Bährer-Kohler (Ed.)

Self Management of Chronic Disease

Alzheimer's Disease

Springer

Sabine Bährer-Kohler (Ed.)

Self Management of Chronic Disease

Alzheimer's Disease

Sabine Bährer-Kohler (Ed.)

Self Management of Chronic Disease

Alzheimer's Disease

With 13 Figures and 13 Tables

Springer

Dr. Sabine Bährer-Kohler
Postfach 3244, 4002 Basel
SWITZERLAND

ISBN 978-3-642-00325-7 Springer Medizin Verlag Heidelberg

Bibliografische Information der Deutschen Bibliothek
The Deutsche Bibliothek lists this publication in Deutsche Nationalbibliographie;
detailed bibliographic data is available in the internet at http://dnb.ddb.de.

Springer Medizin Verlag
springer.com

Planning: Hanna Hensler-Fritton, Heidelberg
Projectmanagement: Ulrike Dächert, Heidelberg
Copy-Editing: Hilger Verlagsservice, Heidelberg
Design: deblik Berlin
Typesetting: TypoStudio Tobias Schaedla, Heidelberg
Printer: Stürtz GmbH, Würzburg

SPIN: 12626922

18/5135 – 5 4 3 2 1 0

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

Table of Content

List of Contributors

Editor:
Bährer-Kohler, Sabine Dr.
holder of a Doctorate in Social Science (rer.soc). – University of Tübingen, a Diploma in Education – University of Education – Freiburg, and a Diploma in Social Work and Social Education – Protestant University of Applied Sciences – Berlin.
Address: Postfach 3244, 4002 Basel,
SWITZERLAND
E-mail:
sabine.baehrer@datacomm.ch

Deliens, Luc Prof. Dr.
Professor of Public Health and Palliative Care
VU University Medical Center, EMGO Institute for Health and Care Research,
& Vrije Universiteit Brussel, End-of-life Care Research Group
Van der Boechorststraat 7
1081 BT Amsterdam
THE NETHERLANDS

Eloniemi-Sulkava, Ulla PhD, MHSc, R.N.
The Central Union for the Welfare of the Aged
Malmin kauppatie 26
00700 Helsinki
FINLAND

Ephraim-Oluwanuga, Olusola T. Dr. MBBS, MSc, FWACP
Consultant Psychiatrist
National Hospital
Abuja
NIGERIA

Greenblat, Cathy Professor
Emerita of Sociology,
Rutgers University
122, Boulevard Carnot
06300 Nice
FRANCE

Guillo-Ben Arous, Francoise MD
110 Bleecker Street 26D
New York, NY 10012
USA

Hemmeter, Ulrich MD, PhD
Kantonale Psychiatrische Dienste
St.Gallen, Sektor Nord
9500 Wil / SG
SWITZERLAND

Hintermann, Julia Lic.
Finkelerweg 62
4144 Arlesheim
SWITZERLAND

Icelli, Ilkin Prof. Dr.
Atatürk Caddesi 288 Güneş Apt.
Daire 2
Alsancak 35220
Izmir
TURKEY

Kalbermatten, Urs Prof. Dr.
Berner Fachhochschule
Hallerstr. 8
3001 Bern
SWITZERLAND

Karl, Dorothee Priv.-Doz. Dr.
Seckenheimerstr. 63
68165 Mannheim
GERMANY

Kiejna, Andrzej Prof. Dr
Department of Psychiatry
Wroclaw Medical University
Wybrzeże Ludwika Pasteura 10
50-367 Wroclaw
POLAND

Krebs-Roubicek, Eva MD
Praxis für Psychiatrie Rehalp
Forchstr. 364
8008 Zürich
SWITZERLAND

Kropiunigg, Ulrich Prof. Dr.
Institut für Medizinische Psychologie
Zentrum für Public Health der Medizinischen Universität Wien
Severingasse 9
1090 Wien
AUSTRIA

Kurz, Aleksander Prof. Dr.
Department of Psychiatry and Psychotherapy
Klinikum rechts der Isar
Technische Universität München (TUM)
Möhlstr. 26
81675 München
GERMANY

Leszek, Jerzy Prof. Dr.
Department of Psychiatry
Wroclaw Medical University
Pasteura 10
50-367 Wroclaw
POLAND

Milićević Kalašić, Aleksandra PhD, MD
Trnska 7
11000 Belgrade
SERBIA

Petrov, Ignat Prof. Dr.
Bulgarian Association on Ageing
Blvd. Vitosha 36
Sofia 1000
BULGARIA

Pitkälä, Kaisu Prof. Dr.
University of Helsinki
Department of General Practice
and Primary Health Care
PO BOX 41
00014 Helsinki
FINLAND

Professor Franz Müller-Spahn, MD
Medical Director
University Psychiatric Clinic
Wilhelm Klein-Strasse 27
CH-4025 Basel
SWITZERLAND

Roy Kuriakose, Jakob Dr.
ARDSI- Alzheimer's and Related
Disorders Society of India
P.B. NO. 53
Guruvayoor Road
Kunnamkulam – 680 503
Thrissur Dist, Kerala
INDIA

Saarenheimo, Marja PhD
The Central Union for the Welfare
of the Aged
Malmin kauppatie 26
00700 Helsinki
FINLAND

Tataru, Nicoleta MD
Senior Consultant Psychiatrist
Spitalul de Psihiatrie si pentru
Masuri de Siguranta Stei
Bihor District
ROMANIA

Van der Steen, Jenny PhD
VU University Medical Center,
EMGO Institute
Department of Nursing Home
Medicine and Department of
Public and Occupational Health
Van der Boechorststraat 7
1081 BT Amsterdam
THE NETHERLANDS

Yung-Jen, Yang MD
Section of Geriatric Psychiatry,
Department of Adult
Psychiatry, Tsao-Tun Psychiatric
Center
No. 161, Yu-Ping Road
Tsao-Tun Township,
Nan-Tou County
TAIWAN, 54246

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

Sabine Bährer-Kohler, Eva Krebs-Roubicek

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 cooperative 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

accommodate restrictions through the health condition.

3. Coping with the chronic condition in terms of dealing with emotional consequences of the condition.

These aspects relate to future perspectives, dealing with disease-related emotions such as anger, anxiety and depression which are frequently experienced by patients with a chronic disease.

According to the concept of Corbin and Strauss, self-management programs should thus include medical or behavioural aspects, role and emotion management. This comprehensive view of self-management is also helpful to evaluate existing chronic disease-management models which very often focus on only one or two of these three components. An important feature of self-management programs is that they should be based on perceived problems of the patient rather than on a health professional's view. In addition, not only is it important, what patients could do in terms of self-management, but how they could do it. It is important that key messages for self-management are formulated in a simple, clear and consistent way and those messages should also comply with current knowledge of the best clinical practice.

As far as decision-making on a day-to-day basis is concerned, it is important for the patient to learn how to make these decisions. This includes proper attention towards its own symptoms and behavior, but as well learning to identify situations, when action will be necessary.

A major challenge within self-management programs is how to make self-management effects to happen. While changing health behavior can be related to future health status, this is less the case in chronic conditions. For example, improvement in health behavior does not necessarily lead to improvement in health status of patients with chronic diseases. However, one major mechanism operating in self-management programs is the increase of self-efficiency. Self-efficiency can be defined as the belief in one's own capability to change the lifestyle, to comply towards certain behavior or to engage in a specific mode of action. According to Bandura (1977), enhanced self-efficiency beliefs can be expected to lead to improved behavior motivation, thinking patterns and emotional well-being. Therefore, not only motivation, but also self-efficiency beliefs seem to be an important factor for stringent engagement in and success of self-management processes. Self-management is closely connected with the context of social learning theory (Bandura 1979; Meichenbaum 1979; Kanfer 1977).

The studies performed by Lorig et al. (1999) could in fact show that increase in self-efficiency is associated with improved health status, especially if self-efficacy is present at the start of a program; future changes are more likely, self-efficiency and changes in health behavior are then related to change in health status. In her work she published with Holman, Lorig is stating, that perceived self-efficiency can increase the confidence to accomplish a particular goal (Holman and Lorig 2004).

Thus, the enhancement of self-efficiency is an important element of every self-management program and should be supported by examples, modeling, interpretation of symptoms and social persuasions. In addition, coping, social support and health locus of control can be seen as an important mediator for the impact of health condition.

Nevertheless, although a seemingly fundamental need for self-management is required, not all patients want an active role in disease management. The patient's willingness to participate should be assessed and strategies have to be adapted accordingly.

Aspects of New Approaches Towards Self-Management

The new approach towards management of chronic disease sees the patient as an expert, patients can become key decision-makers in the treatment process. By ensuring that knowledge of their condition is developed to a point of view where they are empowered to take some responsibility for their own management and work in partnership with their health and social care providers, patients can be given greater control over their lives.

Therefore self-management involves a person with chronic disease to engage in activities that protect and promote health, to monitor and manage symptoms and signs of illness, to manage the impact of illness on functions, emotions, interpersonal relationships and to adhere to treatment regimes.

Markwick et al. (2002) formulated the key components of self-management for »good« self-managers«:

1. Have knowledge of your condition.
2. Follow a treatment and care plan agreed with your health professionals.
3. Actively share in decision-making with health professionals.
4. Monitor and manage signs and symptoms of your condition.
5. Manage the impact of the condition on your physical, emotional and social life.
6. Adopt lifestyles that promote health.

Chronic disease self-management programs aim to support patients by providing information and teaching skills and techniques to improve self-care and also healthcare provider–patient interaction, with the ultimate goal of improving quality of life (Jordan et al. 2007).

Benefits of Self-Management

Several studies concerning chronic conditions like the following ones underline the importance of the evaluation of socio-economic factors.

Redman (2007). »Accountability for patient self-management of chronic conditions; ethical analysis and a proposal«. The author discusses the access to patient's self-management in high socio-economic classes and suggests development of a standard dataset to facilitate the description of the effectiveness of existing programs and comparison across programs.

Wheeler et al. (2003). »Can a disease self-management program reduce healthcare costs? The case study of older women with heart disease.« Wheeler and his group measured hospital admissions, inpatient days, emergency department visits for women with heart disease and found that a heart disease self-management program can reduce healthcare utilization and potentially yield monetary benefits of a health plan.

Bourbeau et al. (2006). »Economic benefits of self-management education in COPD«. The authors documented new programs of self-management and positive economic benefits with increased patient caseloads and rising costs of hospitalization.

Kennedy et al. (2004) for the North-West Regional Gastrointestinal Research. They analyzed socio-economic factors in a randomized controlled trial to assess the effectiveness and cost of a patient-oriented self-management approach to chronic inflammatory bowel disease.

Kennedy et al. (2007). They were able to document in a different study that lay-led self-care support groups are effective in improving self-efficacy and energy levels among patients with long-term conditions and that they are likely to be cost-effective over 6 months at conventional values of a decision-maker's willingness to pay. They concluded that this may be a useful addition to current services in the management of long-term conditions.

Richardson et al. (2008). The »Expert Patient Program« has been introduced in the USA and UK to over 30,000 patients. Those programs offer training and counseling of chronically ill patients and their families. The training is offered in small groups for two hours over 6–8 weeks. The following topics will be discussed:

- relaxation techniques,
- nourishment,
- exercise,
- coping with tiredness,
- coping with symptoms of the disease,
- use of medication,
- communication between patient and the professional helper.

The participants are learning to formulate realistic aims in coping with their conditions, and introduce them in their daily life. Six months later the majority of the participants in comparison with the waiting group could show higher convincement in the ability to cope with the illness. They could show higher vitality, drive and well-being, had better relationship with their medical doctors and higher ability in relaxation compared to the waiting group.

The Issue Brief Number 4 of the Center on an Aging Society at the Institute for HealthCare Research and Policy – Georgetown University January 2004 concerning disease-management programs (»Improving health while reducing costs?«) document:»Medicare beneficiaries in a diabetes management program improved many of their self-monitoring practices and used fewer inpatient services. Over a two-year period, the average monthly cost per participant was about 20 percent lower than per non-participant«.

Two years after enrolling in a disease management program for congestive heart failure, Florida Medicaid beneficiaries were monitoring their condition more closely and were spending fewer days in the hospital. The number of days spent in the hospital decreased by 39 percent over the two-year period, and healthcare expenditures for the 2500 beneficiaries decreased by 16 percent – a savings of $ 4.4 million of costs. Persons aged 40 and older, suffering from heart disease, lung disease, or arthritis enrolled in a six-month disease management program also used fewer healthcare services. Two years later, patients reported that they were feeling less distressed about their health and could manage their conditions in a better way. A reduction in outpatient visits, including emergency room and physician visits, and hospital stays reduced health care expenditures by 50% per participant over a period of two years«.

The medical service for the city of Zürich developed a program for the empowerment of chronically ill elderly under the name »AllFit«. The providers oriented themselves on the Chronic Disease Self-Management Program of the Stanford University. The results show, that 99% of the participants could formulate individual and realistic aims and that 80% could reach those aims during the program, which was running for one year (Wettstein et al. 2003).

Global studies (e.g. Lorig et al. 1999) show that chronic disease self-management can be very successful in maintaining, or even improving, the patient's health status, also because of the improved communication between patients and healthcare providers. Lorig et al. (2001) show in their analysis of the chronic disease self-management program during measurement over 2 years of health status and healthcare utilization, that the program can improve elements of health status while reducing healthcare costs in populations with various chronic diseases.

In 2008 the California HealthCare Foundation argues in the same direction: »Patient self-management aims to help improve chronic disease care and curb the escalating economic and public health impact of chronic illness. Due to daily decisions about diet, exercise, self-measurement and medications, people with chronic illness are encouraged to play the central role in determining the course of their diseases. However, to be successful, they need the support of their healthcare providers to make and sustain changes in these areas«.

Cost of Health

See ◘ Table 1.5 and ◘ Table 1.6: OECD Health Data 2008 and Eurostat 2008.

Aware of the rising costs and the burden of chronic disease, countries are taking a compre-

◘ **Table 1.5.** OECD Health Data 2008-Version: December 2008 and Eurostat 2008- total expenditure on health

	OECD 2006 [%]	**EUROSTAT 2008** [%]
Austria	10.1	10.2
Belgium	10.3	10.3
Canada	10.0	10.0
Finland	8.2	7.5
France	11.0	11.1
Germany	10.6	10.7
Poland	6.2	6.2
Sweden	9.2	9.1
Switzerland	11.3 e	11.6

E: Estimate

Table 1.6. Countries profile considering the expenditure on health (OECD Health Data 2008)

	Austria	Belgium	Canada	Finland	France	Germany	Poland	Switzerland	Turkey	USA
Hospital beds per 1000 population	7.6	6.7 b	–	6.9	7.2	8.3	6.5	3.5	2.7	3.2
Practising physicians Density per 1000 population (head counts)	3.6	4.0	2.1	2.7	3.4	3.5	2.2	3.8	1.6	2.4
Total expenditure on health/capita, US$ purchasing power parity	3606	3462	3678	2668	3449	3371	910	4311e	591 in 2005	6714

B: Break in series
E: Estimate

hensive approach. Non-communicable diseases challenge health systems, and absorb substantial amounts of resources as chronic conditions are estimated to account for 70–80% of healthcare expenses in Denmark and comprise 8 of the top 11 causes of hospital admissions in the United Kingdom. The economic impact of non-communicable diseases goes beyond the costs of health services. Indirect costs, such as those from lost of productivity, can match or exceed the direct costs. In addition, a significant proportion of the total costs of care has to be taken care of by the patients and their families. Non-communicable diseases were estimated to reduce the domestic product in the Russian Federation by 1% in 2005, with heart disease, stroke and diabetes causing an estimated loss of national income equivalent to US$ 11 billion. In the United States, the estimated total healthcare costs resulting from heart disease increased from US$ 298 billion in 2000, to US$ 329 billion in 2001 and US$ 352 billion in 2002 (American Heart Association 2001; WHO 2005).

