

Is everyone with a chronic disease also chronically ill?

by

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Abstract

Caring for chronic patients is a major challenge for society in the Western world. All governments are introducing measures to benefit chronic patients. The question here is: what are chronic diseases and who is chronically ill?

A chronic disease in general practice is an episode of treatment for a defined disease that extends over a long period and is so serious that without treatment "ordinary" everyday activities for the patient's age and sex will be hindered by it to a significant extent and over a long period. The term "chronic" does not say anything about the seriousness of the condition or the stage of disease that has been reached: the patient might have diabetes mellitus which is effectively controlled by oral antidiabetics.

A chronic patient is a person with a chronic disease which has a major impact on the everyday activities which are normal for his/her age and sex.

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There are a number of important principles when it comes to taking measures and making decisions. 1. A positive approach must be taken to the care situation. The starting point should be self-reliance, not the need for care. The new International Classification of Functioning from the World Health Organisation is a useful starting point for this purpose. 2. Clear goals must be established. 3. These must be linked to the real need for care. 4. All this must be assessed on a multidisciplinary basis. 5. Re-evaluation over a period of time is necessary.

Keywords

Chronic disease, social security.

Introduction

Health care in the Western world developed at a time when acute diseases and problems were still very much the central focus of the assistance and care that was provided. As a result, a structural and regulatory framework has come into being which is very disease-oriented.

At present chronic diseases have become an important challenge for health care. Forecasts in the Netherlands show an expected increase over the next 20 years of 30 to 40% for cardiovascular conditions, Chronic Obstructive Pulmonary Disease (COPD), asthma and degenerative conditions such as arthrosis and dementia (1). A very large number of people is facing these problems. The social prevalence of chronic conditions is 52%: one out of every two patients who visit their GPs are either facing a chronic condition themselves or have a member of their households who is affected (2). The World Health Organisation (WHO) states that 24 million people per year, which is 50% of all deaths worldwide, die as a result of chronic conditions (3). Public authorities in Belgium are also struggling with this problem. The Federal Government stated in her declaration on 14 July 1999 and 17 October 2000 that patient contributions to medical costs will be lowered for chronic patients and that specific initiatives will be set up to improve the quality of care provided to chronic patients. However, a definition of chronic patients was not given.

Before society makes increasingly radical decisions concerning new reimbursements and benefits, it is important to know more about the impact of chronic disease. Choices also have to be made: how chronic diseases are defined, who is chronically ill, who awards the label "chronic disease/chronic patient" and what elements can and should be taken into account in any special benefits for these patients. That is what we will try to do in this essay.

The impact of chronic diseases

Chronic patients and chronic diseases are concepts that do not completely overlap. Psoriasis, cancer, hypertension, schizophrenia and dementia are chronic conditions. Psoriasis is a very common condition that can emerge at a very young age and mainly has an impact on the quality of life through esthetic and social limitations. It requires the chronic use of medication without otherwise making the patient very ill at all. Cancer is a condition which is often associated with a relatively short (survival) prognosis, for which the health care system is used to varying degrees. In many cases it has a very clear impact on the quality of life, often causing inactivity and a breakdown of the normal pattern of life. Nevertheless there are top athletes who overcome a malignancy and continue to achieve top-level performance (4). There is clearly a difference between the cost and reduction in quality of life for a well-controlled hypertension patient who takes one tablet a day or a young schizophrenic who sees a whole professional career vanishing before his eyes. The situation can also differ considerably for the same condition. A person with dementia at a certain stage of Alzheimer's disease who is living quietly with his/her partner has completely different care requirements to a demented neighbour who is living alone with the same stage of Alzheimer's disease. These examples demonstrate that there is no linear and unambiguous link between the presence of a condition that can be labelled as chronic on the one hand and the need for social support on the other¹. That contrasts with the image in the social debate and in the lay press according to which every person with a chronic complaint is in need of a high level of care and has to bear heavy financial costs.

Who labels?

