care from the general practitioner to the district nurse.³¹ During the nineteen-seventies, the *nurse specialist in palliative care* was introduced in the Anglo-Saxon countries, initially for the practical side of the care.³² Over time, this function has been extended so that it includes not only clinical tasks but also other parts of the care such as emotional support, education, research, and organization of the care. At present, emotional support is the most important reason for referral to a nurse specialist in palliative care for two-thirds of the patients involved.³³

In contrast with the robust care programmes in the areas of the chronically ill, the nature of the palliative care services is such that the substitution of care is largely limited to the subdisciplinary area. For example, nurses will hardly ever be allowed to change a medication regime. Although nurses play a large part in pain management and observation, the intervention that is aimed at pain reduction is nearly always performed by physicians. This is partly due to the fact that even physicians are not always familiar with this area of care and that there is often a case of prescribing different drugs to be taken at the same time.

Apart from substitution within the subdisciplinary area, nurses are very capable of taking on the role of case-manager and of acting as the first professional care provider to be contacted by the patient and his/her family. It goes without saying that this must be discussed with the patient so that he/she is aware of the situation and accepts it. One task of the case-manager is to take care of the continuity of the care and to ensure a well-reported and transferable care file.

6.8 Education

During recent years, more attention has been drawn to the aspect of education in the principles of palliative care in the Netherlands. Until recently, the pioneers were trained either abroad or with an internal training. A separate medical specialism for palliative care does not exist in the Netherlands. In addition, it does not seem likely that such a specialism will be started up in the near future. The Dutch College of General Practitioners does have a management training within its framework for palliative care for general practitioners. This training is aimed at general practitioners so that they can act as consultant for their colleagues and be a leading figure in the developmental process of palliative care in their region. A number of higher professional education courses (HBO) are available for nurses in the area of palliative care. These include both categorical training as well as the training needed for palliative teams.

Presuming that the care for the dying person will fall under the responsibility of professionals who are not specialized in palliative care (medical specialists, general practitioners, nursing home physicians, nurses and carers) it is also essential to develop care packages for the regular training courses of these practising professionals. In this respect, it is essential not only to concentrate on the medical or nursing content of the expertise but also on the emotional, communicative and organizational aspects of this part of the care. One ideal chance of bringing these aspects all together within their context, is in the training for physicians where medical students on clinical placement return to college for follow-up days.

6.9 Protocols

The purpose of protocols is to outline exactly how to handle concrete practical situations. In the case of care programming, the arguments for a guarantee of quality and gain in efficiency play a role. Although on a national level people face global standards or guidelines, in order to achieve concrete collaboration and bearing in mind the efficacy of care, it is essential to record on paper the details of any agreements. This process enables choices on how to treat to be made from options that are seemingly equal.

Usually, material that is already on hand will be used to make regional or local agreements. In recent years, various organizations have amply contributed to this process. The academic centres for the Development of Palliative Care that are encompassed in the Comprehensive Cancer Centres (IKC-en) have stimulated the development of collective protocols within their separate regions. The collective Comprehensive Cancer Centres have compiled a pocket book on palliative care.³⁴ In the non-medical area, organizations such as the Institute for Quality and Applied Home Care Innovation (KITZ) provide excellent advice on how to avoid for example, complications, how to give home artificial nutrition, and how to avoid pressure sores and subcutaneous pain.³⁵ In addition, advice is given on how to make transmural working agreements, how to support informal carers, and make choices on the supply of the various parts of palliative care. The prevention of pressure sores has, in the meantime, also gained the attention of general practitioners through the guidelines that have been brought out on this subject.³⁶ The Dutch Institute for Healthcare Improvement (CBO) has renewed the consensus on pressure sores.³⁷

6.10 Technology

In principle, technology is not an aim in its own right but a means of achieving something else. Although this statement may be true, it is too simple as it stands. Technology is, after all, not something passive but regulates and determines our existence to a large extent.³⁸ There is a kind of aversion to the use of advanced technology in palliative care. People often choose the home situation in which to spend their last phase of life because they want to die in their own surroundings in a non-medical atmosphere. In this respect, people are worried that technology will replace the inter-personal communication and that the sick room will be transformed into a hospital room. In addition, the development of non-spectacular technology is not an attractive proposition for the health care market.³⁹ On the other side of the coin, however, technological development enables terminal patients to remain in their own environment at home for longer or to die there. Specially developed plasters and electronic pumps have enabled pain management to be well-regulated.

Technology in palliative care applies not only to the patient but also to the care providers.⁴⁰ Many informal carers experience their task as a heavy one and the use of technology can bring some relief in this.

Technology can be applied to various areas of the care:

- as a means of maintaining autonomy for as long as possible by assistive devices to help with daily functions such as mobility or going to the toilet
- as a means of combating symptoms, such as the use of pumps to administer fluids or medication such as morphine
- as a means of communication such as voice recognition computers and advanced telephones
- as a means of registration such as electronic patient files
- as a means of monitoring the patient, such as all kinds of apparatus for measuring the vital signs
- as a means of enhancing quality, such as, for example, by recording the results of certain benchmarks
- as a means for information, such as admission to a Website through Internet, or to a helpdesk where people can go for further information.

Often, applications in many different areas will be made. For example, electronic patient files (EPF) are an excellent means of recording patient data. At the same time, they can be used as a means of communication between various professional care providers especially when the care plan is laid out in the file.

When using technology, the following points should be kept in mind:

- the location in which they are used
- the use and reliability of the materials
- the willingness of caregivers to participate in their use
- the expertise of the caregivers involved
- the availability of 24-hour support
- juridical consequences of their application in certain locations.⁴¹

Professionals working in the primary care services are not very familiar with the application of complicated health care technology in the home situation. Little experience has been gained in primary care with other forms of technology such as ascites drainage equipment. Often, such technology will have to be provided by the hospital or in any case supported by the hospital. In such situations, it is essential that the points named above will receive the necessary attention and that the agreements made are carefully recorded in writing. In addition, it is advisable to pay attention to the practical side of things such as limiting the types of infusion pumps used and involving pharmacists in the supply and delivery of medications and infusion materials.