The costs of chronic disease can be estimated in three ways:

1. accounting cost of illness,
2. economic growth models, which estimate the impact of chronic diseases on national income through variables such as labor supply and savings,
3. full-income method, which attempts to measure the welfare losses associated with ill-health in money terms.

The majority of published studies on costs of chronic disease have employed the accounting cost of illness method, which is not efficient enough (WHO 2005).

Current Legislation and Policies

In the following paragraphs chosen policies and legislation are described:

Health in *Europe*: a strategic approach in 2007 documented the latest developments concerning policies to build up the focus of strategy on core issues, on health in all aspects and in addressing global health issues. These three elements are also found within the proposal for a Program of Community Action in the Field of Health for 2007–2013, adopted by the EU commission in May 2006. Core issues are protection and improvement of health across the EU, as, for example, to improve prevention, to support citizens and patients, to provide easier access to healthcare services and to improve information for patients, to promote health and help to address key determinants (health in Europe).

In *Finland* the law for patient's rights clarifies the role of the patient to decide in its care process. The patient has the right to receive all relevant information concerning his disease, and to negotiate with physicians or other healthcare professionals about the options of care and the decisions concerning the care process. He has the right to decide whether or not he will receive the care recommended. Thus, he has a right to refuse the recommended care but not to command what care should be implemented.

In the *United Kingdom*, the White Paper of the Department of Health with the title »Saving lives: our healthier nation« was published in 1999. In 2001 its results expanded into a publication of the Department of Health in UK with the title »The expert patient«, implementing that the patients can become key decision-makers in the treatment process. Self-management programs can be specifically designed to reduce the severity of symptoms and to improve confidence, resourcefulness and self-efficacy.

A recent national evaluation of the Expert Patients Program examined disease-specific modules in areas such as diabetes, asthma, heart disease, epilepsy, chronic obstructive pulmonary disease and depression. The evaluation demonstrated the benefits of self-management for certain conditions. The Expert Patient Program is now taking forward the development of programs for other conditions such as substance misuse, learning disturbances and dementia.

The Ljubljana Charta on Reforming Health Care in 1996 recommends training in teamwork with multi-professional and interdisciplinary cooperation, a problem solving approach and active patient involvement in managing their chronic disease (WHO 1998).

Romania has a Mental Health Law which became effective in 2002 and a Hospital Law from 2004, which are regulating the healthcare system in a general perspective, but is not concerned about any specific chronic disease.

The National Health Program is a long-term health policy project in *Poland* (Ministry of Health, 2006–2015) addressing the population with special attention to mother-and-child protection, young adults, older and disabled people. Besides the improvement of the health status and quality of life of the Polish population one of the aims is to reduce social and regional differences. The three main directions during this NHP are the following:

- reduce differences in access to health services,
- support healthy lifestyle choices, and
- create a healthy environment (for example workplace, educational setting).

During the Conference on Ethical Issues in Chronic Care (Lisbon, 2003) the main interest of the participants was dedicated to the different ethical aspects related to chronic care, an extraordinarily actual topic. They postulated in conclusion, that patients with chronic conditions have to take part in the decision-making processes regarding their care.

The WHO regional office for Europe, headed by Singh, published a policy concerning chronic disease in 2008, e.g. how can chronic disease management programs operate with information about the strong evidence of self-care education (WHO 2008).

According to the specific policies of single European countries, the WHO forces in general a stepwise framework policy:

- Planning step 1: estimate population need and advocate for action.
- Planning step 2: formulate and adopt policy.
- Planning step 3: identify policy implementation steps as: population-wide intervention, national level, sub-national level, interventions for individuals (WHO 2005).

Summary

Based on the facts on chronic disease and on the concept of self-management, a standard design of possible action with a flexible approach to both delivery and program content is necessary. This standard concept has to be implemented in current legislations and policies in the field of chronic conditions in general and hopefully also for the Alzheimer's disease.

The following chapters will be in general concerning the aspects of aging and of the Alzheimer's disease self-management.

References

American Heart Association (2001) www.americanheart.org

Bandura A (1977) Self-efficacy – toward a unifying theory of behavioural change. Psycholog Rev 84:191–215

Bandura A (1979) Sozial-kognitive Lerntheorie. Klett-Cotta, Stuttgart

Bourbeau J, Collet JP, Schwartzman K, Ducruet T, Nault D, Bradley C (2006) Economic benefits of self-management education in COPD. Chest 130:1704–1711

California HealthCare Foundation (2008) Patient Self-Management, Oakland, CA. http://www.chcf.org/

Center on an Aging Society Institute for Health Care Research and Policy (2004) Issue Brief number 4 on Challenges for the 21st Century: Chronic and Disabling. Washington, DC. Georgetown University. http://ihcrp.georgetown.edu/agingsociety.

Corbin J, Strauss A (1988) Unending work and care: Managing chronic care at home. Jossey-Bass Publishers, San Francisco

Creer TL, Christian WP (1976) Chronically ill and handicapped children, their management and rehabilitation. Research Press Co., Champaign

Department of Health (1999) Saving lives: our healthier nation. Stationery Office, London

Department of Health (2001) The expert patient: a new approach to chronic disease management for the 21st century. London

EU Commission (2006) COM. 234

Eurostat News Release (2008) http://epp.eurostat.ec.europa.eu

Eurostat: Data in Focus (2008) Health expenditure 2003–2005. Based on the joint health accounts questionnaire launched by EUROSTAT, OECD, WHO

Ferri CP, Prince M, Brayne C et al. (2005) Alzheimer's disease international. In a Delphi consensus study. Lancet 366:2112–2117

Goldstein NE, Back AL, Morrison RS (2008) Titrating guidance. A model to guide physicians in assisting patients and family members who are facing complex decisions. Arch Intern Med 168:1733–1739

Gruffydd E, Randle J (2006) Alzheimer's disease and the psychosocial burden for caregivers. Community Pract 79: 15–18

Health in Europe (2008) http://ec.europa.eu/health-eu/news/

Holman H, Lorig K (2000) Patients as partners in managing chronic disease. Partnership is a prerequisite for effective and efficient health care. BMJ 320: 526–527

Holman H, Lorig K (2004) Patient self-management: A key to effectiveness and efficiency in care of chronic disease. Public Health Report 119, USA

Jordan JE, Osborne RH (2007) Chronic disease self-management education programs: challenges ahead. Med J Aust 186:84–87

Kanfer F (1977) Selbstmanagement-Methoden. In: Kanfer F, Goldstein A (Hrsg) Möglichkeiten der Verhaltensänderung. Urban & Schwarzenberg, München

Kanfer FH, Reinecker H, Schmelzer D (1996) Selbstmanagement-Therapie. Ein Lehrbuch für die klinische Praxis. Springer, Berlin Heidelberg New York

Kennedy AP, Nelson E, Reeves D et al. and the North-West Regional Gastrointestinal Research Group (2004) A randomised controlled trial to assess the effectiveness and cost of a patient orientated self management approach to chronic inflammatory bowel disease. Gut 53: 1639–1645

Kennedy A, Reeves D, Bower P et al. (2007) The effectiveness and cost effectiveness of a national lay-led self care support program for patients with long-term conditions: a pragmatic randomized controlled trial. J Epidemiol Community Health 61: 254–261

Leszek J (2007) EU Project EMPOWER contribution. Poland

Lorig KR (2000) Self-management education: context, definition, and outcomes and mechanisms. Chronic Disease Management Conferences, Sydney

Lorig KR, Ritter P, Stewart AL et al. (2001) Chronic disease self-management program: 2-year health status and health care utilization outcomes. Med Care 39:1217–1223

Lorig KR, Sobel DS, Stewart AL et al. (1999) Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. Med Care 37:5–14

Markwick M, Reece M, Battersby M (2002) The development and implementation of a generic assessment tool in chronic disease self management. Conference Presentation

Meichenbaum D (1979) Kognitive Verhaltensmodifikation. Die Bedeutung des inneren Dialogs für das menschliche Erleben und Verhalten. Der Umgang mit Bildern und Vorstellungen im therapeutischen Prozess. Urban& Schwarzenberg, München

OECD (2009). OECD Health Data 2008. http://www.oecd.org

Pajunen P, Pääkkönen R, Juolevi A et al. (2004) Trends in fatal and non-fatal coronary heart disease events in Finland during 1991–2001. Scand Cardiovasc J 38:340–344

Papastavrou E, Kalokerinou A, Papacostas SS, Tsangari H, Sourtzi P (2007) Caring for a relative with dementia: family caregiver burden. J Adv Nurs 58:446–457

Parker MG, Thorslund M (2007) Health trends in the elderly population: getting better and getting worse. Gerontologist 47:150–158

Press Release EURO/05/06 – WHO Press Release (2006) http://www.euro.who.int/healthtopics

Redman BK (2007) Accountability for patient self-management of chronic conditions; ethical analysis and a proposal. Chronic Illn 3:88–95

Richardson G et al. (2008) Cost effectiveness of the Expert Patients Programme (EPP) for patients with chronic conditions. J Epidemiol Commun Health 62:361–367

Sobngwi E, Chenu C, Delarroqua R, Cottez ML, Passa P (2002) Knowledge of type 2 diabetic patients on their disease. Diabetes Metab 28:411–412

Statistic Federal Office of Germany (2008) http://www.destatis.de

Statistik.at (2008) http://www.statistik.at

Strauss A, Corbin JM (1994) Grounded theory methodology: An overview. In: Denzin NK, Lincoln YS (eds) Handbook of qualitative research. Sage Publications, Thousand Oaks, pp 273–285

Swiss Health Interrogation, BFS (2002) http://www.bfs.admin.ch/

Takeda M (2007) Epidemiology and management of Alzheimer's disease: Focus on Japan and the Asia Pacific Region. IPA-congress contribution, Osaka

Tataru N (2007) EU project EMPOWER contribution. Romania

The Chronic Disease Management Initiative in British Columbia (2008) www.health.services.gov.bs.ca

The Robert Wood Johnson Foundation. Chronic care in America: 21st century challenge (2008) Robert Wood Johnson Foundation, Princeton, NJ, USA. http://www.rwjf.org/global/contactus.jsp

Thoesen Coleman M, Newton KS (2005) Supporting self-management in patients with chronic illness. American Family Physician 72:8

Valvanne J, Erkinjuntti T, Tilvis R (1992) Helsinki Ageing Study. Report 71/1992. Helsinki

Wettstein A, Baldegger E, Weber M, Bonsack S, Andermatt C, Latzel G (2003) Can empowerment of elderly with chronic disease be achieved in Switzerland: First results of the ALLFIT-programs in Zürich. Schweizerische Rundschau für Medizin PRAXIS 92: 1171–1176

Wheeler JR, Janz NK, Dodge JA (2003) Can a disease self-management program reduce health care costs? The case of older women with heart disease. Med Care 41:706–715

WHO (1997) Health report. http://www.who.int/

WHO (1998) Therapeutic patient education, report of a WHO working group. WHO, Geneva

WHO (2005) Preventing chronic disease, a vital investment: WHO global report. WHO, Geneva

WHO (2008a) http://www.who.int/topics/chronic_diseases/en/

WHO (2008b) http://www.who.int/features/factfiles/chp/02_en.html

WHO (2008c) http://www.who.int/dietphysicalactivity/publications/facts/chronic/en/index.html

WHO (2008d) www.who.int./chp/chronic_disease_report

WHO (2008e) http://www.who.int/features/factfiles/diabetes/02_en.html and http://www.who.int/features/factfiles/diabetes/10_en.html

WHO Regional Office for Europe and European Observatory on Health Systems and Policies; Health Services Management Centre, University of Birningham, UK, Singh D (2008) Policy brief: How can chronic disease management programs operate across care settings and providers?

World population prospects – Department of Economic and Social Affairs, Population Division, United Nations (2008) Division world population prospects – the 2006 revision. http://www.un.org/esa/population/publications/

Aspects of Aging

Nicoleta Tătaru, Urs Kalbermatten

2.1 General Aspects

Nicoleta Tătaru

> »Peu de gens savent être vieux«
> (La Rochefoucauld)
>
> »The value of human being is not diminished by even profound forgetfulness« (S.J. Post)

Background

»Interest for the health and well-being of the elderly has existed since antiquity. Over the centuries some observations were made regarding the health, the mental changes, and the care of the elderly. During the twentieth century, many behavioral and biological theories about aging postulated that ageing is a multidimensional phenomenon. *Ageing* is a progressive decline in function and performance, which accompanies advancing years. Cicero (104–43 BC) noticed that *old people preserve their cognitive functions if they maintain their interests.* Ageing is a privilege and an achievement of the society. It is also a challenge, which will impact on all aspects of the 21st century (WHO 2003a).

To the social, economical and medical problems that old age raises to society, one may add the continued increase of the proportion of old people in general population. The ageing of population is becoming a reality in developed and less developed countries, too. In EE (Eastern Europe) countries, around 10–12% of the general population are over 65 (in Turkey only 6%, in Macedonia 8,5%), in Romania around 12%, compared to Northwest Europe where 14–19% are over 65. In the USA 10%, in Canada 9%, but in Japan only 7% are over 65 (in India only 2–3%) (WHO 2003b). Robert N. Butler has called the phenomenon of increasing number of elderly *a triumph of survivorship,* rather than a cause of despair (Butler 1977).

In 2000, more than 600 million people worldwide were older than 60; there will be 1,2 billion by 2025 and 2 billion by 2050. This rapid increase in the ageing population is causing an increase of physical and mental health problems of the elderly, including dementia and a reduction of general mental well-being and quality of life (WHO 2004). By 1990, a majority (58%) of the world's population older than 60 was living in developing countries. By 2020 this proportion will have risen to 67%. In the developed world, the very old (age over 80) is the fastest growing population group. Women outlive men in all societies; consequently in very old age, the ratio of women to men is 2:1.

This demographic change will be accompanied by changes in social organization of family life. The elderly face a multiple burden in most countries; one in particular is the increase of mental disorders associated with ageing and with decreasing number of family support systems (WHO 2004; Patel and Prince 2001). In a traditional Romanian society the elderly normally enjoy much respect and care. The social and cultural changes with an increase in urban life style and a decrease in the three-generation family are leading to a dwindling of the traditional family life, but they also represent a challenge.

Normal, Active and Successful Aging

We have to talk about a conceptual definition of normal ageing and also about active and successful ageing and their differentiation from morbid ageing. What is normal? Lawrence Kubie (1955) defined normality as »the ability to learn by experience, to be flexible, and to adapt to a changing environment«, while Otto Rank wrote in his book *Psychology and the Soul* that normality »is the capacity to live without fear, guilt, or anxiety and to take responsibility for one's own actions« (Rank 1998).

While there are clear diagnostic criteria for morbid ageing, there is a less clear picture for »normality« at old age. It is useful to differentiate between *successful ageing* and *typical normal ageing.*

Normal ageing is an ageing process without any clinical somatic or mental disorder whereas *morbid ageing* is characterized by a process presenting clinical disorders which affect the somatic and mental health. Normal ageing will be frequently accompanied by comorbidities, such as hypertension, coronary artery disease, sensory abnormalities and benign senescent forgetfulness (Nagash et al. 2005). More than 80% of persons older than 65 present at least one chronic disorder and 50% present osteoarticular disorders. (De Mendonca Lima 2004). *Active ageing* is the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age. *Active ageing* allows people to realize their potential for physical, social, and mental well-being throughout their life course and to participate in society, while providing them with adequate protection, security and care if needed.