With regard to chronic diseases and patients the question also arises of who is entitled to attribute this label. Doctors and patients, even if they come from the same social and cultural background, usually have different views of disease and health (5). The term "disease" is used to refer to an entity that has diagnostic and therapeutic significance for doctors. It is defined from the doctor's perspective. As a result of developments

¹ Social support refers to all interventions which are provided and/or reimbursed by society: medication, paramedical assistance, disability, integration and other benefits, day care, residential care (home for the elderly, nursing home), special training and employment programmes, home care etc.

in medical technology, diseases are increasingly defined by objective, demonstrable changes in the body. This increasingly gives rise to conflicts with the patient who feels ill in the absence of complaints that can be objectively ascertained. The term “illness” is defined from the patient’s perspective and refers to the patient’s feelings when he or she does not feel well. A person can feel ill without having a disease, and a person can also have a disease without feeling ill (e.g. hypertension). Finally, “sickness” is the usual way of expressing illness in the general population (5, 6). The same disease or symptom can be experienced and interpreted in completely different ways by two individuals. With the same degree of illness, two people can show completely different degrees of sickness.

We think labeling has to be done in an open dialogue between patients and health care professionals.

Defining chronic diseases

In a recent book on chronic diseases the authors stated that “(...) the term “chronic diseases” creates the image of a homogeneous and clearly defined category of patients. On closer investigation, however, there are very diverse conditions, with extremely divergent consequences in terms of the quality of life and the associated needs” (7).

In literature, chronic diseases are defined from various perspectives. We discuss four of them: using characteristics such as the duration of the condition, using consensus lists that have been produced, using (inter-)national and authoritative bodies or using the logic of certain classification systems.

2.1. Duration of the condition

In his doctoral thesis on chronic diseases, Voorn simply uses the duration of the condition as a basis (8). In the “International dictionary for general practice/family medicine” (WONCA), the term “chronic disease” is no longer used as such, but the emphasis is put on an “episode of treatment”: the period starting with the first contact in relation to a health problem or disease with a care provider (a general practitioner (GP) in this case) up to the last contact relating to the same problem. In the case of a relapse, a new episode begins. The progression over time can be defined as acute (an episode of disease lasting four weeks or less), sub-acute (an episode of disease lasting from four weeks to six months) or chronic (a period of six months or more).

2.2. "Common sense diagnosis" lists

According to Voorn, a second method is based on a decision that classifies conditions into lists. Very often the basis for this decision is extremely unclear and has more to do with "common sense", which is easier if sufficient vagueness and unclarity are allowed to remain. These are referred to as so-called "nosological" descriptions. One of the oldest lists is the English "E list" named after the English doctor Eimerl, who helped to design the list that is derived from the ICD-6. In current sickness and invalidity benefit regulations in Belgium², lists are used on the basis of medical systems (table 1) or on the basis of political or budgetary necessity in the context of a separate convention (table 2). These lists are in accordance with certain positions that are far from explicit but are based on the interaction between medical insights, societal, social and cultural developments. These lists can be misleading because they give the impression that chronic diseases can be

TABLE 1
Non-exhaustive list of chronic diseases drawn up by RIZIV/INAMI

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1. Heart and vessel diseases in a chronic phase (cardiac failure attending heart transplantation)
 2. Asthma, Chronic Obstructive Pulmonary Disease
 3. Chronic diseases of the alimentary tract
 4. Chronic endocrinological disease (diabetes, Addison, ...)
 5. Chronic and progressive osteo-articular diseases (osteogenesis imperfecta, spondylarthritis, rheumatoid polyarthritis)
 6. Neoplastic disorders and metastases
 7. Chronic renal disorders requiring dialysis
 8. Urologic diseases
 9. Neurologic diseases: vascular, degenerative, narcolepsy, epilepsy, dementia
 10. Chronic infectious diseases (tuberculosis, malaria, AIDS, ...)
 11. Chronic dermatologic disorders (psoriasis, eczema, ...)
 12. Mental disease (autism, psychosis, depression, chronic anxiety)
 13. Dental injuries
 14. Chronic Ear-Nose-Throat disorders (deafness, speech disturbances)
 15. Chronic eye diseases
 16. Chronic hematologic disorders
 17. Transpathologic condition with mixed causes (chronic pain, Chronic Fatigue Syndrome, incontinence)
 18. Progressive disorders causing invalidity and requiring a need for care for more than six months.
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² In Belgium these rules are provided by the national institute of health insurance abbreviated as RIZIV(Dutch)/INAMI(French). Further on in this text we will mark "RIZIV/INAMI".