6.11 Communication

In the areas of disease management, transmurial care, and care programming, much focus is put into communication with the patient because this is a key area needed to change behaviour and to achieve treatment compliance. In palliative care, communication is equally of paramount importance. However, here we are concerned less with achieving clearly-cut goals and more with ensuring that the dying process conforms with the realistic needs and wishes of the patient himself. Therefore, it goes without saying that the actual care given is organized in such a way that it totally suits the needs of the patient. In this respect, there is often a paradox present as both patients and their physicians are inclined to hold on to hope, even when this is not realistic. Physicians give all kinds of reasons for carrying on with aggressive forms of treatment even when the chance of healing is extremely small. There is then a kind of unfounded optimism for recovery whereby physicians and their patients are acting out a role and in which nurses are expected to play along without being asked for an opinion.⁴² Whilst for patient-centred care the autonomy of the patient should be encouraged, there is often in these situations a paradox present. Patients avoid being well-informed and leave the decisions concerning their treatment up to the doctors. The doctors are inclined to rather spend their time monitoring aggressive treatment therapies than on carefully communicating and patiently waiting with the patient.⁴³ On the surface, this seems to fit in with a patient-centred approach as the patient indicates that he/she does not want information. Daily practice however, has shown that the realistic situation can be talked about if the doctor adheres to a pattern of communication

that is aimed at exploration.⁴⁴ Such an exploration fits in very well when the doctor has an attitude that is based on participation with the patient. A lack of communication hinders a clear marking of the point of transfer from a curative to a palliative treatment approach. This means that it is not clear when palliative care should start. The implications therefore, extend beyond just the consultation on diagnosis and prognosis. If the approaching death is not a topic of discussion, the patient and those around him/her will not be able to prepare for it whereby all kinds of diversions will be made that distract from the real problems. Nurses in particular often find it difficult to deal with this kind of situation. The way in which doctors and patients communicate therefore has consequences for the whole pattern of communication between the caregivers. Now that medication aimed at curation is continued longer, it is to be expected that the problems surrounding communication will occur more and more often. It is therefore essential that medical specialists, general practitioners, and nurses come together and make this issue a point of discussion.

Another aspect of communication is that referring to intercultural relationships. It is, after all, easier to communicate with someone who has the same background as with someone who has a different cultural or religious background. If we are to take seriously the point on palliative care paying attention to questions on existence and the meaning of life, then we have to pay attention to who will do this and how it will be done. When compiling palliative teams, the cultural and religious individuality and the multiformality of the region where such a team works should be taken into account. Furthermore, these factors should be remembered when the team is being trained.

6.12 Funding

We have indicated that palliative care concerns the integration of the various disciplines involved in the care. The nature of palliative care in the terminal phase is accompanied by the fact that there is always a physician involved and that the duration of the care is limited. This means that there is no reason not to consider palliative care in the terminal phase as simply medical care and to finance it as such. At present, palliative care in the terminal phase is still financed by various means: the Exceptional Medical Expenses Act (AWBZ), health care insurance and other regulations. The AWBZ is mainly intended for long-term care which doesn't concern us here. The funding of palliative care in the terminal phase belongs to the second of the arrangements mentioned above, i.e. that of health care insurance. If palliative care is to be of suitably good quality, then it is reasonable to assign special rates for it. These can be differentiated according to the various functions involved and their levels. Here, we should think of rates for the hotel function, the medical function, the nursing function, and the paramedical function. In addition, it is reasonable to establish a rate for consultants.

6.13 Does palliative care comply with the definition and the characteristics of disease management?

Palliative care encompasses all disorders for which someone dies. There is therefore no question of specific diseases and health problems contained in the definition of disease management. Palliative care is focussed on the combat of symptoms that occur during the last phase of life. Although these are usually tied to a particular situation, they can also be recognized by certain patterns. There is equally no question of a tightly programmatic and systematic approach. The aim is the enhancement of the quality of the process of dying. The actual fulfilment of efficacy is however, in the background.

The following can be stated on the characteristics:

1. The target population of palliative care concerns, therefore, not groups of people with the same health problem but people who find themselves in the same situation i.e. during the last phase of life.
2. Palliative care is anticipatory care (prevention), it has to link up with the previous phase of the care process, is given in an explicitly integrated form and includes the grieving of loved ones following the death.
3. Much attention is paid to gaining information on the situation as far as diagnosis and prognosis are concerned. The purpose of this is to fulfil as far as possible the needs and wishes of the patient concerned. In this respect there is little room for self-management in this situation.

4. Palliative care adheres to protocols in order to combat many commonly occurring symptoms.
5. Classifying patients according to sub characteristics does not take place. It may be possible to improve the differentiation between low-complex and high-complex cases.
6. Whilst benchmarking is not easy due to the variation in the problems, palliative care is particularly suitable for feedback and critical evaluation of the chosen approach and effectivity.
7. Nurses play a large role in disease management; decisions on medical interventions however, are only made by physicians.
8. Enlargement of the use of information and communication technology is essential due to the large number of care providers involved in palliative care, the need for signalling and monitoring and the possibilities for drawing up protocols for the approach of care problems such as, e.g., pain management and nausea.
9. Palliative care is not organized on a large-scale or robust basis. However, attempts are being made to try to support the small-scale care facilities from a large-scale perspective coming from local and regional support teams.
10. There is no question of central steering; this is also not something that the population desires.

6.14 Conclusion

This chapter has looked at palliative and terminal care from the perspective of care programming. We have determined that even more than is the case with care programmes for chronic disorders, palliative care is concerned with increasing the quality of the care. The areas of palliative and terminal care are still very much in a developmental phase. This is partly due to the contribution made by new parties such as local government and patient organizations as well as idealistic groups. A balance is being sought between the creation of conditions for the care of patient-centred care in a homely environment, and a link up with the regular care for the necessary expertise and back-up function in unexpected situations. The Comprehensive Cancer Centres have taken on the task of the development of local or regional palliative teams and the support that these can give on a national level. They concentrate mainly on the development of the organizational aspects and the traditional activities of the Comprehensive Cancer Centres such as case studies, training, and other forms of the enhancement of expertise.