Successful ageing is an ageing process in favorable environmental conditions to promote individual development. Rowe and Kahn (1987) made the distinction between »usual« and »successful« ageing: *usual ageing,* at the age of 90 to be suffering from several illness, and *successful ageing,* to be fit at 90 (Rowe and Kahn 1987, 1998). *Successful ageing* is a state of health that allows individuals to function effectively and successfully as they age (Kaye et al. 1994). The components of successful aging, or the factors that strongly impact our quality of life as we age, comprises of high level of engagement with life, low risk of disease, high physical and cognitive function levels (Scheeman 2000). A variety of attributes were identified that were thought to be essential for successful and active ageing: importance of family, particularly grandchildren, and friends, accepting the negative experiences of ageing, remaining active – physically, emotionally, socially, intellectually and psychologically – and remaining independent. The elderly who remain as active, productive and socially integrated as possible are most likely to have a sense of life satisfaction.

Morbid Aging and Mental Health

The transition between normal ageing and mental disorders till dementia is characterized by cognitive changes as benign senescent forgetfulness (Kral 1962), age-associated memory impairment (Crook et al. 1986), and ageing-associated cognitive decline (Levy 1994), which reflects some extreme aspects of normal ageing, while mild cognitive impairment is recognized as pathological entity (Petersen et al. 1999).

We can consider not only the presence or absence of a disorder but also its impact on someone's quality of life. Impact of mental disorders on quality of life is one of the important issues for public health priority. Healthcare is in the midst of a process of fundamental and rapid change, and psychiatry could use this process of change to the benefit of people with mental illness (Sartorius 2004). The loss of the functioning capacity could be considered as a marker of a clinical disorder (de Mendonca Lima 2004). Katz (1983) defined the patient capacity according to activity of daily living if he/she is able to live independently within a community (the ability to eat, take a bath, dress, use toilet, maintain continence, etc.). Low functional capacity is often caused by emotional problems of the aged: loss is a predominant theme and depression is seen as the maladaptive response, with loss of appetite, sleep disturbance, loss of interest, the feelings that life is no longer worth living, with cognitive impairment and irritability.

If old people lose the significant roles and become ill, their dependency on family and long care institutions increases. For those who live alone, this period is more difficult. As much as more than 40% of our elderly population is lonely, sometimes concomitantly depressed. For the elderly, social isolation and loneliness are among the most frequent causes of hospitalization and its duration and of placement in nursing homes. The sad truth is that many old people suffer in silence until it is too late and they form one third of those who commit suicide. If the community understood better the *loneliness* deriving from social isolation, it could also understand better the necessity of social integration.

The infirmities associated with ageing lead to increasing dependency, cause pain and discomfort, restrict mobility and impair enjoyment of life. The caregivers and community team try to help the elderly to be capable of self-assertion, to keep control over the surroundings and over their destiny as far as possible.

Multiple losses in old age – death of relatives and friends, declining health, loss of status and roles, low economical level, loss of independence, loss of security of accommodation – play an important role in the decrease of the quality of life and the increase of mental health problems in the elderly.

Mental health is more than the absence of mental illness. There are three important risk factors for poor mental health in the elderly: financial difficulties, social isolation and poor physical health (WHO 2004).

International bodies can ensure that countries at all stages of economic development are aware of the importance of mental health to community development. Mental health is essential for well-being and functioning of individuals. Good mental health is an important resource for individuals, families, communities and nations and contributes to the social, human and economic capital of every society. WHO can assist countries in developing appropriate strategies and programs to promote mental health of the elderly (WHO 2004). To support policy and programs with a strong legislative platform and resource allocation are some of society's and government's tasks.

Mental health, neglected for far too long, must be seen in a new light. Improving mental health and lowering the personal and social costs of mental illness can only be achieved through a public health approach (Sartorius 1998). The aim of any intervention for older adults is to preserve and to enhance the patient's *personal autonomy* and *self esteem* necessary for his/her own project for the end of their lives, *permitting them to live and die with dignity.* Success of interventions to improve mental health of the elderly include: social support, supportive relationship, involvement in group activities, community empowerment interventions, promoting healthy lifestyle, befriending programs (especially for older women), providing hearing aids, etc.

As intermediate outcomes of improving mental health we could observe an increased sense of belonging, self-esteem, self-determination and self-control, and some of the most important long-term benefits improving physical health were less anxiety and depression, and improved quality of life and life expectancy.

Ageism, Elder Abuse and Stigma

Old people, especially when they are ill, are considered as being *non-contributors* to society; dependent on the help of others and vulnerable to cruelty or exploitation. There are people (the ageists) who belittle the needs and importance of the elderly, as being half senile; therefore they should not be granted full human rights (WHO 2002). In 1968, Robert N. Butler used this definition for ageism: »Ageism can be seen as a process of systematic stereotyping of and discrimination against people because they are old« (Butler 1969). Older people with mental health problems are at high risk of abuse. There are many forms of elder abuse including psychological, physical, sexual, financial, and social abuse as well as neglect and abandonment. Elder abuse is often hidden and under-reported (WPA OAP 2008). Stigma remains a major obstacle to ensuring access to good care for elderly with mental disorders, these patients suffer from a double jeopardy of stigmatization (old age and mental disorders). In some countries, older women may face further stigmatization because of their gender. Poverty may lead to even further discrimination. The need to reduce stigma and discrimination is ethically mandated by their harmful consequences including perpetuation and worsening of mental illness (WPA OAP 2008). Both stigma and discrimination against old persons depend on the type of mental disorder and we have to protect them against discrimination and improve their quality of life. Stigma against the old mentally ill people leads to the development of negative attitudes (including those of professionals), poor quality of treatment and care services, and inadequate funding at both national and local level. Standards need to be raised in basic mental health care, and in relation to patients' needs and quality of life (accommodation, food, sheltered housing, sheltered workplaces and community involvement).

Thus, the psychiatrists have to face these challenges and treat and care the elderly with or without mental disorders including dementia, assuring them the best quality of life as it is possible. One of the important problems for psychiatry is the replacement of economic by ethical arguments for the provision of mental healthcare.

Elderly with or without mental disorders, especially those with dementia, need adequate and continued care in a stable, safe and stimulating environment.

In Romania, like in all developing countries, the quality of life of the elderly with or without mental disorders is related to money, thus it is reduced. Too many of the elderly are not able to manage their lives, and they live in cold and hunger, and are always worried about price rises. It is very difficult to talk about quality of life of the elderly patients with or without mental disorders, because it is difficult to ensure the basic physical and psychological needs, their food, clothing, heating, minimum comfort and elementary medication (Tătaru 2005). The basic psychological needs are respect, security and self-determination. The basic physical and psychological needs are necessary to be known and accepted by a care team. The special needs of mentally ill people were not always recognized and respected by the care-provider services. The socio-economic situation of any individual affects the perception of his/her own ageing process. The elderly, even if suffering from dementia, have physical, emotional and spiritual needs. The respect for the dignity of the elderly with or without mental disorders and for their emotional and spiritual expectations may be beneficial in enhancing their well-being. (Baloyannis 2007). A rich spiritual life can make a significant contribution to mental health promotion (Underwood-Gordon 1999).

Mature Mind and an Optimistic View of Aging

In a single generation, the view on life after fifty has changed dramatically. Today's society is shaped by unprecedented growth in the number of people living in their »golden years«.

Many people see ageing as a time of cognitive and physical decline. For the past three decades, most scientists and the general public have accepted this negative age-stereotype as the norm, but fortunately this view is changing now. New findings show that well-being and a positive view on ageing are major protective factors against the effects of age on the organism (Lupien and Wan 2004). Thus, in the past years, there have been more and more studies about active and successful ageing, probably inspired by Cicero, who believed that the old individual is usually not poorer, but even richer in force of character, reflection and judgment.

Gene Cohen, in his book *Mature Mind* (2005), changes the traditional view on ageing. »While we get older we actually get better at thinking if we respect the rule of mind: use it or lose it« (Cohen 2005). Cohen identifies five activities to sustain power and clarity of mind: exercise mentally and physically, pick challenging leisure activities, achieve mastery, establish strong social networks. Cohen describes »developmental intelligence« in terms of three forms of thinking that actually improve with age: *relativistic thinking*, where understanding is based on a synthesized combination of disparate views; *dualist thinking*, where contradictions in opposing views are uncovered and opposites are held in mind at the same time without judgment; and *systematic thinking,* which allows the person to see the forest as well as the trees. Gene Cohen debunks harmful myths about aging as an inevitable decline of body and mind, and shows how the combination of age, experience, and creativity can produce inner growth and infinite potential for everyone (Cohen 2000).

Gene Cohen introduces the concept of developmental intelligence, a »maturing synergy of cognition, emotional intelligence, judgment, social skills, life experience, and consciousness«. Cohen postulates that there are four phases of psychological development in mature life: *midlife re-evaluation,* a time of exploration and transition; *liberation,* a desire to experiment; *the summing-up phase* of recapitulation, resolution, and review; and *encore,* the desire to go on (Cohen 2006).

Finally, we must have an optimistic view of this last stage in the life cycle and the belief that the elderly have a proper place in society, being a reservoir of wisdom due to their accumulated years of experiences. All aged persons deserve respect from all those around them and society must assume their passing away. The quality of care and rehabilitation in old age is an expression of social development, culture and civilisation level.

References

Baloyannis JS (2007) Ethics in care-giving to patients who suffer from dementia. The 35th Congress of EAGP, June 2007, Santiago de Compostela, Spain

Butler RN (1969) Ageism: another form of bigotry. Gerontologist 9:212–252

Butler RN (1977) Successful aging and the role of the life review. In: Zarit SN (ed) Readings in aging and death: contemporary perspectives, 2nd edn. Harper & Row, New York, pp 13–19

Cohen GD (2000) The creative age: awakening human potential in the second half of life. New York, Avon Books

Cohen GD (2005) The Mature Mind. Basic Books, New York

Cohen GD (2006) The mature mind: the positive power of the aging brain. Basic Books, New York

Crook T, Bartus RT, Ferris SH, Whitehouse P, Cohen GD, Gerson S. (1986) Age-associated memory impairment: proposed diagnostic criteria and measures of clinical changes – Report of a National Institute of Mental Health Work Group. Developmental Neuropsychology 2:261–267

Kaye JA, Oken BS, Howieson DB, Howieson J, Holm LA, Dennison K (1994) Neurologic evaluation of the optimally healthy oldest old. Arch Neurol 51:1205–1211

Katz S (1983) Assessing self-maintenance: activities of daily, mobility, and instrumental activities of daily living. J Am Geriatr Soc 31: 721–727

Kral VA (1962) Senescent forgetfulness: benign and malignant. CMAJ 86:257–260

Kubie LS (1955) The Fundamental Nature of the Distinction between Normality and Neurosis. Int J Psycho-Anal 36:423

Levy R (1994) Aging-associated cognitive decline. Int Psychogeriatr 6:63–68

De Mendonça Lima CA (2004) Effects of old age in Psychiatry. IPA EE Initiative-ARG, Course on Geriatric Psychiatry, Oradea, Romania, September 2004

Lupien SJ, Wan N (2004) Successful ageing: from cell to self. The Royal Society, Published online 19 August 2004

Nagash S, Geda YE, Petersen RC (2005) Mild cognitive impairment – clinical characterization. In: Burns A, Ames D, O'Brien J (eds) Dementia, 3rd edn. Hodder Arnold, London, 338–346

Patel V, Prince M (2001) Ageing and mental health in developing countries: who cares? Qualitative studies from Goa, India. Psychol Med 31: 29–38

Petersen RC, Smith GE, Waring SC, Ivnik RJ, Tangalos EG, Kokmen E. (1999) Mild cognitive impairment: clinical characterization and outcome. Arch Neurol 56: 3003–3008

Post SG (1995) The moral challenge of Alzheimer disease. John Hopkins University Press, Baltimore

Rank O (2003) Psychology and the soul. Johns Hopkins University Press, Baltimore

Rowe JW, Kahn RL (1987) Human aging: usual and successful aging. Science 237: 143–149

Rowe JW, Kahn RL (1998): Successful aging. Pantheon Books, New York

Sartorius N (1998) Universal strategies for the prevention of mental illness and the promotion of mental health. In: Jenkis R, Ustun TB (eds) Preventing mental illness: mental health promotion in primary care., John Wiley, Chichester, pp 61–67

Sartorius N (2004) The context of treatment in psychiatry. Treatments in Psychiatry: an update. WPA Congress, Florence, Italy, 10th–13th November, 2004

Sheeman T (2000) Successful aging: fact or fiction? Fall Community Meeting 2000, UCLA Schools of Medicine

Tătaru N (2005) Impact of care on life quality of elderly with mental disorders. In: Baloyannis SJ (ed) Perspectives in Neurosciences. Thessaloniki, pp 563–572

Underwood-Gordon LG (1999) A working model of health: spirituality and religiousness as resources: applications to persons with disability. Journal of Religion, Disability and Health 3:51–71

World Health Organization (2003a) The World Health Report 2003: Shaping the Future. WHO, Geneva, pp 1–131

World Health Organization (2003b) The World Health Report 2003: Annex 4, Healthy life expectancy (HALE) in all member states; Estimates for 2002. WHO, Geneva, p 166

World Health Organization (2004) Promoting Mental Health, Summary Report, A report of WHO, Department of mental Health and Substance Abuse, in collaboration with the Victorian Health promotion Foundation and the University of Melbourne. WHO, Geneva

WPA old Age Psychiatry Section Consensus Statement Conference on Ethics (2008) Prague, Czech Republic, September 2008

2.2 Consequences for Dementia

Urs Kalbermatten

Defining Old Age as a Phase of Life

There are various definitions of old age as a phase of life. The negative images and stereotypes of old age that prevail today are as marked by deficit models as they have been for decades. True, it is generally appreciated that the process of ageing has changed, and that the changes due to degeneration occur later in life. To document this, gerontological studies of old-age stereotypes (Filipp and Mayer 1999) have asked how long people feel young in old age. In contrary to this opinion, we will be presenting a definition in which old age is accepted (no anti-ageing) instead of being offset against youth (no call to remain young), and in which old age is accorded its positive aspects. If ageing is largely equated with physical degeneration and biological processes (Schröter 2008), older people are bound to find it difficult to identify with old age.

In this article, we will define old age as a phase of life, like childhood or youth. In social terms, it is defined by the transition from work to retirement. Consequently, old age does not imply any change in mental characteristics or the onset of illness or degeneration. Old age is marked by duties, challenges, roles, and situations that differ from those of earlier life phases. In our view, old age includes all those forms of life that occur after generally accepted retirement age. Old age, therefore, constitutes an autonomous, normal phase of life. Consequently, it is not what remains of a person's life and cannot be defined solely in terms of ceasing to work. This being so, gerontology should, at long last, provide specific metaphors to describe this phase of life instead of merely defining it as disengagement or retirement (Ammann and Kolland 2008). These are not tempting visions or scientific concepts which an older person could adopt as a basis for planning 20 or even 30 years of his or her life consciously and actively. Until now, old age has remained socially under-determined in comparison to other phases of life in which the expectations and duties that confront people are much more explicitly defined by society. Old age in the countries of Western Europe offers now more freedom because elderly people are much better provided for than they used to be, thanks to the various pension systems. This gives them a wide scope of individual action, to be exploited according to their individual interests, which they do to a highly variable extent. It is known, that people are influenced by the greater freedom available to them after retirement to diversify their lifestyles much more than in the preceding phases, when they tend to be somewhat similar because of the demands of working and bringing up children (Perrig and Widmer 2008).

Old age is characterized by specific duties and challenges that begin with preparing for retirement. To begin with, this involves building up new action interests, personal resources, and support systems that provide one with a range of meaningful activities and a social network after the ageing person left the working life behind. All this permits one to embrace old age and develop a pro-ageing attitude. Optimally designing the old age begins with organizing the daily life. What meaningful things are there to do in the time that was used to spend working or bringing up children? In addition, to utilizing the mental and physical potentials one should be looking at new things in old age: build up new interests, develop creative action programs, and address innovations in technology, lifestyle, knowledge, and culture. This deliberate reorientation is indispensable in old age to ensure participation and integration in the life of society. Such a consciously receptive attitude towards new things will increase the resilience when the elderly are confronted with new challenges with which they have to deal in old age, such as limitations, degeneration processes, chronic diseases, and coping with deaths in the family as well as with own finiteness. To accept oneself as an old person together with any new facets caused by physical changes and diseases is a difficult process influencing the identity during ageing.