TABLE 2
List of diseases with specific RIZIV/INAMI conventions

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- A. Mucoviscidosis
 - B. Neuromusculair disorders
 - C. Muscular dystrophy and subsets
 - D. Rare hereditary monogenetic metabolic disorders
 - a. Amino-acidopathy
 - b. Other organic acidopathies
 - c. Disorders of carbo-hydrate metabolism
 - d. Disorders of the mitochondrial metabolism
 - e. Smith-Lemli-Opitz syndrome
 - f. Adrenoleukodystrophy
 - g. Refsum's disease
-

unambiguously defined, that there is a direct link between the disease and the need for care and social support and because they give rise to lobbying activity of patients' and other associations, hoping that official recognition of their chronic disease will solve their care-related and financial problems.

2.3. Authoritative organisations and national and/or international reports

An organisation which undeniably has considerable authority, the World Health Organisation, devoted its 1997 annual report entirely to chronic conditions. Remarkably, even there no definition of chronic conditions was provided (3); only a list of categories of conditions with varying duration and impact was drawn up (table 3).

TABLE 3
Categories of diseases listed in the WHO report on chronic diseases

-
- Cancer
 - Cardiovascular disorders
 - Chronic Obstructive Pulmonary Disease
 - Metabolic disorders
 - Genetic disorders and birth defects
 - Musculo-skeletal disorders
 - Mental and neurologic disorders
 - Disorders caused by risky behaviour (e.g. violence, suicide)
 - Visual disorders
 - Hearing deficits
 - Mouth diseases
-

Let us take a critical look at the most recent and very comprehensive definition of chronic diseases in the report of the scientific council of the RIZIV/INAMI (8 May 2000). The official version gives the following definition of chronic diseases (translated): *Chronic diseases correspond to a general clinical condition of variable duration (“period of disease”) following the initial diagnosis of the condition and appropriate acute treatment or often irreversible changes that arise in the context of the specific pathology of these diseases. This condition is characterised by local and/or general symptoms that develop slowly or, in some cases, not at all, and that are linked to the disease or the consequences of treatment, that are often similar or even identical regardless of the diversity of the original diseases. Without appropriate additional treatment and/or compensation for the deficiencies (“limitations”³), this period of disease results in a reduction of both quality of life and the autonomy of patients, and also a change in their social status (social handicaps*). Even where purely bodily and metabolic conditions are concerned, all persons with a chronic condition show associated psychological symptoms to varying degrees.*

In the majority of cases chronic diseases require a complex, multi-disciplinary and long-term treatment, in which various medical specialisms and paramedical professions play a part.

The social economic consequences are variable and the chronic patients in question may need supervision and treatment for the rest of their lives.

This definition seeks to describe a very large number of aspects. It is still not unambiguous and is therefore confusing for several reasons.

- What is understood by a “general clinical condition”? Are there no acute deteriorations of chronic conditions (e.g. multiple sclerosis)?
- A distinction is made between bodily and metabolic conditions. Are psychological symptoms therefore only to be understood as a subset of bodily conditions?
- What is understood by “supervision”: is it the need for the physical presence of a third person or does it refer to the need for medical monitoring?
- The terms “autonomy” and “quality of life” are open to interpretation (9). In this definition it is not clear what is meant by these terms (10).

³ Wood sequence: disease/condition → disorder → limitation → handicap.

- This definition also does not refer to the reference group: limitations and quality of life are interpreted differently by a young diabetes patient and an older diabetes patient. The reference to the so-called Wood sequence, which is now outdated, suggests a linear link between disease, condition, restriction and handicap.
- The definition also fails to indicate the impact of the seriousness or stage of the disease on the limitations and handicaps the person in question is facing.
- The lack of clarity is demonstrated by the fact that mild essential hypertension does not fit in with this definition and is still included on the associated non-exhaustive list. So on the basis of which criteria has this list been drawn up?
- In its pragmatic implementation work, the RIZIV/INAMI gets bogged down with the definition and therefore often makes its decision on an “ad hoc” basis. Hence influenza vaccine is reimbursable for patients with “chronic conditions”. These conditions are defined as follows: cardiac, pulmonary or renal conditions, diabetes, haemoglobinopathy, immunodepression or situations that make people particularly susceptible to complications of influenza. In these regulations a very broad view of the term “chronic disease” can be taken by the certifying doctor.