At this point, it remains to be seen whether or not palliative care lends itself to the strict, disciplinary approach of disease management and care programming. In any case, a considerable amount of room should be left free for the contribution of the patient himself and on the prevention of unnecessary medicalizing the dying process. At the same time, we should expect the practising professionals to follow the rules of their expertise (here, scientifically proven evidence plays a large part) and harmonize their activities so that they are both goal-oriented and efficient. There must also be insight into the process and the results of the care in order to maintain and improve quality. Good documented information based on comparisons between case studies and registration are an ideal means of doing this. Further, attention must be paid to improving the organization of the care.

In the Dutch situation, it is not considered desirable to set up separate departments for palliative care and that this kind of care is given exclusively by those people who are specialized in it. Specialists are indeed necessary, but their most important task consists of supporting others, providing education and monitoring the quality.

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7 The realization of disease management in the Dutch context

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7.1 The story behind this book and, in particular, this chapter

In the Netherlands, health care concepts such as transmural care, chain care, and care programmes have been developing since the beginning of the nineteen-nineties. In the United States, the concept of disease management appeared at the same time. In 2002 a review article was published in the British Medical Journal of approximately 100 papers and reports which showed that three sorts of interventions used in American disease management programmes lead to greater quality and efficacy compared to care-as-usual. These three interventions are: patient education, supplementary education for care providers, and feedback to the care providers on the achievements gained. These favourable results led to the Netherlands Organization for Health Research and Development (ZonMw) honouring a research proposal from the Julius Center of the University Medical Center of Utrecht with a research question as follows: *What is the extent to which it is advisable to apply the ten characteristics of the American concept of disease management to patient care in the Netherlands in the long term?*

From the very beginning, the intention was to find the answer to this question for five totally different groups of patients for which disease management programmes or similar care programmes exist in the United States. The patient populations that were finally studied were those of cystic fibrosis (chapter 2), diabetes (chapter 3), depression (chapter 4), heart failure (chapter 5), and palliative patients (chapter 6). Representatives of the Council for the Chronically Ill and Disabled (CG Raad) made the choice for these five patient populations. The idea was to cover a wide range of disorders affecting the young (cystic fibrosis) to the old (heart failure, palliative care) to psychiatric (depression) and somatic illnesses (other patient populations) and on more common disorders (diabetes, heart failure) and less common disorders (cystic fibrosis, palliative care).

During the first phase of the study, the then financial director of the University Medical Centre of Utrecht, Marianne Acampo, visited five locations in the United States that were working with good examples of disease management programmes. These locations represented one example per patient population. When American patient associations were approached, they recommended these centres as leading innovative centres that were closely connected to the concept of disease management. The next phase consisted of literature studies and five meetings with Dutch experts: one meeting per patient population. Finally, the authors were requested to prepare a summary in the form of a chapter on each patient population studied and together to formulate the answer to the research question.

For this purpose, the authors have taken as their starting point the following definition of disease management: *the programmatical and systematic approach of specific diseases and health problems by using the management instruments that aim at the advancement of quality and efficiency.* This definition is based on the literature study that was carried out by C. Spreeuwenberg for his research into the material covered in the first chapter. This definition was necessary in order to compare the content of the various chapters and will also be adhered to in this final chapter.

The ten characteristics of disease management that were derived from the literature and laid out in chapter 1 are as follows:

1. relates to one health problem and aimed at clearly-defined patient populations and sub-populations
2. methodological education and the advancement of self-management
3. orientation on the integration of the various parts of the care process including preventive interventions
4. disease management protocols that are based on evidence-based diagnostics and treatment
5. classification of patients in clinical pathways based on sub-characteristics
6. reshuffling of duties/responsibilities from doctors to nurses
7. use of information and communication technology
8. focus on the use of a range of management instruments such as benchmarking and feedback
9. large-scale and robust organizational structure
10. direction and funding coming from a central point.

The characteristics are thus classified according to patient care (characteristics 1 through 5) organization of the patient care (characteristics 6 and 7) and the management of patient care (characteristics 8 through 10).

The authors used five sources in order to describe the care for the various patient populations, as follows: first, their own experience and expertise (please see appendix 2), second, recent articles published during 1999-2004 and found by searching via Pubmed and Google, third, the travel reports made by Marianne Acampo who visited one location per patient group in the United States, fourth, expert meetings in the Spring of 2004 between prominent care providers for each patient population, project leaders and policy-makers in the area of chain care in the Netherlands, and, lastly, individual analytical and judgemental abilities. On the basis of this last-named point, the authors reached conclusions concerning whether or not it is advisable to apply the ten characteristics of disease management to their particular patient population. In order not to force the various arguments into shackles, the editor of this book, Guus Schrijvers, has not attempted to run the ten characteristics parallel with each other according to the paragraph headings per chapter. However, all characteristics are discussed in each chapter.

In the present chapter, the authors reach a collective and broadly-outlined answer to the research question. This synthesis was brought about by using key words for each of the ten characteristics per patient population. These are laid out in the diagrams 7.1 – 7.10 below. At this point, it should be made clear that any summary made from subtle distinctions between various arguments by using just a few key words, will inevitably lead to both a loss of information and to some loss of context. This is equally unavoidable for a synthesis. The reader should be aware that the remarks made on each of the diseases covered in the diagrams represent the opinions of the author(s) concerned. With regard to this, it is not necessary that all the other authors share the same opinion. Further, we should point out that the remarks made against a particular patient population mean that this point has been covered in the relevant chapter. It may be the case that the remark also applies to the other patient populations even though this has not been explicitly stated in the chapter concerned. Finally, we would like to point out that in this final chapter, we do not make new referrals to the relevant literature as underlying support for the arguments, as this has already been done in the relevant chapters.

In paragraph 7.2, the authors first roughly look at the ten characteristics and compare the agreements and differences between the various patient populations. Subsequently, in paragraph 7.3, a discussion of this comparison follows in which conclusions are drawn. The chapter ends (paragraph 7.4) by considering the implementation of disease management programmes in the Dutch context.

7.2 The ten characteristics of disease management compared per patient population

From diagram 7.1, it is clear that the authors of the first four patient populations covered in this book consider that, with the help of criteria, it is possible to differentiate between clearly-defined patient populations and health problems. This point is also covered in the first few pages of their relative chapters. Regarding this, the authors point out that there is often a question of comorbidity and sometimes even multiple pathology: this is for example, often the case for patients with cystic fibrosis, diabetes, and depression. For palliative patients, although there is certainly a clearly-defined patient group i.e., patients who are all in the last phase of life, there is not a clearly-defined health problem.