Life Design

The design approach implies a subjective, autocreative process of construction in which making choices, giving meaning, and assuming personal responsibility play an important part. Compared to the other phases of life, old age offers more degrees of freedom in individual design. Old people differ greatly in the way in which they utilize their scope of action. The key problems to be solved probably are designing the daily life, finding a meaning in it, and giving a shape to the life in old age. According to Rowe and Kahn (1998), choosing a lifestyle is of particular importance for the length, healthfulness, and quality of life. In our understanding, life design is a higher-order category which influences health and illness. Conversely, chronic diseases raise questions not only about how to manage them but also about how to design the life with the disease. This approach turns the spotlight not on illness but on life as a whole.

Gerontological literature shows very well how varied the resources are that are available to older people for coping with their life situation, their deficits, and their problems. Most working models start out from a deficit, dedicating less space and fewer concrete approaches to the prevention of degeneration processes and the creation of support systems. Might it not be equally important to know much more about the facts of life in old age? Why could this be important?

- Designing daily life and giving a personal meaning to it constitutes a challenge in old age that is very often underestimated.
- A holistic design of daily life that covers mental, physical, and social aspects as well as the interaction with the environment affects the health and the length of life. Even if health is the general theme, designing daily life is important. The choice of design can promote illness and cause problems.
- When we are working on coping with crises or curing diseases, one way of reaching our goal is to design a life that is normal. This calls for research into and knowledge about how to design a »good« daily life.
- Those who find meaning in their daily life in old age (instead of feeling that they are no longer needed and have nothing to live for) may act differently when they fall ill. In coping with old age, finding a meaning and concrete goals play an important part.
- If the method used is based on resources, the individual will need to begin by building resources in daily life. This runs contrary to the approach under which one begins looking for resources only when somebody falls ill or has another problem. Life design also calls for knowledge about how to build up resources.

Action Theory and Self-Organization

As life design and self-organization constitute key aspects in dementia as well as in other diseases, we will be using selected action-theory contents and models in our analyses and our work at various levels. In this context, we will also show that specific processes partly depend on underlying theoretical assumptions about human nature. Our model organizing human action contains some key assumptions of the general systems theory about conscious, target-oriented action (von Cranach et al. 1982; Kalbermatten 1987; Valach and Stevens 2007). At this juncture, we will briefly outline those parts which we have been using for some years in our research and in teaching gerontology. Systems theory holds that human action is both active and reactive. Now, gerontological research concentrates mostly on the reactive side. Considering that old age is characterized by degeneration processes and losses, reactive processes such as adaptation and coping with or compensating deficits (Baltes and Smith 1999) do indeed play a crucial role. Thus, it appears natural that gerontology should concentrate on reactive requirements. On the contrary, we consider the active side of human competence to be just as important, so that life plans, meanings, and goals acquire great significance for the old and the chronically ill. They form part of any holistic gerontological approach. People, whether old or young, are distinguished by their ability to reflect on themselves and control their own actions. However, it is precisely these components that are neglected in gerontology. Older people are not considered to have much of a future. Mnemonic performance (storing and forgetting), biographical work and optimum deficit compensation occupy the foreground. Similarly, the methods available in the field for planning or reorienting one's life are few in number compared to reactive interventions. Thus, for example, nursing reports cover the past of elderly inmates but rarely describe their current aims in life. Development programs for staff and elderly people hardly contain any courses oriented towards the future.

Our model of organizing action at various levels guides us in the selection of phenomena to address in our consultation, research, and education activities. The criterion we use to differentiate between various levels is cognitive representation and control. To begin with, we should like to present the model's four levels from bottom to top:

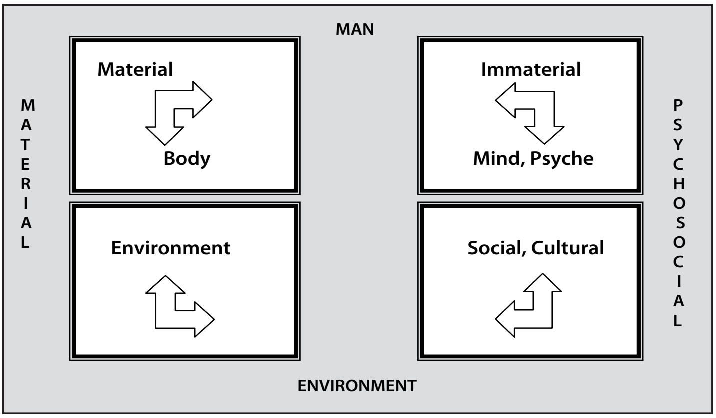
1. The level of *structures* deals with action elements such as movements or as verbal output which are generally represented in the subconscious.
2. The level of *functions* integrates structures in steps and in strategies.
3. The level of *action* develops purpose and meaning of an action consciously.
4. The level of *identity*, at which self-consciousness arises from action, and various actions and roles are integrated in the identity.

To explain the model, we should like to refer to an intervention study by Egloff (2005) involving patients with severely impaired hearing. At the structural level, interventions use various means, even surgical procedures such as cochlea implants. The questions addressed here are purely acoustic. At the functional level, patients are trained in communication. Once they are able to hear and talk, their scope of action widens at the action level. Many interventions stop at the communication training stage without targeting its implementation in daily life. People who have suffered from a severe hearing disorder for many years need support in organizing their own lives, particularly at the action level. Among couples, additional questions of social interaction arise, such as the redistribution of roles, interpersonal perceptions, or partnership relations (Egloff 2005). New actions tend to change the perception of both the self and the other, and new facets of identity may develop at the fourth level. Action theory suggests that people should be supported at various levels, not only in developing their functionality but also in the discovery of meanings and in the development of new goals and a new identity. This multi-dimensional analysis and methodology is also helpful in the treatment of dementia patients as it provides orientation about the level at which we are going to intervene. It is only by integrating its different levels that we can address the complexity of the organization of human action in some detail. Moreover, it is superior to a linear understanding of the behavior of people with dementia as far as supporting and instructing them is concerned.

The research of our working group revolves around concrete action. In the process, we forge a link between manifest, observable actions (communicative and physical activities) and cognitive representations, about which we learn through interviews. For example, we should like to quote a study on self- and co-determination in patients with dementia and other chronic diseases. When we question inmates or caregivers about how self-, extraneous, or co-determination is handled in a particular institution, things look good in the retrospective of an interview. However, if we record everyday actions on video and ask the actors to comment on them in self-confrontation interviews, we acquire a different set of insights about the actions in which co-determination is not supported and about where and how co-determination is facilitated in other actions. In research and practice, systematically observing concrete actions may provide a starting point before we begin investigating attitudes and interpretations. Interviews that relate to the concrete actions of care-giving show how carers interpret their own interactive actions.

Interaction and Dementia

Advising and caring for old people as well as for dementia patients calls for an interdisciplinary approach. The model of the four spheres of life (◘ Fig. 2.1) is based on one person (physical and mental-psychic factors) interacting with his or her environment (social and material factors).



◘ **Fig. 2.1.** Model of the 4 spheres of life

Dementia and its manifestations are determined not only by mental and physical deterioration but also by the social and ecological life environment. Current publications (Kruse 2008; Dieckmann 2008; Rudolph 2008; Granzin and Weber 2008) concentrate on the social participation of dementia patients and their relations. In 2008, Gronemeyer and Rothe presented the concept of a »dementia-friendly community«. The actual configuration of the ecological environment affects both the course and the manifestation of dementia (Pawletko 2008), while the social and cultural components greatly influence the quality of life of people suffering from dementia.

In the following, we will proceed to the aspect of dementia as a construct of social interaction. The actions of demented people as well as the course of the degeneration process are partially determined and influenced by interpersonal processes. In one and the same dementia patient the manifestation and progress of the disease can differ depending on whether that person is staying at home or in an institution, or changing between the two environments. Depending on the interaction between partner and the environment of the patient, either institutions or private care may offer better support in the individual cases. In that sense, we regard dementia as a social construct. Interaction is partly responsible for generating its manifestations. In each interaction, dementia is perceived and experienced differently by both sides. Categories of social perception, such as stereotypes and the labeling of dementia images give rise to dissociation and differences in dealings with others (Schelling 2005). Persons who are unaware of the dementia label deal more normally with the disease. To illustrate the influence of various forms of social interaction, we will quote a few examples from our own observations in the field.

Small children who have relatives with dementia living in their families will approach these persons much more actively, trying to make them join in their games or some other enterprise. They do notice that something is wrong, or that grandma is in a depressive mood, but when they do, they try very energetically to get some action happening. In their attempts, they show no evidence of the many barriers which other family members or caregivers observe as fear of being disrespectful. Children are often successful in their attempts because any encounter with children triggers deeply rooted behavioral patterns. In this context, it is important that dementia patients should succeed in understanding the meaning and the playful intent of the children's actions.

In a group of very old people living in private accommodation, three persons were dying within a short period of time, which caused depressive feelings within the remaining members of the group. When the manager asked the group what should be done now, one member recalled that weddings used to improve the mood of the people in her village. Consequently, a simulation exercise was set up in which members prepared a wedding over a certain period of time. They bought a white dress in a second-hand shop and selected presents for the couple. Even the demented members of the group understood the meaning of these activities. At the simulated wedding ceremony, everyone dressed up, and a sumptuous meal was served. The group's mood changed radically, sustained by the fact that many wedding photographs were posted on the walls for some time afterwards.

In many ways, social interaction with people with dementia greatly depends on what you believe they are capable of. If you allow them to exercise their skills and abilities as far as they can and will go, their feeling of self-esteem will be strengthened. It is important for demented persons to recognize the meaning of a particular action; if they do, they can organize their activities so that they serve its objectives. (Where relatively complex and long-lasting activities are concerned, it is important for carers to maintain the red thread of the path of action.) Caregivers can see whether or not a meaning has been identified from the way in which a demented person executes an activity as well as from his or her verbal and non-verbal emotional feedback. There are well-known examples of demented patients taking part in dancing groups or stage productions where they suddenly performed much better than what was expected of them. Dementia may also induce patients to become receptive towards activities that are new to them, such as experiencing nature or the arts, activities which they formerly considered unconformable with their personal internalized norms and self-attributed capabilities.

Interactive activities often provide people with dementia with the esteem they need to experience themselves as valuable members of a community. This may change their image in their own as well as in others' eyes. To illustrate this, here is another field of observation made in an old people's home. A very old inmate who was singing with a group told us that her demented fellow inmates were unable to join, and that she had always felt that her friends were sad, when the others left. She eventually decided to take over the next-room neighbor, who was completely gone mentally, for a meeting of the group. And as the neighbor was utterly incapable of singing with the group, she pressed a rattle into his hand. And the man began tapping out the rhythm with his rattle without losing the beat. This opened up another sphere of activity for him, and he was always pleased to come along from then on. It is interesting to note that the woman gave us an interpretation that corresponded exactly to our four-level action model. Because of what she had done, the group had completely changed their image of the person concerned. This example fits in well with the theoretical approach suggested by Kitwood (2004) who described a downward spiral in the progress of dementia disease. However, he emphatically stated that this spiral can be broken, improving the patients' well-being and ensuring the success of their integration and a positive experience for all partners in the interaction.

Social support for demented patients may also be important because it ensures that the range of meaningful activities offered is wide enough, that the ultimate aim is not lost in prolonged actions, and that sufficient inducements and suggestions are offered. Some steps may have to be carried out by caregivers so that complex activities can be completed. Positive feedback is crucial whenever an action is completed successfully.

In any interactive activity, it is highly important to understand the strategies with which demented persons try to master their self-perceived deficits. Understanding implies, among other things, to appreciate the fears that beset these people, and to support them. However, working on one's own personality is also important. Thus, for example, many care-giving relations believe that their work is without avail because at the end of the day, the person they are looking after is getting worse and worse. The literature on the subject (Steinfort and Matip 2008) quite rightly mentions this severe strain which may induce caregivers to view the disease with great discouragement. Cases have been observed in the field in which patients described their situation more positively than their relatives. In some recent explorative studies, we have gathered case reports describing how caring for demented people at home led to positive changes in relationships and even resulted in greater closeness and tenderness and a more intense examination of the caregivers' own finiteness and other existential questions. Kruse (2008) similarly describes encounters with dementia patients as an opportunity for addressing the fact that one's own personal existence is limited, finite, and transient. In his view, dealing with people suffering from dementia implies not only specialized work but also ethically founded support.

Dementia may also trigger extreme fear in the people affected. There was one demented woman who began calling out her own Christian name at night, continuing until she was tired. Her relatives let her do this without giving her medication. Their interpretation was that their mother was noticing that she was forgetting everything. Now she was afraid to forget her own name some day. She was, therefore, fighting for a last fragment of her identity. Whether this interpretation is correct is impossible to say, for there is no one who knows cause and effect (action theory is an understanding approach). An understanding approach aims at attributing specific reasons to specific behaviors. The subsequent interaction may vary depending on the process of understanding. In the case described above, the mother was given the leeway she required in her existential struggle against alienation, she was deliberately addressed by her Christian name more frequently from then on, and her name was written large under photographs in her room. Given the same behavior, how would the staff of a home understand this woman, and when would she be put under sedation? In a twin bedroom, she would certainly not be allowed to fight with all her strength for her identity at night, no matter how the cause of this persistent loud repetition of her Christian name was interpreted.

Another observation made in the field shows that demented persons will deal with their social environment in different ways and behave differently depending on the context. (We all know reports from long-care-institutions which take their inmates to a hotel for the holidays where they suddenly display perfect table manners of which there was no evidence in the institution.) In another case, a wife tried to feed her demented husband in a home who, however, refused everything. The woman tried all possibilities, even threatened she would no longer take her husband home, but without avail. Appearing apathetic, the man responded to all attempts at interaction by saying »aah«. When the woman left the room, the man got up and went to the toilet, chatting on the way quite normally with the occupant of the neighboring bed. His bodily posture and his verbal competence changed completely within seconds.

A Wide View in Analysis and Promotion

Descriptions in the literature on dementia focus on forgetting. To illustrate the point, here are the titles of some recent publications: Piechotta, *Experiencing Oblivion* (Das Vergessen erleben: 2008), and Stechl et al., *Dementia – Living with Oblivion* (Demenz – mit dem Vergessen leben: 2008). According to Martin (2005), mnemonic and functional training are among the most important psychosocial interventions in cases of dementia. Loss of memory is certainly one of the gravest and most important symptoms associated with dementia, and it is important that intervention strategies should concentrate on it. However, we should like to ask the critical question whether other mental capabilities that are present in demented persons are given the attention they deserve. In that context, we should like to point out that human brain possesses many other faculties besides memorizing, recalling, and forgetting.

Depending on the degree to which their brain centers are affected, there are various cognitive faculties with regard to which demented persons may be met and promoted purposefully. Here is a selection:

- *information absorption:* information search, information selection, orientation;
- *information processing:* evaluation, self-evaluation, experience and expression of emotions, selection of relevant information, rational thought processes such as deliberation, aesthetic consideration;
- *consciousness:* concentration, attention, conscious focusing on something, problem-solving, self-perception, experience;
- *control processes:* setting objectives, planning actions, controlling the execution of actions, selecting action strategies, decision-making, motivation, action organization, creativity;
- *feedback processes:* pain, joy, control;
- *communication processes:* producing and decoding language, sending non-verbal signals.

