Sabine Bährer-Kohler (Ed.)

Self Management of Chronic Disease

Alzheimer's Disease

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With 13 Figures and 13 Tables

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Preface

This book will support an issue as important as self-management of chronic diseases, especially AD, in finding its way into the daily life of patients and their caregivers as well as into treatment worldwide. It is written for healthcare professionals, aging researchers/scientists, patients with Alzheimer's disease and their caregivers, managers of eldercare facilities, public health authorities, umbrella organisations of Alzheimer associations, Alzheimer associations, health care administrators, health economists and government officials.

It is my pleasant duty to thank Merz Pharma (Schweiz) AG in Allschwil-Switzerland to purchase 40 copies of the book.

To finish this book, a long and sometimes arduous path had to be traveled. Now that it is over, I feel profoundly thankful towards all authors for participating in this project, particularly Eva Krebs-Roubicek, MD for her contribution, the three models on the cover of this book; and especially to Julie and Jean-Luc for their great understanding and loving assistance.

Sabine Bährer-Kohler, Editor of the book

Foreword

Alzheimer's disease is one of those diseases which is steadily increasing worldwide. Treating Alzheimer's disease is able to modify its course but does not yet cure it. Alzheimer's disease is an enormous challenge not only for the afflicted person but also for the relatives.

Many publications over recent years have described various topics related to Alzheimer's disease and means of coping with the condition. Coping concerns the way of dealing with the disease by relatives as well as by the afflicted person. Coping strategies can be considered as a part of self-management, as understood by the authors and editor of this book.

The topic of self-management has been described and introduced to the public by several authors in many different countries, for example by Prof. Lorig and her co-workers in the context of chronic diseases. In some of these publications training courses for self-management of chronic disease are described, as they are offered by different institutions. Only seldom these publications address Alzheimer's disease. This lack might be due to different reasons, for instance, directly related to the disease itself, as a consequence of cognitive decline. Another reason could be the doubt that a demented person could manage the disease, and if so, for how long and in which form? It is also questionable whether a relative can take over the role of an expert during the course of Alzheimer's disease.

The aim of self-management in chronic disease is to improve coping mechanisms. It concerns self-determination as well as acceptance by the environment, and includes all questions, problems and active adaptation to changing needs. It means also that during this difficult phase of life one should not just let go, but actively and endurably pursue own interests, manage the activities of daily life and the emergency situations.

Prof. Lorig has clearly documented that a chronic disease is manageable. Training courses concerning self-management in chronic disease can help towards this aim, to cope in a structured and informed way.

This book contains articles describing the work of authors from different professional backgrounds and different countries. The book begins with basic information about self-management, ageing and dementia. Further chapters are concerned with aspects of working with relatives and other caregivers in their care for demented persons. The authors discuss background thoughts as well as end-of-life care. They focus on worldwide used training programs for chronic disease in general, and particular self-management programs for patients suffering from the Alzheimer's disease and their relatives. The book does not avoid another important aspect, the economic situation and applicability of the presented programs. Implementation of such programs will be only possible, if aspects of efficacy and of economic efficiency are considered.

One can only wish that the topic of self-management, with the help of this book, will find its way into day-to-day clinical practice of caring for patients suffering from Alzheimer's disease and their relatives.

Prof. Dr. Franz Müller-Spahn

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Chronic Disease and Self-Management – Aspects of Cost Efficiency and Current Policies

Sabine Bährer-Kohler, Eva Krebs-Roubicek

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Introduction

The focus on self-management is not surprising. The burden of chronic disease worldwide is accompanied by a shift in health policy towards patient-centered care. And the world population is increasing, as seen in the World Population Prospects (2006; ◘ Table 1.1). World Population Prospects also provides figures for life expectancy at birth, in both sexes (◘ Table 1.2).

With regard to these figures, one has to consider that
- the worldwide population will increase and
- grow older at the same time.

As most of the chronic diseases and especially Alzheimer's disease are related to age, medicine will have to concern itself with the management of chronic diseases in the future.

Chronic Disease

Chronic disease is defined as a condition of long duration and generally slow progression. Chronic conditions, such as heart disease, stroke, cancer, chronic respiratory disease and diabetes, are by far the leading causes of mortality in the world, representing 60% of all causes of death (WHO 2008a).

Chronic diseases cannot be cured but may be controlled by the cumulative effect of medication, physical therapy, psychological and social support and therapeutic patient education; the term chronic disease is synonymous with long-term disease (WHO 1998).