For all of the five patient populations described, the methodological education of patients and the advancement of self-management is on the wish list (diagram 7.2). Although interesting and scientifically proven initiatives are named for all patient populations, widely-spread initiatives are not. In addition, the review article that formed the first source of this book,² emphasizes the need for patient education within the context of disease management.

It is interesting that the authors of the first four chapters consider the screening of risk-patients of great importance and that this should make up part of the disease management programme (diagram 7.3). However, they do not consider general population studies for cystic fibrosis, diabetes, and depression to be of any use. For palliative patients, there is a problem regarding early recognition which is significant for the other patient populations. This is mainly due to the fact that it is not easy to prepare people early for an impending death if the patient and the caregiver do not want to talk about the situation. All authors consider that for this characteristic, the encouragement of integration between the primary care and the secondary care levels are important in order to improve the efficacy and quality of care. For patients with depression, the relationship with occupational health care is of increasing importance.

Diagram 7.1: Characteristic 1 of disease management for the care of the five patient populations described: one health problem and aimed at a clearly-defined patient population or sub-population

Cystic fibrosis	A distinction between children and adult CF patients is advisable.
Diabetes	Separate programmes for patients with diabetes type I and type II is advisable.
Depression	DSM IV classification system is useful.
Heart failure	Clearly-defined criteria are available.
Palliative patients	Patients in a terminal phase; care is aimed at various types of patients, not only oncological patients.
General	For the first four patient populations, multipathology and secondary diagnoses occur. This is nearly always the case for palliative patients.

Diagram 7.2: Characteristic 2 of disease management for the care of the five patient populations described: methodological education and the advancement of self-management

Cystic fibrosis	Greatly significant for children with CF and their parents as well as for adult patients. Separate programmes for each phase of life are advisable.
Diabetes	Greatly significant; focus should particularly be on healthy lifestyle, treatment compliance and self-care.

Depression	Psycho-education and the enhancement of self-management are greatly significant. In addition, support towards family members. Written information is available.
Heart failure	Cardiac rehabilitation and the enhancement of self-management following a coronary are greatly significant.
Palliative patients	For dying at home the encouragement of self-management and education, especially to family members is advisable.
General	For all five groups, methodological education and the encouragement of self-management is still in its infancy.

Diagram 7.3 Characteristic 3 of disease management for the care of the five patient populations described: integration of the various parts of the care process including preventive interventions

Cystic fibrosis	Connections and contact between genetic screening, primary care services and CF centres are advisable.
Diabetes	Screening is advisable for the risk groups described as well as case-finding by general practitioners; should be aimed at the integration of primary and secondary care.
Depression	Selective and assessed prevention for the risk groups; close harmonization of primary and secondary care is advisable; primary care is the gatekeeper for the programme. Integration between mental health care and occupational health care services is advisable.
Heart failure	Screening for risk factors; encourage integration of primary care services and heart failure clinics.
Palliative patients	Encourage integration of the various care sectors; early preparation for the terminal phase remains difficult.
General	General prevention and lifestyle interventions should be kept out of the DM programmes; secondary prevention for risk groups and tertiary prevention should belong to disease management programme; for all five groups the focus should be on the encouragement of the integration of primary care and secondary care.

Numerous protocols and guidelines are available for the first four patient populations (diagram 7.4). Furthermore, for the care of patients who have both diabetes and depression, this material has been brought together and put into a multidisciplinary guideline. For this characteristic (4), the area of palliative care is again an exception: care for this group of people is difficult to standardize. However, there is a need for work agreements to be made between the various disciplines, for example, regarding the responsibilities concerning the care outside of office hours if the patient's condition suddenly deteriorates or if informal carers or home care technology fails.

The classification of patients into clinical pathways (diagram 7.5) occurs in all five groups. These pathways work with successive treatment steps, for example, for the groups diabetes, depression, and heart failure patients. In addition, other factors play a role such as the age (cystic fibrosis) of the patient, whether or not there are complications (diabetes) and the complexity of the care demand (palliative patients).

Diagram 7.4: Characteristic 4 of disease management for the care of the five patient populations described: disease management protocols that are based on evidence-based diagnostics and treatment

Cystic fibrosis	Many national and international protocols and standards are available. The complex protocols lead to the centralization of patient care.
Diabetes	NHG-recommendations and other guidelines. These have been brought together in the Dutch Guidelines for Diabetes of the Dutch Diabetes Federation.
Depression	Numerous standards, guidelines and protocols are available.
Heart failure	Numerous standards, guidelines and protocols are available.
Palliative patients	This kind of care is difficult to standardize; there is a need for work agreements on the responsibilities of doctors and nurses, for example, for care needed outside office hours.
General	For the first four patient populations many evidence-based protocols are available. These are not always adhered to in daily practice.

Diagram 7.5: Characteristic 5 of disease management for the care of the five patient populations described: classification of patients in clinical pathways based on sub-characteristics

Cystic fibrosis	The centres for CF have sub-programmes for both children and adult patients; part of the treatment can be carried out by paediatricians working in peripheral centres who have contact with the CF-centre. Heart/lung transplantations should be left out of the programme.
Diabetes	Differentiation should be made in the clinical pathways for patients with and without complications resulting from diabetes; clinical pathways in primary and secondary care should be linked up through work agreements.
Depression	There are three successive clinical pathways: 1. wait and monitor 2. treat in primary care and 3. refer to the specialized GGZ.
Heart failure	The clinical pathways run through the heart failure clinics. Out of these are the flows to primary care and vice versa and to the clinic.
Palliative patients	Classification in clinical pathways is not possible.
General	It is possible for all five patient populations to distinguish the clinical pathways according to the sub-type of patients, according to the complexity of the given care and according to the phase of the disease process.

Nurses play a considerable role in the integration of care for all five groups of patients. This leads to substitution of care or, in other words, a reallocation of tasks from physicians to nurses (diagram 7.6) although the physician remains important for diagnostics, treatment adjustment and medication policy. The delegation of tasks to nurse specialists has only been proved to be effective for specifically defined groups of patients and for standard health problems.