As the list given above shows, work with demented people offers a wide range of options for promoting mental faculties. (The physical sphere certainly offers a similarly wide range of promotion options; see, for example, Ennen et al. 2008.) As Alzheimer's dementia involves no disturbance of consciousness according to Brand and Markowitsch (2005), most of the elements named above are available for promotion. Different dementia diseases affect different functions of the brain, and there are hardly any consistent clinical pictures. This is why the conscious variation of cognitive processes is so important, which we address in our interactive work with demented people. To preserve their self- and co-determination capabilities, we should encourage, inform, and train caregivers to approach people with a dementia illness holistically.

References

Amann A, Kolland F (2008) (Hrsg.) Das erzwungene Paradies des Alters? Fragen an eine kritische Gerontologie. Verlag für Sozialwissenschaften, Wiesbaden

Baltes PB, Smith J (1999) Multilevel and systemic analysis of old age: theoretical and empirical evidence for fourth age. In: Bengtson VL, Schaie KW (eds) Handbook of theories of aging. Springer, New York

Brand M, Markowitsch HJ (2005) Neuropsychologische Früherkennung und Diagnostik der Demenz. In: Martin M, Schelling HR (Hrsg.) Demenz in Schlüsselbegriffen. Huber, Bern

Von Cranach M, Kalbermatten U, Indermühle K, Gugler B (1982) Goal-directed action. Academic Press, London

Diekman A (2008) Demenzkranke und Betreuungsrecht. Archiv für Wissenschaft und Praxis der sozialen Arbeit 4:38–51

Egloff E (2005) Hören heißt dazugeHören – in jedem Alter. Auswirkungen einer Cochlea Implantation auf die Partnerschaft. Masterarbeit in Gerontologie, Berner Fachhochschule

Ennen JC et al. (2008) Einfluss von multimodaler sportlicher Aktivität auf Kognition und Alltagskompetenz bei früher Alzheimer-Demenz. Zeitschrift für Gerontopsychologie & -psychiatrie 21:163–169

Filipp S-H, Mayer A-K (1999) Bilder des Alters. Altersstereotype und die Beziehungen zwischen den Generationen. Kohlhammer, Stuttgart

Granzin U, Weber J (2008) Das Forum Demenz Wiesbaden: ein Beispiel kommunaler Vernetzung von Altenarbeit und Gesundheitswesen. Archiv für Wissenschaft und Praxis der sozialen Arbeit 4:82–89

Gronemeyer R, Rothe V (2008) Teilhabe statt Ausgrenzung: die demenzfreundliche Kommune. Archiv für Wissenschaft und Praxis der sozialen Arbeit 4:90–95

Kalbermatten U (1987) Handlungspsychologie. Kurseinheit 2: Der Berner Ansatz. Fernuniversität Hagen

Kitwood T (2004) Demenz. Der personzentrierte Ansatz im Umgang mit verwirrten Menschen, 3. erw. Aufl. Huber, Bern

Kruse A (2008) Der Umgang mit demenzkranken Menschen als ethische Aufgabe. Archiv für Wissenschaft und Praxis der sozialen Arbeit 4:4–15

Martin M (2005) Demenz: Perspektiven und offene Fragen. In: Martin M, Schelling HR (Hrsg) Demenz in Schlüsselbegriffen. Huber, Bern

Pawletko K-W (2008) Neue Wohnformen für Menschen mit Demenz. Archiv für Wissenschaft und Praxis der sozialen Arbeit 4:96–103

Perrig-Chiello P, Widmer P (2008) Mobilitätsmuster zukünftiger Rentnerinnen und Rentner: eine Herausforderung für das Verkehrssystem 2030? Unveröffentlichter Werkstatt-Bericht eines Forschungsauftrages der Vereinigung Schweizerischer Verkehrsingenieure. (Publikation in Vorbereitung)

Piechotta G (2008) (Hrsg.) Das Vergessen erleben. Mabuse, Frankfurt am Main

Rowe JW, Kahn RL (1998) Successful aging. Pantheon Books, New York

Rudolph J (2008) Das Leuchtturmprojekt Demenz des Bundesministerium für Gesundheit. Archiv für Wissenschaft und Praxis der sozialen Arbeit 4:60–73

Schelling HR (2005) Demenz als Krankheit und Diagnose: Mentale Repräsentationen und Einstellungen. In: Martin M, Schelling HR (Hrsg) Demenz in Schlüsselbegriffen. Huber, Bern

Schröter KR (2008) Verwirklichungen des Alters. In: Amann A, Kolland F (Hrsg) Das erzwungene Paradies des Alters? Fragen an eine kritische Gerontologie. Verlag für Sozialwissenschaften, Wiesbaden

Stechl E, Steinhagen-Thiessen E, Knüvener C (2008) Demenz – mit dem Vergessen leben. Mabuse, Frankfurt am Main

Steinfort J, Matip E-M (2008) Angehörige von Demenzkranken begleiten – Erfahrungen aus dem Projekt »Pflegebegleiter«. Archiv für Wissenschaft und Praxis der sozialen Arbeit 4: 104–111

Valach L, Stevens A (2007) Understanding and analysis of teaching in joint actions, projects and careers. An action theoretical conceptualization of teaching processes. In: Columbus F (ed) Focus on teaching and teachers issues. New York

3

Dementia

Ilkin Icelli, Ignat Petrov

3.1 Mild Cognitive Impairment

Ilkin Icelli

Historical Background and Definition

There was a belief in past centuries that the intellectual power of old people decrease over years. In the twentieth and the beginning of the twenty-first century, scientific and clinical researches showed that most people live a decline in intellectual capacity in their middle- sixties or early seventies, but this does not mean that they are all in a loss of cognitive capacities (Milvain and Iversen 2002).

Mild cognitive impairment (MCI) is a state of cognition that is more impaired than normal, but less impaired than dementia (Ganguli 2007). It can be presented with a variety of symptoms. When memory loss is the predominant symptom, it is called »amnesic MCI«. It is also defined as a syndrome, describing cognitive decline for the individual's age and education level which does not significantly interfere with daily life activities. Many of the persons with mild cognitive impairment appear to remain stable or revert to normal over time, but a meaningful rate progress to dementia within five years (Gauthier 2005), usually 15% of subjects per year develop symptoms of dementia.

The term MCI is presently reserved for persons whose deficits become manifest only in a detailed clinical interview. A person at this stage of his life can generally cope with all his daily life activities (e.g. going shopping, purchasing items without help) but have the difficulty of remembering events and conversation details.

Mild cognitive impairment is also a term generally referring to persons who do not fulfill criteria for Alzheimer's disease or other dementias. Clinical investigators tried to define the boundaries of normal cognitive aging over forty years. In 1962, Kral (1962) asserted the term »benign senescent forgetfulness« (BSF) to describe a population of nursing-home residents with light memory impairment. After that, »age-associated memory impairment«(AAMI) (Crook et al. 1986), «age-consistent memory impairment« (ACMI), »late-life forgetfulness« (LLF) (Blackford and La Rue 1989) and »age-related cognitive decline« (ARCD) are proposed to define that impairment. Later, in contrast to these proposed definitions of »normal« brain aging, Levy's »aging-associated cognitive decline« (AACD) term included subjects who performed below normal levels for their own age group making pathological basis more likely (Levy 1994).

In the 1980s, Global Clinical Staging Scales were introduced to classify the broad spectrum of intellectual performance for the study of the geriatric populations. There were two scales recognized to categorize the subjects who show some cognitive dysfunctions without dementia: The Global Deterioration Scale (GDS) and the Clinical Dementia Rating (CDR). Those are the commonly used scales. The GDS system identifies the following stage of relevance:

- stage 1: no subjective or clinically evident impairment;
- stage 2: subjective deficit only;
- stage 3: subtle deficits manifest, which may interfere with executive tasks;
- stage 4: clearly manifest deficits which may interfere with instrumental activities.

Recent reviews have noted that »the term MCI was a term coinciding with the description of Global Deterioration Scale Stage 3« (Reisberg et al. 2001). The syndrome that appears to have become widely accepted is that of mild cognitive impairment (MCI) (Flicker et al. 1991; Bruscoli and Lovestone 2004). In 1995, Petersen et al. (1995) used the term mild cognitive impairment as an independent diagnostic category not linked to a previously defined rating scale.

Causes and Risk Factors

The most direct hypothesis would be a selective loss of neurons from the frontal lobe in old age. Neuropathological and neuroimaging evidences suggest that biological changes associated with dementia and Alzheimer's disease in particular, occur long before, perhaps decades before the onset of symptoms (Brookheimer 2000). Therefore, it is probable to say that there are indicators of incipient dementia occurring before the onset of the full dementia syndrome (Jonker et al. 2000).

The brain changes caused by Alzheimer's disease or other types of dementia are seen in MCI. The difference between them is that the MCI changes are limited. These changes can include the abnormal clumps of beta-amyloidal plaques, the abnormal clumps of tau protein tangles, shrinkage of the hippocampus which is an important area for memory, strokes and the abnormal clumps of Lewy bodies associated with Parkinson's disease (Mayo Foundation for Medical Education and Research 2008).

Although many persons with MCI appear to remain stable; according to an International Psychogeriatric Association's debate held in Sweden in 2005 in the 12th Congress, it is said that quite a number of people with MCI progress to dementia (Gauthier 2005). In a recent study realized in the Netherlands that investigates a ten-year risk of dementia in subjects with MCI, the majority of the subjects did not progress to dementia in the long term (Visser et al. 2006).

Symptoms

There is an evidence of decreased capacities in various areas. Concentration and calculation deficits may be noted on serial subtractions. Decreased performance on queries related to person's orientation may not be evident or suspect. There can be moderate deficits in performance on a variety of cognitive tasks that reflect the ability to perform some arithmetic calculations or to perform in other areas (Reisberg and Saeed 2004).

The most frequently subjective complaints of memory deficit are forgetting where one has placed familiar objects and forgetting names formerly known well. Manifestations can be seen in one of the following areas: patient may have got lost when traveling to an unfamiliar location, co-workers become aware of patients' relatively poor performance, word- or name-finding deficit becomes evident to intimates, one may read a passage or a book and retain relatively little material, may demonstrate decreased facility of remembering names on introduction to new people, may have lost or misplaced an object of value, may have a concentration deficit, there may be a decreased performance in demanding employment and social settings, denial may begin to become manifest and mild-to-moderate anxiety frequently accompanies symptoms (Reisberg et al. 1982). Longitudinal studies indicate that many of these persons manifest deterioration when followed over intervals of a few to several years. Therefore, it is useful to follow up the elderly with mild cognitive impairment every year by neuropsychological examinations and neuroimaging if it is needed. However, a substantial minority of these subjects does not manifest deterioration even when followed over a decade or longer. Their deficits may be associated with subtle brain trauma (which may not be clearly evident by neuroimaging or other investigations) or undetected medical or psychiatric conditions (Reisberg et al. 2004).

In 2002, an investigation on the neuropsychiatric symptoms in mild cognitive impairment held by Lyketsos et al. showed that the most frequent symptom was depression (20%), followed by apathy (15%) and irritability (15%); the most frequent clinically significant symptom was sleep disturbance. From that point, the researchers also speculate that the intermediate prevalence of these symptoms supports the hypothesis that MCI is a precursor syndrome to dementia (Obrien and Barber 2003). A research study on the psychiatric co-morbidity with MCI suggested that depression was common in these subjects (Verhey et al. 2001). There are some other researches that investigate the early clinical markers that may predict a likely progression from mild cognitive impairment to Alzheimer's disease. For the moment, the number of subjects investigated in these researches is not sufficient to reach an objective opinion (Marcos et al. 2006).

Diagnosis

There is no specific test to diagnose mild cognitive impairment. As it is stated previously, persons in the stage of MCI can generally carry out all daily life activities in which they were formerly engaged. The memory deficits may be suspected on detailed questioning or when the patient repeats queries or phrases in the course of conversation. Orientation of the patient may be decreased and this decrease may be evident or suspect. Beside this, there can be a decrease in performing simple arithmetic calculations. At this stage, the deficits can not be detected by ordinary people. The MMSE may result a perfect score, but the subject may demonstrate recall deficits. Apart from clinically deficits, deficits in psychometric test performance, executive functions and other clinically relevant domains may occur in this MCI stage (Reisberg and Saeed 2004). An attentive neurological examination may reveal signs of strokes, Parkinson's disease or space occupying process or other medical conditions which impair memory functions. Blood tests must be obligatory, because vitamin B12 deficiency and underactive thyroid gland may also impair memory functions.

Neuroimaging research in MCI has focused on the medial temporal lobe, with particular emphasis on such structures as the hippocampus and entorhinal cortex. In-vivo studies confirm that hippocampeal atrophy is a frequent characteristic of MCI. More recent MRI studies have found atrophy of the entorhinal cortex in MCI patients with greater volume reductions; but longitudinal studies in MCI, using combinations of brain imaging, psychometric testing and CSF sampling are still need to be performed (Golomb et al. 2004).

Complications

Amnesic mild cognitive impairment is highly predictive of future development of Alzheimer's disease. In the Austrian study of Fisher et al. (2007), 476 subjects were followed up to 30 months. Over this frame, the conversion rates to Alzheimer's disease were found high (Barber and Baldwin 2007). According to a more recent study, symptoms and signs that are currently used to define MCI are not always present in persons who develop Alzheimer's disease (Palmer et al. 2007).

Treatment

Actually there is no specific pharmacological treatment for MCI; but clinically there appears to be a growing use of the medicines of Alzheimer's disease in MCI. These cholinesterase inhibitors (tacrine, donepezil, rivastigmine, galantamine) are all approved for the treatment of mild-to-moderate Alzheimer's disease (Reisberg and Saeed 2004, p. 488).

Tacrine, at the end of three years of study, is not recommended for its potential hepatic toxicity (Reisberg and Saeed 2004, p. 488).

Donepezil, after three years of study, showed no difference in the rate of progression from MCI to Alzheimer's disease (Mayo Foundation for Medical Education and Research 2008).

Rivastigmine, in a research of six-month follow-up study, the rate of patients improving or not worsening was 56% (Reisberg and Saeed 2004, p. 960).

Galantamine increases the risk of sudden death from heart attacks and strokes when used in MCI (Mayo Foundation for Medical Education and Research 2008).

Memantine, an NMDA (N-Methyl-D-Aspartate) receptor agonist, was superior to placebo on global measures of functioning and on activities of daily living scores (Reisberg and Saeed 2004, p. 964).

The therapeutic approach would be to test those drugs and to use those proven in diseases (Bruscoli and Lovestone 2004).

In case of vitamin B12 deficiency, if the clinician attributes cognitive loss to that deficiency, monthly B12 injections may restore some function or prevent further deterioration (Stapler et al. 1997).

Treatment of vitamin E works no better than placebo in relieving the symptoms or delaying the progression of MCI (Kral 1962).

It is still uncertain if Gingko can help the memory problems associated with MCI (Mayo Foundation for Medical Education and Research 2008).

In elderly people with mild cognitive impairment, depression is common and that co-morbid disorder may cause memory problems. By treating depression, the memory will improve and coping with life events will be less difficult.

Management

Management needs in aging depend on the stage of the condition. Special management strategies include support groups. Support groups are sometimes available for patients, mainly in mild cognitive impairment and appear to be useful. Spouse and family member support groups have long been available and are an important, frequently used and useful resource (Reisberg and Saeed 2004, p. 487). Complex situations may cause anxiety, so it would be better to keep the elderly with MCI out of these situations. Physical exercise, engaging in intellectually challenging activities, joining in social activities and having a good sleep can be part of a healthy lifestyle for older people with mild cognitive impairment (Mayo Foundation for Medical Education and Research 2008).