The most frequent chronic conditions (WHO 1997) are:
- arterial hypertensive disease,
- cerebrovascular disease,
- Cohn's disease,
- diabetes mellitus,
- HIV/AIDS,
- tuberculosis,
- Alzheimer's disease,
- depression,
- osteoporosis,
- rheumatoid arthritis,
- epilepsy,
- multiple sclerosis,
- paraplegia,
- Parkinson's disease,
- bronchial asthma.

Chronic disease has a serious impact on day-to-day life and is highly onerous because it
- has major adverse effects on the quality of life of affected individuals,
- causes premature death and
- creates large and underappreciated adverse economic effects on families, communities and societies in general (WHO 2005).

◘ Table 1.1. World Population Prospects

Year	Population
2010	6.5 billion
2050	12 billion

◘ Table 1.2. Life expectancy at birth

Year of birth	Life expectancy [years]
2000–2005	66.0
2005–2010	67.2
2010–2015	68.5
2015–2020	69.8
2020–2025	70.9
2045–2050	75.4

Chronic Disease Worldwide

In the past 50 years chronic disease has become the number one in terms of both morbidity and mortality in the United States of America, accounting for three fourths of the total health care expenditure (The Robert Wood Johnson Foundation 2008).

From a projected total of 58 million deaths in 2005, chronic diseases will account for 35 million or 60% of all causes, which is double the number of deaths from all infectious diseases, maternal

and prenatal conditions and nutritional deficiencies combined (WHO 2005).

According to the World Health Organization's global health report, chronic conditions have dramatically increased everywhere, but particularly in the so-called industrialized countries. While in earlier times, acute illness was the main cause of morbidity and mortality, chronic health conditions have now taken that position. However, it seems that the longer people are living the more they are suffering from chronic diseases (Parker et al. 2007).

Even if chronic diseases occur in all countries in the world and affect women and men almost equally (WHO; Sing 2008), 80% of chronic-disease deaths occur in countries of low and middle income (WHO 2008b).

A relatively few risk factors – high cholesterol, high blood pressure, obesity, smoking and alcohol – cause the majority of chronic diseases. A change in dietary habits, physical activity and tobacco control might have a major impact on reducing the rates of these chronic diseases.

Heart attacks and strokes kill about 12 million people every year; another 3.9 million die from hypertensive and other heart conditions. More than one billion adults worldwide are overweight; at least 300 million of them are clinically obese. About 75% of cardiovascular disease can be attributed to the majority risks: high cholesterol, high blood pressure, low fruit and vegetable intake, inactive lifestyle and tobacco (WHO 2008c).

Moreover, current trends in Europe indicate that the proportion of the population over 65 will almost double by 2050, from 25.9% in 2010 to 50.4% in 2050 (Eurostat News Release 2008). Because of the increasing incidence of diabetes and the increasing prevalence of psychiatric disorders in old age, such as depression and dementia, as well as the shift of some chronic diseases to older age cohorts, a higher number of elderly people will require prolonged medical care and assistance for independent living.

As the incidence of chronic disease grows, so do its management costs. But it would be wrong to think that chronic diseases mainly affect old people. It is known that almost half of the chronic-disease deaths occur in younger persons under 70 years of age; one quarter of all chronic-disease deaths involve persons younger than 60 years (WHO 2005).

Several studies have been performed in Europe, e.g.:

Finland documented that the group (cohort) of the elderly over 80 will grow faster than that of 65–80 years. More than 90% of persons over 74 suffer from at least one disease that impairs their daily functioning (Valvanne et al. 1992).

Among 38.5 million inhabitants of *Poland* in 2008 there were almost 4 million patients with chronic diseases; 2,347,000 live in cities, 1,473,800 in the countryside. Approximately 600,000 suffer from dementia, including 250,000 Alzheimer's patients, and every year 300,000 to 400,000 persons are diagnosed with depression. There are 50,000 patients with diabetes type 1 and almost 2 millions with type 2. Additionally, there are patients with chronic cardiovascular disease, of which 100,000 suffer from myocardial infarction every year (Leszek 2007).

As far as *Romania* is concerned, there are no hard figures for chronic mental disorders. The statistical material contains no separate documentation for dementia and depression. But there are data from the Ministry of Health's National Information Center in Bucharest for 2006: of the 516,820 patients with diabetes, 73,388 are of type 1; 430,000 persons suffer from cardiovascular disease; 1,652,010 from high blood pressure; 263,140 from cerebrovascular diseases and 235,276 from chronic mental disorders. Romania is a developing country in Eastern Europe with a population of more than 22 millions (2008). The proportion of the national budget spent on the health system is 5.5%, and 2% of the total health budget is allocated to mental health (Statistical Department of the Ministry of Health 2007). 14% of the general population is over the age of 65. There are 192 physicians per 100,000, but only 40 psychiatrists for the same number of people (Tataru 2007).