The application of modern information and communication technology for the specific patient groups is a well-awaited occurrence on the part of the authors (diagram 7.7). They argue in favour of common digital care records, and also for the tele-monitoring of patients

at home (coronary patients, depressed patients) as well as for the possibility for primary care professionals to access an interactive Internet site (e.g. for palliative patients) through telephone contact or Web-based technology for consultation.

Diagram 7.6: Characteristic 6 of disease management for the care of the five patient populations described: substitution of care from doctors to nurses

Cystic fibrosis	Gradually, CF nurses in the Netherlands are extending their tasks from patient education and training to also include medical-technical interventions.
Diabetes	Practice nurses and diabetes nurses play an increasingly bigger role; the general practitioner remains a key figure holding final responsibility; the deployment of nurse case-managers and nurse specialists does not seem to hold added value.
Depression	Social-psychiatric nurses play a large part as treating professional and case-manager; medication regimes largely remain a task for the physician.
Heart failure	Nurses play a large part in the heart failure clinics.
Palliative patients	Nurses play a large part; the physician remains a key figure.
General	The role of the nurse is reinforced for all five groups whilst the role of the physician remains important.

Diagram 7.7: Characteristic 7 of disease management for the care of the five patient populations described: use of modern information and communication technology

Cystic fibrosis	A digital care record is greatly significant for preventive interventions, diagnostics and therapy.
Diabetes	A digital care record is greatly significant for preventive interventions, diagnostics and therapy.
Depression	A digital care record is of great importance for diagnostics; monitoring patients through telephone contact by nurses is a promising possibility.
Heart failure	A digital care record is greatly significant for diagnostics and therapy. Tele-monitoring with Health Buddies appears to be a promising possibility. Separate ICT for emergency care is recommended.
Palliative patients	A digital care record is greatly significant as well as the possibility for consulting a helpdesk by telephone or with digital means.
General	A digital care record is advisable for all five groups. The application of such dossiers is still limited. The possibilities for tele-monitoring and consultations with experts through telephone contact or digital means need to be expanded.

The authors consider the aspects of feedback to patients, care providers and policy-makers on the basis of bundled, statistical information to be very important for the first four patient populations (diagram 7.8). On this point, we are concerned both with clinical outcome measures as with business indicators of the clinical pathways and other care processes. It is

not, however, clear whether or not this should always be done through external benchmarking. Benchmarking, is not, for example, suitable for palliative care. Here the processes per patient are too varied for valuable comparisons to take place. Critical reflections and systems of quality safeguarding are more suitable for this purpose.

The authors hold different opinions on the question concerning robust organizational structures (diagram 7.9). All authors argue in favour of *unity of policy*, *combining expertise* and *compulsory collaboration*. However, there is no consensus on whether or not this will lead to separate centres, such as is the case with CF patients. A formalized, compulsory network organization of small-scale care units within a large-scale administrative setting, such as the diabetes services currently working in a few areas of the Netherlands, is preferable. Regional care programmes that are in place in more than one location but work with a clear unity of policy are already in operation in the GGZ. The idea of robust organizations for palliative care has been completely rejected. These would, after all, repel the necessary input of social organizations and individual citizens.

Arguments in favour of central funding (diagram 7.10) based on just one financial source, such as the new basic healthcare insurance policy, appear in the chapters on cystic fibrosis and palliative care. The authors emphasize the necessity for financial incentives in the chapters on cardiac failure and depression. These incentives are needed in order to stimulate the care providers to improve both the quality and efficacy of the care. Perhaps funding on the basis of the transmural or non-transmural Diagnosis and Treatment Combinations (DTCs) will stimulate working with disease management programmes; this, at least can be derived from the chapters on cystic fibrosis, diabetes and depression. As far as the necessity for central steering is concerned, the authors have made some comments that can be found in the accompanying text for diagram 7.9.

Diagram 7.8: Characteristic 8 of disease management for the care of the five patient populations described: focus on the use of a range of management instruments such as information based on benchmarking and feedback

Cystic fibrosis	A businesslike comparison of the CF-centres is advisable although competition between the centres makes this difficult.
Diabetes	Benchmarking is still in its infancy and only takes place sporadically; it is important to take measurements with a wide range of clinical outcomes and indicators for the care processes.
Depression	Numerous clinical process indicators and outcome measures are available but are either not or hardly ever used.
Heart failure	Although it is absolutely essential to compare operational figures, this does not happen.
Palliative patients	Although benchmarking is not advisable, critical reflection and feedback is.
General	Statistical feedback on the operational processes is considered important for the first four groups. This concerns both clinical outcome measures and process indicators. For palliative care, critical reflection and feedback is sufficient.

Diagram 7.9: Characteristic 9 of disease management for the care of the five patient populations described: large-scale and a robust organizational structure

Cystic fibrosis	The seven CF centres with an average of 200 patients each are on the small side when compared internationally; the centres are robust and are part of a large hospital.
Diabetes	Separate categorial diabetes centres such as those for CF patients are not advisable; network organizations such as regional diabetes services where the general practitioners play a central role are preferable.
Depression	Unity of policy for care providers and managers is more important than the presence of a robust organization.
Heart failure	Heart failure clinics are robustly organized and are part of a hospital. They should expand into becoming the central point of a network organization with branches reaching out to primary care and nursing homes.
Palliative patients	Robust organizations are not advisable: this would lessen the contribution of citizens and their organizations. Network organizations are of great importance and are already operating.
General	Different views exist on the robust organizational structure. Apparently there are different needs for each disease.

Diagram 7.10: Characteristic 10 of disease management for the care of the five patient populations described: direction and funding coming from a central point

Cystic fibrosis	It is advisable to fund all care for CF patients from basic healthcare insurance. Funding should not come from the separate sources of the AWBZ and basic healthcare insurance. Subcontracting of paediatricians in the periphery is advisable: they are then remunerated through the CF-centre.
Diabetes	Diabetes care in the Netherlands is relatively cheap. Care programmes initially lead to an increase in costs because of better treatment but this process is later reversed.
Depression	Financial incentives are advisable in order to work effectively and qualitatively higher. At present, these are totally absent. Perhaps DTCs will change this situation.
Heart failure	Favourable financial incentives for cardiologists are advisable. Savings made from fewer admissions and the number of nursing days should be reallocated within the programme.
Palliative patients	It is advisable to fund all care for palliative patients from basic healthcare insurance. Funding should not come from the separate sources of the AWBZ and basic healthcare insurance. Payment per function is advisable.
General	For all five groups, working with financial incentives in order to improve efficacy and quality should be supported. Exactly how these incentives will be developed is not yet clear. It is important that all care is funded from basic healthcare insurance and not partly from the AWBZ.