References

Barber R, Baldwin R (2007) Predicting conversion from MCI to dementia. IPA Bulletin 2: 14

Blackford RC, La Rue A (1989) Criteria for diagnosing age-associated memory impairment. Proposed improvement from the field. Dev Neuropsychol 5:295–306

Brookheimer SY, Strojwas MH, Cohen MS, Saunders AM, Pericak-Vance MA et al. (2000) Patterns of brain activation in people at risk of Alzheimer's disease. New Eng J Med 343:450-456

Bruscoli M, Lovestone S (2004) Is MCI really just early dementia? A systematic review of conversion studies. Int Psychogeriatrics 16:129–140

Crook T, Bartus RT, Ferris H, Whitehouse P, Cohen GD, Gershon S (1986) Age-associated memory impairment: proposed diagnostic criteria and measures of clinical change. Dev Neuropsychol 2:261–276

Fisher P, Jungwirth S, Zehetmayer S, Weissgram S, Hoenigschnabl S, Gelpi E, Krampla W, Tragl KH (2007) Conversion from subtypes of mild cognitive impairment to Alzheimer dementia. Neurology 68: 288–291

Flicker C, Ferris H, Reisberg B (1991) Mild Cognitive Impairment in the elderly: predictors of dementia. Neurology 41:1006–1009

Ganguli M (2007) Prevalence and outcomes of MCI subtypes in a rural American community Cohort. Int Psychogeriatr (IPA 13th International Congress Abstract Book) 19 (Suppl 1): 43

Gauthier S (2005) Mild Cognitive Impairment. Int Psychogeriatr (IPA 12th International Congress Book, IPA Debate) 17 (Suppl 2): 386

Golomb J, Kluger A, Ferris SH (2004) Mild Cognitive impairment: historical development and summary of researches. Dialogues Clin Neurosci 6: 351–363

Jonker C, Geerlings MI, Shamand B (2000) Are memory complaints predictive for dementia. A review of clinical and population-based studies. Int J Geriatric Psychiatry 15:983–999

Kral VA (1962) Senescent forgetfulness: benign and malignant. Can Med Ass J 86:257–260

Levy R (1994) Aging-associated with cognitive decline. Int Psychogeriatr 6:63–68

Lyketsos CG, Lopez O, Jones B, Fitzpatrick AL, Breitner J, DeKosky S (2002) Prevalence of neuropsychiatric symptoms in cognitive impairment. IPA Bulletin 1: 17

Marcos A, Gil P, Barabash A, Rodriguez R, Encinas M, Fernandez C, Cabranes JA (2006) Neuropsychological markers of progression from mild cognitive impairment to Alzheimer's disease. Am J Alzheimer's Disease and Other Dementias 21: 189–196

Mayo Foundation for Medical Education and Research (MFMER) (2008) Mild Cognitive Impairment, August, 26th, 2008

Milvain E, Iversen S (2002) Cognitive change in old age. In: Jacoby R, Oppenheimer C (eds) Psychiatry in the Elderly. Oxford University Press, Oxford New York, p 43

Obrien JT, Barber R (2003) Neuropsychiatric symptoms in cognitive impairment. IPA Bulletin 1: 17

Palmer K, Backman L, Winblad B, Fratiglioni L (2007) Early symptoms and signs of cognitive deficits might not always be detectable in persons who develop Alzheimer's disease. IPA 13th International Congress Abstract Addendum, p 2

Petersen RC, Smith GE, Ivnic RT et al. (1995) Apolipoprotein E status as a predictor of the development of Alzheimer's disease in memory-impaired individuals. JAMA 273:1274–1278

Reisberg B, Ferris SH, de Leon MJ, Crook T (1982) The Global Deterioration Scale for assessment of primary degenerative dementia. Am J Psychiat 139: 1136–1139

Reisberg B, Franssen E, Shah MA, Weigel J, Bobinski M, Wisniewski HM (2004) Clinical diagnosis in dementia. In: Sadavoy J, Jarvik L, Grossberg GT, Meyers BS (eds) Comprehensive Textbook of Geriatric Psychiatry. WW Norton, New York London, p 469

Reisberg B, Kluger A, Franssen E H Colomb J (2001) Mild cognitive impairment: Definition, diagnosis and prognosis: perspective from the GDS/FAST staging system. Int Psychogeriatr (10th International Congress Book) 13 (Suppl 2): 36

Reisberg B, Saeed UM (2004) Alzheimer's Disease. In: Sadavoy J, Jarvik LF, Grossberg GT, Meyers BS (eds) Comprehensive Textbook of Geriatric Psychiatry. WW Norton, New York London, pp 468–469

Stapler SP, Lindenbaum J, Allen RH (1997) Vitamin B12 deficiency in the elderly: current dilemmas. Am J Clin Nutr 66: 741–749

Verhey FR, Visser PJ, Ponds RW, Jolles J (2001) Psychiatric Comorbidity in Subjects with Mild Cognitive Impairment. IPA 10th International Congress, IPA Debate; 13 (Suppl 2)

Visser PJ, Kester A, Jolles J, Verhey F (2006) Ten-year risk of dementia in subjects with Mild Cognitive Impairment. Neurology 67: 1201–1207

3.2 Dementia. State of the Art – Cognitive, Behavioural and Psychopathological Symptoms

Ignat Petrov

Dementia is the most common cause of mental impairment in older persons. It is now recognized to be a major medical, psychiatric, neurologic, epidemiologic, psychologic, sociologic, and economic entity throughout the contemporary world (Reisberg 1987). Dementia may occur at any age, but affects primarily the elderly. Dementia is an acquired, global, progressive and usually irreversible deterioration of cognition. It affects multiple cognitive functions.

The article aims to survey the full spectrum of cognitive, behavioral and psychopathologic symptoms of dementia disorders, which are essential aspects of diagnosis and treatment. Other elements of the complex diagnostic process (neuroimaging, neuropsychologic etc.) and of the therapeutical approach (pharmacology, psychotherapy, and organization of cares) are not a target of this survey. The course of dementia disorders is examined only partly.

Main Features of the Dementia Syndrome

Dementia is a syndrome, not a disease; it is a pattern of symptoms that can be caused by many different illnesses affecting the brain. Three key features characterize the dementia syndrome:

It is acquired and persistent, and it impairs cognition globally (it involves multiple impairment of intellectual functioning) (Zarit and Zarit 1998; Diagnostic and Statistical Manual of Mental Disorders 1994).

Dementia, as distinguished from mental retardation, is an acquired disability. Symptoms of dementia persist and worsen over time. In contrast, people who suffer a head trauma may stabilize or even improve in cognitive functioning. Symptoms of cognitive impairment in other psychiatric disorders, such as depression, tend to be transitory. Finally, dementia involves deficits in multiple cognitive functions – language, memory, visual spatial skills, general intellectual abilities, abstract thinking, judgement and insight. By comparison, head trauma or stroke often involve deficits of one or two localized functions (Zarit and Zarit 1998).

According to the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) of the American Psychiatric Association (1994), the three main criteria for diagnosis of dementia are:

1. memory impairment;
2. cognitive disturbances in at least one other area of functioning (e.g., aphasia, apraxia, agnosia, or a disturbance in executive functions), and
3. the cognitive deficits must be sufficiently severe to cause impairment in occupational or social functioning and must represent a decline from a previously higher level of functioning.

Cummings and Benson (1992) point out that memory impairment is not always present in some forms of dementia, for instance, in early and middle stages of Pick’s disease. They suggest an alternative definition, that dementia involves impairment in at least three of the following areas of functioning: language, memory, visuospatial functioning, other cognitive abilities, emotion or personality.

Dementia disorders share roughly common symptom presentation but are based on diverse etiologies. The most common entities according to etiology are: dementia of the Alzheimer type, vascular dementia, dementia due to HIV disease, dementia due to head trauma, dementia due to Parkinson’s disease, dementia due to Huntington’s disease, dementia due to Pick’s disease, dementia due to Creutzfeld-Jacob disease, dementia due to other general medical conditions, substance induced persistent dementia, dementia due to multiple etiologies (Diagnostic and Statistical Manual of Mental Disorders 1994). The dementia syndrome can develop from many different disorders, including some that are currently largely treatable and reversible. Examples are dementia syndromes due to metabolic disorders, like hypothyroidism or vitamin-B12 deficiency (Zarit and Zarit 1998). Among the irreversible diseases are Alzheimer’s disease and vascular dementia. Both are the most common types of dementia.

The particular pattern of dementia syndrome varies according to the areas of the brain affected by the underlying disorders. According to this principle, dementia syndromes may be classified in cortical, subcortical or combined. They may also be described by some features of the specific brain lesions. Other common types of dementia are Lewy body dementia and frontotemporal dementia (Zarit and Zarit 1998; Merck Manual Professional 2007a).

Patients may have more than one etiology (mixed dementia). For example, many people have a combination between both most common types – Alzheimer and vascular dementia (Zarit and Zarit 1998; Merck Manual Professional 2007a).

Common Cognitive Symptoms

Memory and Learning

We emphasize that dementia involves multiple impairment of cognitive functions. At the same time many specialists find that impairment in short-term memory and learning of new information is the first and prominent symptom in most types of dementia (Cummings and Benson 1992; Folstein 1983). Another opinion is that – in a transversal look – most individuals with dementia have impairment in their ability to learn new material and simultaneously they forget previously learned material. But it is sometimes difficult to demonstrate the loss of previously learned material early in the course of the disorder (Diagnostic and Statistical Manual of Mental Disorders 1994).

At the beginning as well as at the intermediate stages of dementia, the earlier obtained memory material seems to be better conserved that the newly learned material. So, the loss of memory follows to some extent the rule of Ribot (1882) – it goes from the newest, recently obtained knowledge to the older and more durable memories. This course is typical for the primary atrophic Alzheimer type of dementia. The person with dementia may answer to the question where he lives indicating an address of 20 or more years before in the past. This year I consulted a 79-year old man who, walking at the streets of his city, became lost and could not find his home. Finally he succeeded to find the railway station and to take the train to his native village, 40 kilometers far from the capital city (where he has lived for many years).

In the 1980s, I consulted an 84-year old politician, a former minister and parliament member for many years in the period after the World War II. At our first meeting at an old age home I asked him about his occupation and place of living. He answered: »I am a lawyer in the town P.« Knowing about his brilliant political career in the capital city, I was astonished at his answer, but later I knew that he really has lived and worked in the provincial town P. up to the age of 40. He has forgotten the most successful period of his life embracing his middle and late years.

The course of each type of dementia is a continuum of progressive impairment of interwoven cognitive functions (Reisberg 1987; Merck Manual Professional 2007a). Regarding memory in early dementia, people may have progressive difficulty in learning and retaining new information, difficulty in finding words, difficulty in orientation and activities of daily living, e.g. remembering where they put things. They may not recognize well-known persons or recall their names. They may lose valuables like wallets and keys, forget food cooking on the stove, and become lost in unfamiliar neighborhoods (Reisberg 1987; Merck Manual Professional 2007a).

In the middle stages of dementia, individuals become unable to learn and recall new information. Memory of remote events is reduced but maybe not totally lost. Patients may require help with basic activities of independent daily living (e.g. bathing, eating, dressing, toileting). According to the evolution of the memory decline, many old persons with dementia could imagine that they were still young, still studying, and living e.g. with their parents (»a life in the past«; Zhislin 1965; Sternberg 1977). By middle stages, patients have lost all sense of time and place because they cannot effectively use environmental and social cues. They often get lost; they may be unable to find their own bedroom or bathroom. They remain ambulatory, but are at risk of accidents secondary to confusion (Merck Manual Professional 2007a).

In advanced stages of dementia, memory impairment is so severe that the person forgets his or her occupation, schooling, birthday, family members, and sometimes even name. Recent and remote memory becomes completely lost. Patients cannot walk, feed themselves, or do any other activities of daily living; they may become incontinent and mute (Diagnostic and Statistical Manual of Mental Disorders 1994; Merck Manual Professional 2007a).

Alzheimer's disease is characterized by an insidious onset and continuing, gradual, steady deterioration of the memory and of all intellectual capacities (Diagnostic and Statistical Manual of Mental Disorders 1994; Jorm 1987). In vascular dementia, and especially its most common type – the multi-infarct dementia, onset is usually sudden and abrupt, followed by a stepwise and fluctuating course (Diagnostic and Statistical Manual of Mental Disorders 1994; Merck Manual Professional 2007a). It is characterized by rapid changes in functioning rather than slow progression. Cognitive loss may be focal or partial especially in early or intermediate periods of the disorder. Certain cognitive functions may be affected early, whereas others remain relatively unimpaired. Short-term memory may be less affected than in other forms of dementia. The pattern of deficits is »patchy« depending on which regions of the brain have been destroyed. Because infarction is the cause, vascular dementia and the cognitive decline tends to progress in discrete steps; each episode is accompanied by cognitive decline, sometimes followed by modest recovery. Patients may be stable for periods of time and then experience a sudden drop in functioning. Not all people with vascular dementia, however, follow this pattern. The course may be highly variable, and an insidious onset with gradual decline is also encountered (Diagnostic and Statistical Manual of Mental Disorders 1994; Merck Manual Professional 2007a). And, at the advanced stages of disorder, most individuals with vascular dementia have an already global deterioration of cognition and resemble to the patients with Alzheimer's disease.

In Lewy body dementia the short-term memory is less affected than in Alzheimer's disease. More expressed are deficits in alertness and attention than in memory acquisition. Fluctuating cognitive function is a relatively specific feature of Lewy's body dementia. Periods of being alert, coherent and orientated may alternate with periods to being confused and unresponsive to questions, usually over a period of days to weeks but sometimes during the same interview (Merck Manual Professional 2007a).

Asking the person to register, retain, recall and recognize information may test the memory. The ability to learn new information may be assessed by asking the individual to learn a list of words. The individual is requested to repeat the words (registration), to recall the information after the delay of several minutes (retention, recall), and to recognize from a multiple list (recognition). Persons with difficulty learning new information are not helped by clues or prompt (e.g. multiple-choice questions) because they did not learn the material initially. In contrast, clues and prompts can help individuals with primarily retrieval deficits, because their impairment is in the ability to access their memories. Remote memory may be tested by asking the individual to recall personal information or past material that the individual found of interest. It is also useful to determine (from the individual and informants) the impact on the individual's functioning (e.g. ability to work, shop, cook, pay bills, return home without getting lost) (Diagnostic and Statistical Manual of Mental Disorders 1994).

Language

Impaired ability to comprehend or use language (*aphasia*) may be manifested by difficulty in producing the names of individuals and objects. The speech of individuals with aphasia may become vague or empty, with long circumlocutory phrases and excessive use of terms of indefinite reference such as »thing« and »it«. Comprehension of spoken and written language and repetition of language may also be compromised. In the advanced stages of dementia, individuals may be mute or have a deteriorated speech pattern characterized by echolalia (i.e. echoing what is heard) or palilalia (i.e. repeating sounds or words over and over) (Diagnostic and Statistical Manual of Mental Disorders 1994). Language is tested by asking the individual to name objects in the room or body parts, following commands (»point at the door and then on the table«), or repeating phrases (like »no ifs, ands, or buts« from MMSE of Folstein 1983).

Apraxia i.e. impaired ability to perform previously learned motor activities – despite intact motor abilities, sensory function, and comprehension of the required task. Individuals with dementia will be impaired in their ability to pantomime the use of objects or to execute known motor acts. Apraxia may contribute to deficits in cooking, dressing and drawing. Motor skill disturbances may be tested by asking the individual to execute motor functions (e.g. to show how to brush teeth, to copy intersected pentagons, to assemble blocks, or to arrange sticks in specific design) (Diagnostic and Statistical Manual of Mental Disorders 1994).

Agnosia i.e. impaired ability to recognize or identify objects despite intact sensory function. For example, individuals with dementia may have normal visual acuity but lose the ability to recognize objects such as chairs or pencils. Eventually they may be unable to recognize family members or even their own reflection in the mirror (the symptom of the mirror; Sternberg 1977). Similarly, they may have normal tactile sensation, but be unable to identify objects placed in their hands by touch alone (e.g. a coin or keys) (Diagnostic and Statistical Manual of Mental Disorders 1994; Merck Manual Professional 2007a).