2.4. International system for the classification of diseases

The most widely used international classification of diseases, the ICD-10 classification, does not include a list of chronic conditions as such. The classification is subdivided into 21 chapters. No single chapter refers to “chronic diseases/conditions” as such. There are blocks in some chapters for chronic conditions (J-30-J-39: chronic conditions of the respiratory tract). Some conditions are also named “chronic” (e.g. I-25: chronic ischaemic cardiac disease). In the description of causes of death, chronic conditions that are a late consequence of a disease are mentioned. The term “late” means more than one year after the disease has arisen (e.g. E 64.3 Late consequences of rachitis).

Based on the International Classification of Primary Care (ICPC) (11), the classification system which is most widely used in first line care and which is supported by the WONCA, a clear definition has been developed (12): *A chronic disease in general practice is an episode of treatment for a defined disease that extends over a long period and is so serious that without treatment “ordinary” everyday activities for the patient’s age and sex will be hindered by it to a significant extent and over a long period. Once the hindrances have been alleviated or virtually eliminated by*

treatment, this treatment must be continuous and, in principle, regular medical care will be required. The care that is provided must, in addition to interventions directly linked to the progress of the disease, also cover the interventions aimed at the significance of the disease and the treatment associated with it for an individual patient.

The term “chronic” does not say anything about the seriousness of the disease and the stage that the disease has reached: it might be a patient with diabetes mellitus which is effectively controlled by oral antidiabetics.

Table 4 shows the list of conditions in the ICPC which can be “matched” to the stated definition of chronic conditions. This definition focuses on the activities referring to the age and/or reference group, the breaking of any assumed linear connection between condition, disorder and limitations, and the breaking of the link between the presence and seriousness of the disease and the stage that has been reached. It also makes room for significance and for total patient care.

If the aim is to define a chronic disease, it seems to us that the latter is most useful. However, are people who are suffering from a chronic disease as defined above therefore chronically ill?

TABLE 4
“Transitieproject”: list of chronic conditions

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- Malignant disorders
 - Perniciosa
 - Chronic enteritis/colitis ulcerosa
 - Blindness, all types
 - Rheumatoid arthritis, rheumatic heart disease
 - Myocardial infarction
 - Chronic ischemic heart disease
 - Heart failure
 - Non-rheumatisch vlave disease
 - Cerebro-vascular disease, exclusion stroke
 - Arteriosclerosis
 - Arthrosis
 - Multiple sclerosis
 - Parkinson’s disease
 - Epilepsy, all types
 - Psychoses, all types
 - Chronic bronchitis, bronchiectasis
 - Emphysema, Chronic Obstructive Pulmonary Disease
 - Asthma
 - Diabetes mellitus
-

Defining chronic patients

A number of attempts has been made recently to come up with operational descriptions of chronic patients. In 1998 the Belgian government issued a Royal Decree defining the standards that a chronic patient must meet in order to receive an annual lump sum of €247.89 (BEF 10,000) to compensate for extra expenses (table 5). This Royal Decree uses a dual basis for allocating the label "chronic patient": there must be a certain level of medical expenses combined – broadly speaking – with a certain degree of dependency. The limitations of this way of proceeding are that the patient contributions for pharmaceutical specialities are not counted and dependency is essentially narrowed down to its physical aspects. An initial evaluation by the largest sickfund in Belgium led to the conclusion that the lump sum for treatment does reach the right people, but is inadequate to cover the needs of these and other chronic patients (13). A large number of chronic patients is therefore not dependent on care but still has higher health care expenditure. In the first regulations concerning the General Medical File (GMF) held by GPs, the same stipulations were used to admit persons aged under 60 to the benefits of the

TABLE 5
Criteria Chronic Diseases
(Koninklijk Besluit-Arrêt Royal Chronic diseases, 1998, Belgium)