7.3 Discussion and conclusions

In this book, the authors for the five studied patient populations have explored the extent to which ten characteristics of the concept of disease management are advisable in the long-term for certain types of patient care. This information has been summarized for each characteristic and is laid out in the diagrams 7.1 to 7.10. With this task completed, the authors will now place their additional comments in a more opinionated manner.

1. It was possible to adhere to the ten characteristics of disease management in order to describe future care for the five patient populations covered. The authors did not have to make uncomfortable moves in order to discuss the characteristics: these were visible for all of the patient groups. Apart from the question of whether or not disease management programmes should come to the Netherlands, the aforementioned conclusion means that the concept of disease management and the ten characteristics can be considered as a conceptual framework for describing care plans for the future care of specific patient populations.
2. Disease management largely depends on the possibilities of describing a specific patient population that has a specific health problem as well as a specific approach. This is possible for the first four patient populations described but not for the group of palliative patients. The presence of this possibility means that it is also possible to standardize the care scientifically (characteristic 1), classify patients into clinical pathways (characteristic 5), use management instruments (characteristic 8) and provide some robustness and central steering to the organizational structure (characteristic 9). In contrast, these characteristics are considered to be either unadvisable or not possible for palliative patients. For these patients, managed care seems to be more appropriate than disease management. It is unimpeded that for this group, the other disease management characteristics are seen as advisable, e.g. encouraging methodological education (characteristic 2), integration of primary and secondary care services (characteristic 3), strengthening of the position of nurses (characteristic 6), improved exploitation of ICT (characteristic 7) and central funding from one financial source (characteristic 10). However, in future publications, the authors should not place a care programme for palliative patients under the flag of *disease management*: the presence of a specific health problem is a crucial aspect of such a classification. This conclusion also means that disease management programmes are not a solution for all kinds of care demands. A need remains for care that is not aimed at one specific patient category such as generalized primary care, emergency care provided by hospitals, front door programmes in the GGZ and also palliative care.
3. For those patient populations that do have a specific health problem, there is regularly a question of comorbidity, complications and intercurrent conditions. This means that care providers within a disease management programme regularly call on the help of care providers in primary and secondary care who have the necessary expertise that falls outside the specific domain of the programme. For this reason, the authors reject categorial and isolated disease management programmes (these are called out-carved in the American literature). Their position supports the concept of a programme that is embedded in or in-carved in the primary and secondary care levels.
4. The screening of risk groups, methodological education, enhancement of self-management and support of informal carers can easily be fitted into a disease management programme and linked up with the treatment of the patients concerned. In this respect, there appears to be a synergy. Whether or not this multimodal approach, i.e. the integrated and simultaneous supply of various interventions, is more effective than a collection of isolated interventions has not yet been determined. Some authors see one of the big advantages for disease management programmes in this synergy whilst others are more sceptical. In this respect, targeted research within the Dutch health care sector in the form of carefully set-up trials is desirable.
5. Although disease management programmes are served by evidence-based interventions, there is little knowledge supported by empirical evidence on the added value of such a programme in its entirety. Is the effectivity indeed larger

than that of a collection of isolated interventions as argued under point 4? In addition, the following point is significant here. Spreeuwenberg points out in the first chapter of this book that favourable outcomes from the United States are not necessarily favourable for the Netherlands. In the Netherlands there is already a good functioning primary care level working with NHG guidelines. This is not the case in the United States. This may mean that the added value of disease management as opposed to care-as-usual is greater in the US than in the Netherlands. This hypothesis has not, however, been studied. In addition, Rutten, in his discussion on diabetes care, points out that in the Netherlands this care is relatively cheap when compared to other countries. The implementation of disease management programmes for people with diabetes could, therefore, turn out to be more expensive in the short-term than care-as-usual. This would be the case if screening in risk groups discovers more patients who would then cause extra costs to be incurred. On this point, it would be interesting to develop a new health care economics indicator for the Return on Investments as Spreeuwenberg described in chapter 1. This would concern measuring the long-term returns of the higher expenses (investments) within disease management programmes against the usual expenses incurred in the care-as-usual context. In 2006 a dissertation on this subject has been published by Lotte Steuten at the University of Maastricht.⁴ Ultimately, the disease management programmes will lead to costs related to the safeguarding of the integration and harmonization of the care provision. These costs relate to the aspects of: consultation, feedback, use of modern ICT and policy-making. Here we should ask ourselves whether these so-called extra transaction costs weigh up against an increased effectivity, due to the reduction of admissions and other efforts of paid care providers? Due to these hypotheses that have been proved in theory, the authors conclude that disease management is a promising concept although it has not yet been tested empirically.

6. From diagram 7.5, it is clear that the classification of patients into clinical pathways was possible and also advisable for the first four patient populations that were researched. The consequence of this is, however, that care providers also have to classify work according to patient flows. This means that, for example, a certain psychiatrist sees especially depressed patients while a specialist in internal medicine sees especially patients with diabetes. Also in the area of general practice, it seems that a limited differentiation within a large discipline is indicated. This would encourage the development of large, specific expertise and therefore the efficacy and quality of the care provision, as well as the job satisfaction of the care providers involved. This could however, also lead to the situation where some professionals consider the focus on a specific patient population or clinical pathway to be poorer and protest against this development. All things considered, there should be a weighing up of the gains concerning quality and efficacy on the one hand and professional job satisfaction on the other hand.
7. At the beginning of this book project, the authors expected disease management programmes to lead to the possibility of a large degree of substitution of care from physicians to nurses. Diagram 7.6 shows that the position of nurses has become stronger. What is striking from the descriptions per chapter is that the leading role of the physician for diagnostics, adjustment of treatment and medication for non-standardized health care problems remains the same. The added value of nurse specialists and case managers who are largely responsible for all care provision does not come forward in the Cochrane reviews as Rutten has shown in his chapter. None of the authors argue in favour for the trial of such functions in the Netherlands.
8. Diagram 7.7 shows that the use of digital, web-based files, Health Buddies, telephone monitoring, telephone consultations and interactive websites is useful to disease management programmes. However, first it has to become clear for each programme exactly what these carriers of information contain in terms of professional information as well as who can use them and who is responsible for any consequences towards patients on either correct or incorrect information. The files named are, for example, to regulate authorizations: who has access to which part of which file? Health Buddies and telephone monitoring can provide