»Instrumental« symptoms of aphasia, apraxia, and/or agnosia, usually are more expressed in Alzheimer dementia with earlier onset (presenile type) than at the senile type with a late onset of the disorder (Sternberg 1977).

An **impairment of the speech** (hypophonic, dysarthric) may appear in the course of vascular dementia (with subcortical lesions) earlier than in Alzheimer type of dementia, where speech may be seemingly and formally intact for a longer period.

Slurry speech may also be present in Parkinson's and Huntington's disease (Diagnostic and Statistical Manual of Mental Disorders 1994; Merck Manual Professional 2007a).

Visuospatial functioning

Individuals with dementia may become spatially disoriented and have difficulty with spatial tasks. Asking the individual to copy drawings such as circle or overlapping pentagons (Diagnostic and Statistical Manual of Mental Disorders 1994) can assess visuospatial functioning.

Impairment in Intellectual Functioning and Disturbances in Executive Functioning

Both are interwoven, and both are common manifestations of dementia. Executive dysfunction may be related especially to disorders of the frontal lobe or associated subcortical pathways (Diagnostic and Statistical Manual of Mental Disorders 1994; Merck Manual Professional 2007a). Executive functioning involves the ability to think abstractly and to plan, initiate, sequence, monitor, and stop complex behavior. Impairment in abstract thinking may be manifested by the person having difficulty coping with novel tasks and avoiding situations that require the processing of new and complex information (Diagnostic and Statistical Manual of Mental Disorders 1994).

Poor **judgement** and poor **insight** are also common in dementia. Individuals may exhibit little or no awareness of memory loss or other cognitive impairments. They may make unrealistic assessments of their abilities and make plans that are not congruent with their deficits and prognosis (e.g. planning to start a new business). They may underestimate the risks involved in some activities (e.g. driving) (Diagnostic and Statistical Manual of Mental Disorders 1994).

The ability to abstract can be assessed by asking the person to find similarities or differences between related words. Executive dysfunction is also evident in a reduced ability to shift mental sets, to generate novel verbal or nonverbal information, and to execute serial motor activities. Tests for executive function include asking the individual to count to 20 and/or backward from 20 to 1, recite the alphabet, subtract serial 7s, state as many animals as possible in 1 minute, or draw a continuous line consisting of alternating m's and n's. It is also useful to determine (from the individual and informants) the impact of the disturbances in executive functioning on the individual's daily life (e.g. ability to work, plan activities, budget)

(Diagnostic and Statistical Manual of Mental Disorders 1994).

Memory impairment, aphasia, apraxia, agnosia, or disturbance in executive or intellectual functioning may be severe enough to cause significant impairment in social or occupational functioning (e.g. working, studying, handling finances, dressing, bathing, and other activities of daily living) and must represent decline from a previous level of functioning. The nature and degree of impairment are variable and often depend on the particular social setting of the person. The same level of cognitive impairment may significantly impair an individual ability to perform a complex job, but not a job that is less demanding (Diagnostic and Statistical Manual of Mental Disorders 1994).

In cortical dementia's, such as Alzheimer disease, deterioration of basic intellectual processes of memory, language, judgement, and visual spatial skills are prominent. Typical is the learning deficit. For subcortical dementias, such as Parkinson's and Huntington's diseases as well as vascular dementias with subcortical lesions, more typical is a slowing of cognitive processes and memory and an inability to spontaneously recall or integrate information (retrieval deficit) (Zarit and Zarit 1998; Merck Manual Professional 2007a).

Frontotemporal dementias, including Pick's disease, affect memory less than does Alzheimer's disease. They affect mostly personality, behavior, and language (syntax and fluency). Abstract thinking and attention are impaired, responses are disorganized (Merck Manual Professional 2007a).

Physical and Neurologic Problems Related with Behavior in Dementia

Gait Disturbances and Falls

Dementia is sometimes accompanied by motor disturbance of gait leading to falls. Dementia itself is one of the predisposing factors for falls. Gait abnormalities as well as focal neurologic deficits develop mostly in vascular dementia. They include weakness of an extremity, hemiplegias, pseudobulbar palsy with pathological laughing and crying; other signs of extrapyramid dysfunction.

Incidence of seizures is somewhat increased during all stages of the dementing process (Diagnostic and Statistical Manual of Mental Disorders 1994; Merck Manual Professional 2007a).

Dementia and Stress

Individuals with dementia may be especially vulnerable to physical stressors (e.g. illness or minor surgery). Physical problems (e.g. pain, shortness of breath, dehydration, urinary retention, constipation, physical abuse) can exacerbate behavioral and psychologic symptoms, partly because patients may be unable to adequately communicate. Physical problems can lead to delirium, and delirium superimposed on chronic dementia may worsen the behavioral symptoms.

Psychosocial stressors (e.g. going to a hospital or nursing home, bereavement) may exacerbate the intellectual deficits and other associated problems of people with dementia (Diagnostic and Statistical Manual of Mental Disorders 1994; Merck Manual Professional 2007a).

Behavioral and Psychopathologic Symptoms of Dementia

Personality changes and behavioral disturbances may develop early or late in the course of dementia.

Anxiety and Depression

The multiple cognitive impairments of dementia are often associated with anxiety, mood and sleep disturbances. They may affect behavior and must be identified.

Depression is common among patients with dementia. Depression could be a reaction of the personality toward the perceived intellectual decline. In other cases, depression, especially depression of late life, could precede the onset of cognitive decline. It is known that the history of depressive disorders does increase the risk of future development of dementia. The relationship between late depression and dementia has not been well studied. Perhaps some common organic brain lesions contribute to both disorders. When depression superimpose dementia it may first manifest as an abrupt change in cognition, decreased appetite, deterioration in mood, a change in sleep pattern (often hypersomnolence) withdrawal, decreased activity level, crying spells, talks of death and dying, sudden development of irritability or psychosis, or other sudden changes in behavior. Often depression is suspected first by family members (Merck Manual Professional 2007b). Suicidal behavior may occur, particularly in early stages when the individual is more capable of carrying out a plan of action (Diagnostic and Statistical Manual of Mental Disorders 1994).

Somehow different is the problem of *dementia of depression (depressive pseudodementia).* This affective disorder mimics dementia. It includes cognitive symptoms that are reversible, and it resolves during treatment of depression. Patients look depressed, silent and slow. Unlike the patients with true dementia, people with dementia of depression tend to exaggerate their memory loss, but rarely forget important current events or personal matters. When tested, patients with depression make little effort to respond (a typical answer is »I don't know, I can't«), but people with dementia often try hard but answer incorrectly (Merck Manual Professional 2007a).

When depression and dementia really coexist, treating depression does not fully restore cognition. But in any case treating a coexisting depression will be very useful for improving general condition and quality of life.

Psychosis – hallucinations, delusions, paranoia – occur in about 10% of patients with dementia, although a higher percentage may experience these symptoms temporarily. Delusions are common, especially those involving themes of persecution (e.g. that misplaced possessions have been stolen). Hallucinations can occur in all sensory modalities, but visual hallucinations are most common. Delusions and hallucinations must be distinguished from disorientation, fearfulness, and misunderstanding, which are common among patients with dementia. Delusions without paranoia may be confused with disorientation, but delusions are usually fixed (e.g. nursing home is repeatedly called prison), and disorientation varies (e.g. nursing home is called prison, restaurant, or home). Hallucinations occur without external sensory stimuli; hallucinations should be distinguished from illusions, which involve misinterpreting external sensory stimuli (e.g. cellular phones, pagers) (Merck Manual Professional 2007a,b).

Delirium is frequently superimposed on dementia because the underlying brain disease may increase susceptibility to confusional states that may be produced by medications or other concurrent general medical conditions. It is important to differentiate dementia with psychosis from delirium, because delirium is usually reversible with prompt treatment, and the management of those conditions differs. Attention is assessed first. If a patient is inattentive, the diagnosis is likely to be delirium, although advanced dementia also severely impairs attention. The history, physical examination, and tests for specific causes determine other features that suggest delirium rather than dementia. For example, the duration of cognitive impairment during delirium is usually from days to weeks (Merck Manual Professional 2007c).

Disruptive actions are common among people with dementia and are the primary reason for up to 50% of nursing-home admissions. Disruptive actions include wandering, restlessness, yelling, throwing, hitting, refusing treatment, incessantly questioning, disrupting work of staff members, insomnia and crying. Occasionally, the patients with dementia may harm others by becoming violent (Diagnostic and Statistical Manual of Mental Disorders 1994; Merck Manual Professional 2007b).

Behavioral symptoms of dementia have not been well characterized, and their treatment is poorly understood. They depend on the place of residence of the person. Elderly people with or without dementia feel themselves better when living in her/his own home. Placed in a residence or nursing home, they feel more anxious and insecure. It is a crucial problem to instruct and teach the caregiver how to listen to the person with dementia, how to answer (slowly, clearly) and how to calm her/him through verbal and/or non-verbal contact (touch) (Balkanska 1999). Sometimes it is difficult to know how to lessen the misunderstanding in the dialogue and subsequent tension of the person with dementia.

Deciding what actions constitute a behavioral symptom is highly subjective. Tolerability (what action caregivers can tolerate) depends partly on the patient's living arrangements, particularly safety. For example, wandering may be tolerable if a patient lives in a safe environment (with locks and alarms on all doors and gates). However, if the patient lives in a nursing home or hospital, wandering may be intolerable because it disturbs other patients or interferes with the operations of the institution. Many behaviors (e.g. wandering, repeatedly questioning, being uncooperative) are better tolerated during the day. Whether an exacerbation of disruptive behaviors at sundown or early evening represents decreased tolerance by caregivers or true diurnal variation is unknown. In nursing homes 12 to 14% of patients with dementia act disruptively more often during the evening than during the day (Merck Manual Professional 2007b).

Behavioral symptoms may result from functional changes related to dementia:

- reduced inhibition of inappropriate behaviors (e.g. patients may undress in public places);
- misinterpretation of visual and auditory cues (e.g. they may resist treatment, which they perceived as assault);
- impaired short-term memory (e.g. they repeatedly ask for things already received);
- reduced ability or inability to express needs (e.g. they wander because they are lonely, frightened, or looking for something or someone) (Merck Manual Professional 2007b).

Patients with dementia often adapt poorly to the regimentation of institutional living. Meal-times, bed-times, and toileting are not individualized. For many elderly patients with dementia, behavioral symptoms develop or worsen after they are moved to a more restrictive environment (Merck Manual Professional 2007b).

The Cohen-Mansfield Agitation inventory classifies behaviors as follows:

- physically aggressive: hitting, pushing, biting, scratching, or grabbing people or things;
- physically non-aggressive: for example, handling things inappropriately, hiding things, dressing or undressing inappropriately, pacing, repeating mannerisms or sentences, acting restless, or trying to go elsewhere;
- verbally aggressive: for example, cursing, making strange noises, screaming or having temper outbursts;
- verbally non-aggressive: For example complaining, whining, constantly requesting attention, not liking anything, interrupting with relevant or irrelevant remarks, or being negative or bossy (Merck Manual Professional 2007b).

Specific behaviors and events (e.g. feeding, toileting, drug administration, visits), and time the behavior started and resolved should be recorded; this information helps identify changes in pattern or intensity of behavior and makes planning a management strategy easier. If behavior changes, a physical examination should be done to exclude physical disorders and physical abuse, but environmental changes (e.g. a different caregiver) should also be noted because they, rather than a patient-related factor, may be a reason (Merck Manual Professional 2007b).

As mentioned at the beginning of the article, dementia may occur at any age, but affects primarily the elderly and has to be analyzed always in the context of the whole somatic status of the afflicted person and the possibilities of support e.g. to live so long as possible at home, for example, with an individual concept for out-patient nutrition (Fresenius Kabi 2009).

Dementia is one of the most interesting and challenging problems in medicine and social science. Despite these disorders are in most cases irreversible, there are wide range of possibilities to work with people with dementia and their families in order to improve their condition and quality of life.

References

Balkanska P (1999) Mediko-socialni i psychologichni problemi pri vazrastni i stari hora s dementen syndrom – podhodi za tiahnoto preodoliavane. PhD Dissertation, Sofia, 1999 (in Bulgarian; Abstract in English)

Cummings JL, Benson DF (1992) Dementia. A clinical approach, 2nd edn. Butterworth-Heinemann, Stoneham, MA

Diagnostic and Statistical Manual of Mental Disorders, 4th edn. (1994) American Psychiatric Association, Washington, DC

Folstein MF (1983) The Mini Mental State Examination. In: Crook J, Ferris S, Bartus R (eds) Assessment in geriatric psychopharmacology. Mark Powley Associates, New Canaan, pp 47–51

Fresenius Kabi (2009) Clinical nutrition: parenteral nutrition. http://www.fresenius.de/internet/fag/com

Jorm AF (1987) A guide to understanding of Alzheimer's disease and related disorders. New York University Press, New York

Merck Manual Professional (2007a) Dementia: delirium and dementia. Last full revision. http://www.merck.com/mmpe/sec16/ch213c.html

Merck Manual Professional (2007b) Behavioral and psychologic symptoms of dementia: delirium and dementia. Last full revision. http://www.merck.com/mmpe/sec16/ch213d.html

Merck Manual Professional (2007c) Delirium: Delirium and Dementia. Last full revision. http://www.merck.com/mmpe/sec16/ch213b.html

Reisberg B (1987) Senile dementia. In: Maddox GL (ed) Encyclopedia of aging. Springer, New York, pp 594–600

Ribot T (1882) Diseases of memory. Appleton, New York

Sternberg EY (1977) Gerontologicheskaya psychiatria. Meditsina, Moscow (in Russian)

Zarit SH, Zarit JM: Mental disorders in older adults. fundamentals of assessment and treatment. The Guilford Press, New York London, 1998

Zhislin SG (1965) Ocherki klinicheskoy psychiatrii. Meditsina, Moscow (in Russian)

4

Alzheimer

Jerzy Leszek, Andrzej Kiejna, Ulrich Michael Hemmeter, Ulrich Kropiunigg

4.1 Alzheimer's Disease – A Global Disease Report

Jerzy Leszek, Andrzej Kiejna

History

On November 3rd 1906, Aloys Alzheimer presented to the Meeting of the Psychiatrists the neuropathological and clinical features of Auguste D., who had died of dementing illness at the age of 55. The disease was given its eponym by his senior colleague E. Kraepelin. The description initiated the slow separation between Alzheimer's disease (AD) and other causes of presenile dementia (Hardy 2006).

Alzheimer's Disease (AD)

AD is a complex, slowly progressive neurodegenerative disorder of the brain and is the most common form of dementia (50–70%), followed by vascular dementia (30–40%), and mixed dementia (15–20%). Progressive cognitive decline is often accompanied by affective, behavioral disturbances, also termed neuropsychiatric symptoms (Jacob et al. 2007). In AD,

- depression and apathy are most common at the mild stage-duration time around 3 years;
- agitation, aggressiveness, delusions and hallucinations are commonly associated with the moderate stage-duration time around 3 years;
- patients with severe AD-duration time around 4 years often exhibit agitation, anxiety, abnormal motor behavior and day-night reversal.

The duration of the clinically silent stage may be longer than 9 or 10 years (Tschanz 2006; Glaser 2008). In former times, AD was regarded as a rare presenile disorder. At present, AD shows an increase in incidence and prevalence with increasing age. AD is not the result of a single specific insult, but the consequence of complex cascade of aberrant biological processes involving neural and non-neural systems. An appropriate conceptual model for studying the complex relationship between biochemical/molecular changes and the clinical symptoms, have been searched. Pathologically, AD is characterized by neuronal loss and synaptic degeneration with an increase number of senile plaques (SP), containing dystrophic neuritis, neurofibrillary tangles (NFT) and neuropil threads. The NFT are insoluble intracellular threadlike structures made up of a hyperphosphoryled form of a protein called tau, which normally binds to and stabilizes the microtubules, which run through the neuronal axon and participates in regular cellular events. The neuropathological diagnosis rests on the quantity and location of these morphological changes.