-
1. Patients with urinary incontinence are chronic patients if they receive a (financial) reimbursement depending on their "Kats" score (only for category score B or C) for a period of at least four out of twelve months and when score 3 or 4 is noticed for the item "incontinence".
 2. A person is chronically ill if he meets two of the following conditions at the same time:
 - a. The amount of the personal part of the medical fees exceeds more than 247,98 € during two consecutive years.
 - b. During the mentioned years the person is in one of the following situations
 - during at least three months forfait B or C (Katz), approved by the sick fund
 - approval for at least six months physiotherapy, approved by the sick fund as Category E
 - approval category III or IV "integratietegemoetkoming"
 - approval support for the elderly category II, III or IV
 - grant for "need of help by a third person"
 - approval for payment for invalidity for a person with the need of help by a third person (KB-AR 3.7.96)
 - approval for payment help by a third person (KB-AR 3.6.1996)
-

GMF. The recent Flemish Decree on “Vlaamse Zorgverzekering” is once again based on the principle that the degree of care that is needed, determines the receipt of a benefit.

In other words, this type of regulation takes on a life of its own and becomes so financially significant for some people that henceforward only adjustments are possible.

The Flemish Patients’ Platform has presented a proposal for defining chronic patients (not sickness): “A chronic patient is a person suffering from a condition which affects the person physically and/or psychologically, that may or may not be diagnostically defined, may entail long-term care and/or medical monitoring, causes visible and/or invisible limitations, offers no certainty or full or partial recovery, may have a progressive, fluctuating (= alternating) or stable course, may or may not lead to entire or partial loss of autonomy, causes a reduction in the quality of life and has serious consequences at the medical, and/or social, and/or financial level for the person involved and those around him”. Although this description is clearer than the previous one of the RIZIV/INAMI, there are still areas of unclarity. For example it is not clear what is understood by “diagnostically define”. Are only medical monitoring and care involved, or is self-care covered as well? We assume that the word “limitation” is understood in the sense of the International Classification of Impairments, Diseases and Handicaps (ICIDH) (14). Unclarity remains on the question whether priorities between different criteria (primary and secondary criteria, “and/and” hierarchy or “and/or”) have been defined. As early as 1979, Bachrach defined how the term “chronic psychiatric patient” should be understood (15): “people with a serious psychiatric condition and a long-term history of disease and whose condition has an impact on everyday life.”

There is no clear correlation between the presence of a disease in a person and the need for medical, paramedical or social assistance. In our minds, a person with a chronic disease becomes a patient from the moment he/she is hindered so seriously that ordinary everyday activities for the person’s age are inhibited. In other words, the impact of the disease on the life of the affected person is a crucial element.

Perspectives for the support of chronic patients

Defining whether or not a person has a chronic disease, is in most situations feasible. Assessing the impact however, is difficult. We present some starting points for this discussion.

4.1. *The real needs*

The real needs are far beyond the medical scope. They are situated in different areas (table 6). It goes without saying that this list is not limitative. It is equally clear that the elements summarised in it do interact in complex ways. While the diagnosis of the disease takes place within a medical frame of reference, the areas in which needs arise are situated in a much wider psychological, social and economic field.

TABLE 6
Non limitative list of elements causing need for care in chronic diseases

-
1. Autonomous functioning
 - a. In daily living
 - b. Professional
 - c. Mobility
 2. Supervision and Support
 - a. Need for support by family and friends
 - b. Need for supervision
 3. Health Care
 - a. Medical care
 - b. Paramedical care
 - c. Medication/drugs
 - d. Hospitalisation
 4. Social and financial support
 - a. Payments for invalidity, help by a third person
 - b. Training programmes
 5. Special resources
 - a. Prostheses
 - b. Special housing
 6. Quality of life
-

4.2. *Assessment and regulations must be based on a positive description*

An international development is under way in which is stated that it is essential to approach chronic conditions and their consequences on the basis of a positive description of "normal functioning". The WHO has done some important work in this area in recent years. A new international classification of human functioning has been developed, trans-