continuous information on the health of the patient concerned and is delivered to nurses. How should this information be interpreted? When should professionals decide to contact or not to contact the patient? Also, if telephone consultations or interactive websites are a possibility, who should use them? Just the professionals? Just the patients? And how can the helpdesk regulate queries and advice so that it stays with the main treating professional? Care providers within disease management programmes will have to answer these questions first before going on to build websites or consult web-based technology experts. In all, there are more opportunities for the application of modern ICT within a disease management programme than in the context of care-as-usual. This is due to the fact that care providers within a disease management programme are united in the same programme.

9. The authors have doubts about the use of benchmarking (diagram 7.8). On the one hand, it seems to be a good idea to compare disease management programmes for such factors as outcome measures, process indicators, patient satisfaction and costs. Learning organizations can take over much new knowledge and solutions from each other from benchmarking. On the other hand, the results of benchmarking are not encouraging in a number of care sectors. For the sectors of home care, youth health care, and the health and safety services, the emphasis was put on the comparison of costs and time-spending of professionals. The aspects of clinical outcome measures and patient satisfaction studies seem largely to have disappeared from view. Terms such as *stopwatch nurses, every hour must be billed, working on a time contingent, and consultation maximization* became trendy. If this is the result of benchmarking and other business management techniques in disease management programmes, then these overshoot the objective regarding the advancement of quality and efficacy.
10. As far as robust organizational structure, central steering, and central funding of disease management programmes is concerned, a few comments on the information in diagrams 7.9 and 7.10 have already been made: the preference is for formalized network organizations. The attractive thing concerning this for each patient population is that they were derived from the described clinical procedures, the care needs of the patients concerned and the most individually tailored care supply. Arguing from this starting point, the wishes on structuring, steering and funding came to the forefront. With this line of argument the authors link up with the old principle of organizational theory: *structure follows strategy*. This line of thought is also implicitly contained in the order of the ten characteristics of disease management programmes: the first characteristic concerns the clearly-defined disease and the last the steering and funding.

The authors chose for the steering of disease management programmes to be done by professionals and their managers in network organizations and not for steering by health care insurers and the pharmaceutical industry such as is the case in the United States. The arguments in favour of this choice are that this steering requires a specific mission and competence as well as close contact with the specific patient care. In addition, steering carried out by the health care insurers and/or pharmaceutical industries, however well intended, cannot really be suitably envisaged in the Dutch context. In the Netherlands, non-profit organizations have always felt responsible for the accessibility, quality, and efficacy of care processes.

Now that the content of diagrams 7.1 through 7.10 has been discussed and the relevant comments thereover, the research question should be clearly and succinctly answered. The question remains as follows: *Is it advisable for the ten characteristics of the American concept of disease management to be applied in the long term to patient care in the Netherlands?* The short and concise answer to this question is: yes, this is advisable. Here we refer to the realization of care as a result of collaboration and harmonization, given either simultaneously or successively and containing the ten above-named characteristics. In addition, the comments made in this chapter should be taken into account. We are not talking about simply copying the American models of disease management programmes. The art of the matter is to develop these programmes in the Netherlands with respect for what is already in place and fitting for the developing Dutch context. This part of the implementation will be addressed in the following paragraph.

7.4 The realization of disease management programmes in the Netherlands

Recently two of the authors of this book published reviews on the daily practice of the implementation of transmural care⁵ and on the theories that explain the speed of the dissemination of health care innovations.⁶ In order to avoid a situation of self-plagiarism, we will only briefly describe how the development and dissemination of disease management programmes could take place in the Netherlands without going into too much explicit theoretical argument.

The first point to be considered is whether or not patients, their families and informal carers, as well as their representatives in patient organizations, positively value a transfer of care from traditional methods to care that is given according to the characteristics of disease management. They will have to notice differences: that the course of disease is slower, causes less problems, is more manageable, and that their quality of life improves. Without the support of patients in the broadest sense, disease management programmes will not stand a chance.

The same applies to the care providers. Changing over the style of care will mean coping with a big change. For these reasons, a realistic time path for implementation must be adhered to. It is also necessary for policy-makers and managing professionals to have a sense of urgency and know how to convey this to others. If all those involved in care-as-usual think that it is working well, then we should ask ourselves, in view of all the ifs and buts, if it is really necessary to change. It may sound strange to say the following but, in order to get disease management off the ground, care providers and policy-makers need to have the feeling that there is something wrong with the system as it is and therefore, that change is necessary. This has worked in the GGZ sector. Outside influences worked strongly on ensuring that care programmes became a concept that is now widely accepted in mental health care.

It is also unavoidable that a change such as that towards disease management programmes will be accompanied by confusion, chaos, differences of opinion, directional conflicts and conflicts of interest. Whether or not a change amidst such a turbulent environment can book success, is largely dependent on the powers of persuasion and the strategical and tactical insight of professional initiators and project leaders of new disease management programmes. Initially, it would be wise to concentrate on those areas that hold the most chance of success and to fully make use of experiments and pilot projects.

On this point, strategic policy and vision of the Boards of Management of care institutions and of the Boards of professional organizations who help support and steer the development of disease management programmes is essential. The point here is to have good leaders who are strongly motivated and carry a long-term vision with them in which they strongly believe. Such leadership is necessary but does not provide guaranteed success. The extent to which care and professional organizations will finally go in the restructuring of care depends not only on the need for such change but also on other things. These cover the aspects of structure, capacity, and culture of the individual organizations as well as the presence of support coming from patients, mass media and government. Large-scale mergers, reorganizations and legislated obligatory (due to the so-called Big Bang Reforms) re-allocation of tasks, exercise of power, and registrations slow down the emergence of disease management programmes.