For Switzerland (population 7.58 million in 2008), the following data were published in 2002 in % of the population older than 15 years (Swiss Health Interrogation, BFS; ◘ Table 1.3).

Germany has a population of 82.37 million in 2008. The epidemiological data from 2000 show

Table 1.3. Chronic diseases among the population of Switzerland

	Total	Male	Female
High blood pressure	**14.0**	13.6	14.3
Allergies	**10.0**	9.7	10.2
Rheumatic diseases	**8.5**	6.0	11.0
Depression	**5.0**	4.2	5.8
Dementia	**1.3**	0.4	0.8
Diabetes	**3.4**	3.9	2.9
Cancer	**2.7**	2.2	3.2
Myocardial infarction	**0.9**	1.2	0.7

935,000 patients with dementia, expected to rise to 1,165,000 and 1,415,000 patients by 2010 and 2020, respectively (German Federal Statistical Office). A survey conducted by the health administration in 1998 documented depression in 7.8% of women and in 4.8% of men. Total number of deaths due to chronic disease in Germany contains 748,000 (WHO 2008d).

For *Austria* a health statistic documented for 2008 almost 700,000 clients with chronic disease, 5.9% with diabetes and 21.3% with cardiovascular disease (Statistik.at 2008).

Diabetes

Estimates and projections suggest an epidemic expansion of diabetes incidence and prevalence all over the world. »The number of people who are dying due to diabetes are projected to rise by more than 50% in the next 10 years. Most notably, they are projected to increase by over 80% in upper-middle income countries. Type-2 diabetes is much more common than type-1 diabetes, and accounts for around 90% of all diabetes worldwide. Reports of type-2 diabetes in children – previously rare – have increased worldwide. In some countries, it accounts for almost half of newly diagnosed cases in children and adolescents. 80% of deaths in patients suffering from diabetes are now occurring in low- and middle-income countries. Lack of awareness about diabetes, combined with insufficient access to health services, can lead to complications such as blindness, amputation and kidney failure« (WHO 2008e).

To evaluate trends in type-1- and type-2 diabetes in seven European countries (Finland, Denmark, the UK, Germany, France, Spain, and Italy), a variety of information is available, including population-based studies on small or large cohorts of subjects representative of the general population in a particular country, European co-operative studies, and sales figures for insulin and oral hypoglycemic agents allow extrapolation of the number of pharmacologically treated diabetic patients (Sobngwi et al. 2002). The incidence of diabetes type 1 in young people is increasing in most European countries, as is its prevalence in all age groups. Diabetes type 2 is the major contributor to the epidemic rise in diabetes. From 1995 to 1999, the prevalence of type-2 diabetes increased considerably, particularly in the UK, Germany, and France. Costs of ambulatory and in-hospital diabetic care (including antidiabetic, antihypertensive, and hypolipidemic agents) have increased even more rapidly than the number of affected patients. Diabetes trends in Europe are alarming; healthcare professionals involved in diabetes care must be made aware of these detrimental trends, and healthcare provided for patients with diabetes must be improved (Diabetes/Metabolism Research Reviews 2002; 18 (Suppl 3): 3–8).

Cardiovascular Disease

In the 1970s, Finland had the world's highest rate of death caused by cardiovascular disease. A large-scale community-based intervention was started, involving consumers, schools, social and health services. Due to this intervention, death rates from heart disease in men have been reduced by at least 65%, (WHO 2005). On the other hand, Pajunen et al. (2004) documented that the number of hospitalizations due to unstable angina pectoris increased between 1991 and 1996 ($p = 0.0002$). However, it seems that the prevalence of cardiovascular disease is rather increasing because there is a transition of the disease to older cohorts.

Dementia

In a Delphi consensus study (Ferri et al. 2005) it was estimated that 24.3 million people worldwide are suffering from dementia today, with 4.6 million of new cases every year. ◘ Table 1.4 shows the number of people with dementia living in Europe using Ferri's prevalence rates on the basis of population statistics obtained from Eurostat (the official statistics office of the European Community).

The number of people affected is going to double every 20 years, estimated to 81.1 million by 2040. Rates of increase are not uniform; numbers in developed countries are forecast to increase by 100% between 2001 and 2040 (Ferri et al. 2005). Different numbers were presented by Takeda in 2007 at the IPA congress in Osaka concerning the epidemiology of dementia in 15 Asia-Pacific regions. He could show much higher increase; in 2005 13.7 million people suffered from dementia and the expectation for 2050 implies that 64.6 million people will suffer from dementia.