lated and validated: the International Classification of Functioning, Disability and Health, ICF for short (16) (<http://www.who.int/icidh/>). This frame of reference is intended to replace the outdated scheme of “disorders, limitations, handicaps” (17). They have worked out a system of classification which is based on bodily functions/structure, activities and participation and environmental factors. The ICF systematically classifies aspects of functional health which are linked to health problems such as a disease, condition, injury or trauma. One of the basic purposes behind this was to develop a classification which emphasises what people still can do (18). This is in line with the development and thinking surrounding the importance of rehabilitation, revalidation, the active welfare state and the shift from the deficit to the competency model. A social system that remunerates deficits and limitations causes the paradox of recognition: once they have been labelled with a certain chronic condition, patients are forced to remain in this situation in order to avoid losing certain forms of social recognition and certain payments. This sometimes has disastrous consequences, such as those described in the case of chronic fatigue syndrome (19). One concrete example of this paradigm shift is the new classification of people with a mental handicap (20). As a result of this classification, people with a mental handicap are seen primarily as citizens who can make a valuable contribution to their surroundings. Attention is no longer focused solely on their cognitive deficit, because the whole process of renewing the classification system is based on the belief that it should coincide with a social renewal away from negativism and disease and towards positivism and health.

4.3. Assessment and regulation in relation to the goals when recovery is no longer a possibility

When developing care and treatment plans for people with a chronic disease, the personal ambitions and goals that a person sets for himself must come first. Ten years ago Mold developed the concept of Goal Oriented Medical Care (21). Starting point is the goals that the person with a disease defines for his or her health. In order to be usable the goals must be expressed in the form of observable, measurable behaviours, so that it is possible to check whether the goals are achieved (22). The starting point in this model is not fighting the disease, but achieving the goals among which quality of life figures prominently. The development of the goals should ideally take place through a combined effort by the individual and the assistance providers involved, after estimating its ability to cope, its opportunities and resources.

4.4. Assessment and regulation on the basis of the real care requirement

When developing care for people with a chronic disease, highly differentiated measures must be used depending on the pathology and depending on the person's state of health and need for care. One example of this is the "social contribution". In this system the patient contribution towards medical care is regulated according to the medical and income situation of a person with a chronic disease. For persons with the same disease but less need for medical treatment and/or a better financial situation, the government does not necessarily have to provide extra intervention. Support for people with a chronic disease cannot only be determined by physical dependency on care. Many people with chronic diseases are not dependent on care but still have high levels of health care expenditure. Here, too, steps are taken in the right direction. Hence there are plans to extend the lump sum for care, which has hitherto only been available to persons dependent on care, to persons with frequent and/or long-term hospitalisations (13).

4.5. Assessment from a multidisciplinary perspective

The scope of the various areas in which a real need can arise presupposes a multidisciplinary approach. In addition to measures and interventions for the benefit of the patient itself, adjustments to the way health care is organised are equally important. Here we are thinking, for example, of financing methods that create sufficient incentives for co-operation between disciplines or for reducing the degree of dependency.

Conclusion

The government decides more and more about chronic patients and the possible benefits and provisions they should count on. In this essay we have expressed our concerns about the vagueness and the lack of clarity and the counter-productive effects this may have.

We have developed the idea that having a chronic disease as defined does not necessarily imply that a person is a chronic patient and is therefore entitled to medical and paramedical care and intervention. A person should have clear needs before that is the case. When making an assessment of these needs, which should be done on the basis of a positive frame of reference such as the ICF, it is necessary to take concrete goals into account which are developed in conjunction with or through consultation with the patient and the multidisciplinary offerings from care providers.

When implementing this in practice, in our opinion the following – interrelated – elements must be incorporated.

1. In the first instance, for a particular person with a chronic disease a *balance sheet* of their problems should be drawn up, together with an assessment of the opportunities for growth that still exist, looking for interventions that can at least stabilise the disease. A concrete and preferably multidisciplinary plan, in which the concept of goal-oriented medical care could be a starting point, must be developed. It is clear that the concrete procedure used in making such an assessment must be based on the nature and stage of the disease in question.
2. The consequence of this is that achieving predetermined goals must be made financially attractive. To this purpose, *processes of change* must be initiated on the basis of a positive reference framework (ICF).
3. One factor inherent in working with predetermined goals is that they need to be assessed and adjusted at regular *intervals*. Observation of developments is vital.

Starting from a social security system which is built on the basis of personal deficits, after the publication of the ICF and the underlying reference framework the time has now come for a change in the underlying mentality. This change must take place at every level: among policymakers, professionals working in the health care sector and patients. Is a sea change taking place? In its draft on the future set-up of “Integrated services for home care”, the federal government defines the objective of assessing “self-reliance”. Could it be that new concepts are gradually being given a chance?

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