Eichert et al.⁷ summarize the necessary process for the implementation of American disease management programmes into eight steps as follows:

- the formulation of a common vision by all interested parties (stakeholders) on the mission and the aim of the programme
- charting and understanding the actual situation; in order to achieve results, there has to be a good understanding of the situation as it was before the change
- development of insight into the changes that people want to achieve through the programme; this will enable a vision of the difference between the present and future situation to be formed
- identify the chances and threats for the change, chart the barriers for successful change carefully; here we should think about competence problems, badly functioning

information systems, financial hurdles, personal differences of opinion and other communication problems

- chart the strategic options for calculating the objectives and set priorities accordingly
- identify the options that hold the most chance of success and are the quickest, or those with the least amount of problems which will lead to results
- determine which results will be judged and how these results will be measured
- continually adjust the strategic plan according to the experience gained, be flexible enough to sufficiently adjust without losing sight of the strategic aims.

Eichert et al. have worked out these steps in detail and applied them to fit the concept of disease management.

The fact that there is a hesitancy to begin the development of disease management is not only due to the changing position of the physician in disease management but also to the complications of applying all ten characteristics to the care system as well as the uncertainty of the future position of the health care insurers in the system. A few things have been said on the point of change management in connection with the Eichert model.

The current system of basic health insurance is characterized as being a hotchpotch of a number of organizations that vary in function, size, funding and culture. Any changes made to such a system require vision, leadership, strategic insight and funding in order to realize the change. And above all: a high degree of guarantee that the change to the structure will be cost-effective. In particular, the role and position of the care given by general practitioners and home care professionals as opposed to hospital care will have to be thought about carefully. Hospital care and specialized care are still considered as identical; but shouldn't the care for large groups of chronically ill people require a different organization than this? In this respect, the position of the health care insurers will be an interesting one. Will they restrict themselves to the direction and monitoring of the delivery of quality according to the agreed price, or will they interfere actively with the actual care provision? A number of health care insurers is leaning towards the last of these two options, forced by market deliberations, the necessity for cost control, and the inability of care providers to reorganize their care supply. The authors of this book do not argue in favour of disease management programmes that are directed by a health care insurer. Health care insurers who are inspiring to do this have to realize that the direction of care also requires direct dealing and contact with the patients themselves and that central steering rather limits than enlarges the freedom of choice of patients.

Although it seems as if the future is lying in the hands of the health care insurers, enough space remains for the care providers to work on and develop disease management. In the meantime, insurers also know that they run risks if the functions and tasks of insurers and care providers get mixed up together. A number of insurers are rightly challenging the care providers on these points. The care providers can accept the challenge by putting their own house in order, taking care of transparency and negotiating with the insurer on the organization, funding and guarantee of quality of care provision against a reasonable price in which all relevant aspects of disease management are clearly demonstrated. The question will be whether the care providers will wait for the initiatives of third parties such as insurers or whether, just as the American colleague from the Mayo Clinic, will anticipate the coming developments and organize their own disease management programme.

The step-by-step development of care for people with prevalent chronic disorders by the means of disease management programmes cannot be brought about without the facilitating policy of the government. Their task is to ensure that the preconditions such as training, necessary research, the health insurance package, and the insurance criteria, the qualifications according to the BIG law and the WGBO, the right to prescribe medication and the funding of the care are adhered to.

Although at present we cannot see whether or not disease management will lead to cheaper care in the short-term, the authors are convinced that the concept of disease management programmes must be experimented with in the Netherlands. At the very least, the so-called Returns on Investments are very promising for the long-term prospect.

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APPENDIX I List of Abbreviations

AD	Antidepressants
ADA	American Diabetes Association
AGS	Androgenital syndrome
AMC	University Medical Centre Amsterdam
AWBZ	Exceptional Medical Expenses Act
BIG	Individual Health Care Professions Act
CAU	Care as Usual
CBO	Dutch Institute for Healthcare Improvement
CC(P)	Collaborative Care (Programme)
CF(F)	Cystic Fibrosis (Foundation)
CG	Council for the Chronically Ill and Disabled
CGT	Cognitive Behavioural Therapy
CHOP	Children's Hospital of Philadelphia
CHT	Congenital Hypothyroidism
CM	Case Manager
COPD	Chronic Obstructive Pulmonary Disease
COPZ	Centre for the Development of Palliative Care
CT	Cognitive Therapy
CVA	Cerebral Vascular Accident
DBC	Diagnosis and Treatment Combination
DCS	Depression Clinical Specialist
DM	Disease Management
DMAA	Disease Management Association of America
DSM	Diagnostic and Statistical Manual of Mental Disorders
EADV	First Association of Diabetes Nurses
EBM	Evidence-based Medicine
ECG	Electrocardiogram
ECT	Electro-convulsive Therapy
EMCR	Erasmus Medical Centre Rotterdam
EPD	Electronic patient file
GGZ	Mental Health Care
HMO	Health Maintenance Organization
HTA	Health Technology Assessment
ICT	Information and Communication Technology
IKC	Comprehensive Cancer Centre
IPT	Interpersonal Psychotherapy
IPTG	Interpersonal Group Psychotherapy
KITZ	Institute for Quality and Applied Home Care Innovation
KNO	Ear Nose and Throat

MRSA	Methicillin Resistant Staphylococcus Aureus
NCFS	Dutch Cystic Fibrosis Foundation
NDF	Dutch Diabetes Federation
NHG	Dutch College of General Practitioners
NRV	National Council for Public Health
NYHA	New York Heart Association
PIH	Project Group for the Integration of Hospice Care
PKU	Phenylketonuria
PST	Problem Solving Therapy
RCT	Randomized Clinical Trial
ROI	Return On Investment
SPV	Social Psychiatric Nurse
STG	Health Management Forum
TIA	Transient Ischaemic Attack
UMCG	University Medical Centre Groningen
UMCU	University Medical Centre Utrecht
WGBO	Medical Treatment Agreement Act
WHO	World Health Organization
ZN	Sector Organization for Health Care Insurers in the Netherlands

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Marianne Acampo studied health sciences at the University of Maastricht and is a member of the Board of Directors of the Martini Hospital in Groningen. In 2003 she visited the locations of many disease management programmes in the United States.

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