Alzheimer's Disease

The most common cause of dementia is Alzheimer's disease, a degenerative brain disorder named after the German physician Aloys Alzheimer, who first described the illness in 1906. Alzheimer's disease is a progressive and fatal brain disease with a lot of burden for the caregivers like documented in studies by Gruffydd et al. (2006) or by Papastavrou et al. (2007).

Self-Management of Chronic Disease

Self-management of a chronic disease is the ability of the patient to organize his life under the influence of the chronic illness (Thoesen Colman et al. 2005), to engage in activities and to use the knowledge how to protect and promote health. Defined as a therapeutic approach, it can be understood either as a systematic process of changing the lifestyle in that sense that the chronically ill patients and their caregivers are instructed in active self-control, including analysis of the state of their problems and concentrate on the target of the therapy (Kanfer et al. 1996), or as proactive self-management (Lorig 2000); to manage the situation on a day-to day basis with the following skills:

- problem-solving,
- decision-making,
- finding and utilizing resources,
- forming partnerships with your healthcare providers,
- taking action.

Self-management for people with chronic diseases is now widely recognized as a necessary part of any treatment which tries to improve the coping ability of patients and their caregivers (WHO 2005). Patient self-management as formulated

◘ **Table 1.4.** People with dementia in Europe

Country	Austria	Finland	Germany	Netherlands	Poland	Romania	Switzerland	Turkey
% of total population	1.15	1.13	1.22	1.02	0.79	0.79	1.2	0.11

by the California HealthCare Foundation 2008: »Around 90 percent of the care a person needs to manage a chronic disease must come directly from the patient. Evidence is growing that self-management interventions, such as self-monitoring and decision-making, lead not only to improvement in health outcomes and health status, but also to increased patient satisfaction and reduction in hospital and emergency room costs«.

The Chronic Disease Management Initiative in British Columbia 2008 documented concerning self-management: »Self-management helps people develop skills in maintaining and improving their own well-being and gain greater independence and confidence in dealing with the physical and emotional challenges of a long-term illness«.

Investing in prevention and improved control of non-communicable diseases will improve the quality of life and well-being of people and societies, says Dr. Marc Danzon, WHO Regional Director for Europe 2006 (Press Release EURO/05/06). Action needs to be scaled up now. The burden on people, societies and health systems is unsustainable. Effective interventions already exist, but not everyone can profit. The greatest potential for gain lies in scaling up prevention through better and more adequate health systems. If stronger health systems manage to eliminate such major risk factors as alcohol, tobacco, obesity, etc., it is estimated that 80% of heart disease, stroke and diabetes type 2, and 40% of cancer, could be avoided. WHO sees the prevention and management of chronic disease as an urgent primary health problem (WHO 2005). Next to prevention it is necessary to introduce self-management programs to enhance patient-professional partnership. A number of authors (e.g. Lorig 2000) repeatedly pointed out that neither the healthcare system nor the public health system has so far effectively dealt with these chronic conditions. The public health system has focused on prevention of health conditions but has not adequately dealt with the burden of chronic conditions related to the population. New models may help physicians guide families in facing complex decisions, systematically outlining steps starting with determination of the actual situation of the patient and trying to develop an outline for the further therapy steps (Goldstein et al. 2008).

While the traditional medical model is oriented towards the health condition and treatment options under study, the professionals are trained to diagnose the condition and prescribe treatment, often without considering the patients needs. Persons with a chronic condition may highly profit from learning how to deal with their condition with the aim to lead a life to the fullest capability in terms of well-being and performance. Thus the role of the patients has changed from a passive recipient of medical care to an active partner, trying to manage health condition and its implications for life in a more successful way.

This change in the patient's role is also related to a change in the role of the healthcare professionals. Their new task has been described as acting as consultant, interpreting symptoms, being a resource person, offering treatment suggestions and all in all providing a partnership that is focused on assisting the patient in achieving proactive self-management skills – with the expectation that these skills will help to improve the quality of life and to use the formal healthcare system appropriately (Holman et al. 2000).

In other words, patients have to take part in the decision-making processes regarding their care. The participants of the EACME Conference in Lisbon 2003 doubted the competence of the patients. They found that patients in chronic care, especially those with a chronic psychiatric disorder, seem often unable to reason and to judge their situation reasonably. This may lead to the exclusion of the patient from the decision-making process.

Self-management has been addressed first by Creer (1976); he worked with children suffering from asthma and was contemplating on how to ensure patients' active participation in treatment and management in the best way. Self-management tasks have been described in qualitative studies such as the study by Corbin and Strauss (1988) and Strauss and Corbin (1994), identifying three tasks, namely

1. Medical management of the condition in terms of patient's behaviors, such as medication intake, adherence to treatment regimen or using a specific treatment device.
2. Maintenance, change or creation of meaningful life roles, such as changing behavior patterns to