Expected Cases

Older people with dementia exist in nearly every country in the world. They represent a major problem of health in developed as well as developing countries, with more than 25 million people affected and probably more than 75 million people at risk during the next 20–25 years worldwide (Cacabelos 2007).

WHO projections suggest that by 2025, about three quarters of the estimated 1–2 billion people aged 60 years and older will reside in developing countries (WHO Active Ageing 2002). Thus, by 2040 if growth in the older population continues, and there are no changes in mortality or burden reduction by preventive measures, 71% of 81million dementia cases will be in the developing world (Ferri et al. 2005). About 4–6 million new cases of dementia are added every year, with the highest growths projections in China and its south Asian neighbors. These projections might be confounded by temporal changes due to shorter survival after dementia (Suh et al. 2001), lack of education and awareness, inadequate diagnostic assessment (Raicher et al. 2008) and variability in costs of care of the elderly with dementia (Wimo et al. 2006), all of which could lead to under-estimating of the dementia burden.

In China, for example, 49% of patients with dementia were classified as normally ageing and only 21% had adequate access to diagnostic assessment

(Zhong et al. 2006), compared with 20% and more than 70%, respectively, in Europe (Waldemar et al. 2007). In the 1990s, with demographic ageing proceeding rapidly in all regions worldwide, interest began to focus on the previously neglected topic of dementia in low-and middle-income countries (LMIC). Two-thirds of all people aged 65 years and older, and a similar proportion of people with dementia, were living in LMIC, with rapid increases predicted (Prince 1997).

Most people with AD lived in LMIC: 60% in 2001 rising to a forecast 71% by 2040. Numbers were predicted to double every 20 years to more than 80 million people by 2040, with more rapid increase in developing than in developed regions. In 2005, Alzheimer's Disease International (ADI) commissioned an international group of experts to review all available data and to reach a consensus on dementia prevalence in 14 WHO regions. The results suggested that 24.2 million people live with dementia worldwide, with 4–6 million new cases every year (Ferri et al. 2005). The trend towards a lower prevalence in less-developed regions than in developed settings was endorsed, at least for sub-Saharan Africa and South Asia.

Late-onset AD is the most common subtype of age-related dementia, even in developing countries; 60% of all cases of dementia fulfilled the US National Institute of Neurological and Communicative Disorders and Stroke and Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) criteria. Total population projections suggest that 3.1 million people in China could have AD (Dong et al. 2007). Although unusually high prevalence was apparent in some countries, the mean AD prevalence was estimated to be 3.4% which is slightly lower than in developed countries. Age-adjusted low prevalence (<1.5%) was reported in sub-Saharan Africa (Nigeria) and India (Das et al. 2006). Autopsy studies done in some developing countries have confirmed that the neuropathological changes associated with AD are qualitatively similar to those in patients in developed countries, however, more work is needed, particularly given that reported AD cases could also have cerebrovascular changes (Ogeng'o et al. 1996).

The prevalence of dementia, particularly that of AD, is increasing in the developing countries of Asia and Latin America. Countries in Latin America, such as Venezuela and Argentina, bear a higher burden of over 5% prevalence of dementia. However, reliable age-adjusted estimates indicate a low prevalence of dementia in India and sub-Saharan Africa (Rodrigues et al. 2008; Molero et al. 2007). A systematic analysis of six Indian studies suggests low prevalence (2–3%) of all dementias, with marginally fewer cases in urban compared with rural areas and in the northern versus southern states (Das et al. 2006). Further research is needed to examine why the APOE e(4) allele does not seem to influence AD progression in sub-Saharan Africa.

Socioeconomic Factors

Understanding the burden and costs of dementia is crucial to guide future healthcare and socioeconomic policy (Prince et al. 2007).

The annual treatment costs of AD in the USA are estimated at about 100 billion dollars. The costs increase with severity of the disease, from approximately 18,500 dollars per patient with mild AD per year to more than 36,000 per patient with severe AD per year (Cacabelos 2007). In some countries, approximately 80% of the global costs of dementia (direct and indirect costs) are assumed by the patients and/or their families. It has been postulated that dementia appears to be the most expensive disease in many countries in the population segment >60 years (Campbell et al. 2004). About 10–20% of the costs in dementia are attributed to pharmacological treatment, including anti-dementia drugs, psychotropic (antidepressants, narcoleptics, anxiolytics), and other drugs currently prescribed in the elderly (antiparkinsonians, anticonvulsants, vasoactive compounds, anti-inflammatory drugs, etc). In addition, during the past 20 years more than 300 drugs have been partially or totally developed for AD (Giacobini 2006). With the subsequent costs for the pharmaceutical industry, only 5 drugs with moderate-to-poor efficacy and questionable cost-effectiveness have been approved in developed countries (Clegg et al. 2001; Loveman et al. 2006).

Epidemiology of Dementia in Poland

Even though Poland is still in the group of younger Europe's societies, as the life expectancy increases the number of citizens systematically decreases. In the last National Census (2002) the number of inhabitants reached 38,230,100, among them 19,171,370 women (51.6%) and 18,516,400 men (48.4%). Population aged 65 and over reached 4,852,600 (12.7%), with 3,014,100 women (7.9%) and 1,838,300 men (4.8%). Age structure of Polish inhabitants has two peaks: one represents the 15- to 19-year-olds and second the 45- to 49-year-olds. These two peaks will move gradually and in 2020 the second group will reach the limit of elderly, substantially increasing the size of this population (http://www.stat.gov.pl/english/index.htm). It is a well-known fact that age is one of the important risk factors for cognitive disturbances and because of that relatively high incidence and prevalence rates of dementia might be expected in the years to come. In comparative findings for Europe there have been more than 300,000 persons suffering from dementia in Poland in 2005. This represents 0.79% people with dementia in Poland as a percentage of the total population, which is considerably lower than the EU average of 1.14% (Ferri et al. 2005). This calculation realized in a Delphi consensus method does not take into account any genetic, cultural, environmental, social, racial or other differences across the various countries. As such, it may be highly inaccurate and only give a general indication as to the actual prevalence or incidence of dementia.

In the 1990s and in 2005 four population-based epidemiological studies were carried out in Poland (Gabryelewicz 1999; Rossa 1997; Wender et al. 1990; Bidzan and Turczynski 2005).

Sample sizes vary considerably between studies (from n = 893 to n >7417 subjects), as do the age ranges (from >45 to >65 years). There is also a considerable variation with regard to the spectrum of diagnoses covered in each study (Alzheimer's dementia, vascular dementia, mixed dementia, secondary dementia). All mentioned studies are two-phase studies with a screening procedure including MMSE, followed by a diagnostic examination for screen positives. The results of these studies indicate a relatively high overall prevalence rates for all dementia types 7.8% and 2.3% for Alzheimer's disease in urban population with age range 65–84 years (Gabryelewicz 1999). Similarly high indices of dementia were shown by Bidzan and Turczynski (2005) for rural and suburban population over 60 years old, respectively 6.7% for all dementia types and 5.1% for Alzheimer's disease. The results of these studies are comparable with those obtained by Hofman et al. in 1991 for the Western European countries.

References

Bidzan L, Turczynski J (2005) Environment and cognitive functions in a population 60 years and older (Prevalence of dementia in a rural population). Psychiatr Pol 39: 1211–1218

Cacabelos R (2007) Molecular pathology and pharmacogenomics in Alzheimer's disease: polygenic-related effects of multifactorial treatments on cognition, anxiety, and depression. Methods Find Exp Clin Pharmacol 29: Suppl A

Campbell DE, Lynn J., Louis TA, Shugarman LR (2004) Medicine program expenditures associated with hospice use. Ann Intern Med 140: 269–277

Clegg A, Bryant J, Nicholson T (2001) Clinical and cost-effectiveness of donepezil, rivastigmine and galantamine for Alzheimer's disease: A rapid and systematic review. Health Technol Assess 5: 1–137

Das SK, Biswas A, Roy T et al. (2006) A random sample survey for prevalence of major neurological disorders in Calcutta. Indian J Med Res 124: 163–172

Dong MJ, Peng B, Lin XT et al. (2007) The prevalence of dementia in the People's Republic of China: a systematic analysis of 1980-2004 studies. Age Ageing 36: 619–624

Ferri CL, Prince M et al. (2005) Global prevalence of dementia: a Delphi consensus study. Lancet 366: 2112–2117

Ferri CP, Prince M, Brayne C et al. (2005) Global prevalence of dementia: a Delphi consensus study. Lancet 366: 2112–2117

Gabryelewicz T (1999) The prevalence of dementia in the population of the Warsaw district of Mokotow from 65 to 84 years of age. Psychiatr Pol 33: 353–366

Giacobini E (2006) Cholinoesterases in human brain: the effect of cholinesterase inhibitors on Alzheimer's disease and related disorders. In: Giacobini E, Pepeu G (eds) The brain cholonergic system in health and disease. Informal Healthcare, Oxon, pp 235–264

Glaser A (2008) Merz Pharmaceuticals, Frankfurt. http://www.merz.de/presse/pressemappen_gesundheit/alzheimer/verlauf/

Hardy J (2007) A hundred years of Alzheimer's disease research. NEURON 52: 3–13

Hofman A et al. (1991) The prevalence of dementia In Europe: a collaborative study of 1980–1990 findings. Int J Epidemiol 20: 736–748

Jacob KS, Kumar PS, Gayathri K et al. (2007) The diagnosis of dementia in the community. Int Psychogeriatr 19: 669–678

Loveman E, Green C, Kirby J (2006) The clinical and cost-effectiveness of donepezil, rivastigmine, galantamine and memantine for Alzheimer's disease. Health Technol Assess 10: 1–176

Molero AE, Pino-Ramirez G., Maestre GE (2007) High prevalence of dementia in Caribbean population. Neuroepidemiology 29: 107–112

Ogeng'o JA, Cohen DL, Sayi JG (1996) Cerebral amyloid beta protein deposits and other Alzheimer lesions in non-demented elderly east Africans. Brain Pathol 6: 101–107

Prince M, Acosta D, Chiu H, Scazufca M, Varghese M (2003) Dementia diagnosis in developing countries: a cross- cultural validation study. Lancet 361: 909–917

Prince M, Ferri CP, Acosta D (2007) The protocols for the 10/66 Dementia Research Group population-based research programme. BMC Public Health 2: 165

Prince MJ (1997) The need for research on dementia in developing countries. Trop Med Int Health 2: 993–1000

Raicher I, Shimizu MM, Takahashi DY et al. (2008) Alzheimer's disease diagnosis disclosure in Brazil: a survey of specialized physicians' current practice and attitudes. Int Psychogeriatr 20: 471–481

Rodriguez JJL, Ferri CP, Acosta D et al. (2008) The prevalence of dementia in Latin America, India and China. A 10/66 Dementia Research Group population-based survey. Lancet 372: 464–474

Rossa G (1997) The prevalence of Alzheimer's type dementia and vascular dementia in the district of Swiebodzin. Psychiatr Pol 31: 121–134

Suh GH, Shah A (2001) A review of the epidemiological transition in dementia-cross-national comparisons of the indices related to Alzheimer's disease and vascular dementia. Acta Psychiatr Scand 104: 4–11

Tschanz JT (2006) Conversion to dementia from mild cognitive disorder. Neurology 67:2

Waldemar G, Phung KT, Burns A et al. (2007) Access to diagnostic evaluation and treatment for dementia in Europe. Int J Geriatr Psychiatry 22: 47–54

Wender M, Mularczyk J, Modestowicz R (1990) Epidemiology of Alzheimer's disease in the selected region of Wielkopolska (town and commune Steszew). Przegl Epidemiol 44: 215–221

WHO (2002) Active ageing: a policy framework, 2002 health report. World Health Organization, Geneva

Wimo A, Jonsson L, Winblad B (2006) An estimate of the worldwide prevalence and direct costs of dementia in 2003. Dement Geriatr Cogn Disord 21: 175–181

Zhang ZX, Zahner GE, Roman GC, et al. (2006) Socio-demographic variation of dementia subtypes in china: methodology and results of prevalence study in Beijing, Chengdu, Shanghai, and Xian. Neuroepidemiology 27: 177–187

4.2 State of the Art – Treatment of Cognitive, Behavioral and Psychopathological Symptoms of Alzheimer's Disease

Ulrich Michael Hemmeter

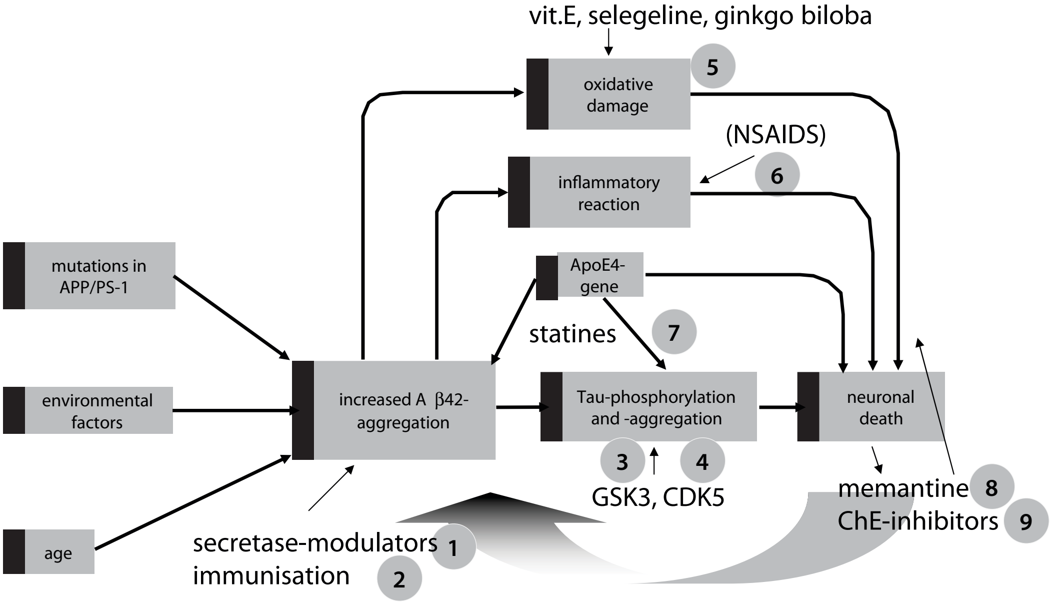
Based on the fact that no established causal therapy of the underlying neuropathology of Alzheimer's dementia is currently available, the treatment interventions are predominantly based on a symptom-orientated approach including pharmacological and non-pharmacological strategies.

The goal of the currently available treatment strategies in AD is therefore an improvement or at least a slowing of the progression of symptoms, which emerge as consequences of the core processes of the disease, i.e. treatment focusing on target symptoms with synaptic agents (compensation of cholinergic deficit, modulation of glutamate) and reduction of oxidative stress and inflammatory processes (◘ Fig. 4.1).

The aim of all of these interventions is not to cure Alzheimer's disease, but rather to relief the progredient course of the disease.

However, the ultimate goal of research into AD therapies is disease-modifying treatment. To date, there is no clear evidence of efficacy for disease-modifying agents currently studied, but there are promising approaches. The main focus of disease-modifying treatment is on the development of amyloid-based therapeutics (immunotherapy, modulation of secretases), in addition, concerning tau-pathology there is research on the inactivation of glycogensynthase-kinase 3 (GSK3) and cycline-dependent kinase-5 (CDK5) (◘ Fig. 4.1).

With respect to the pathophysiological pathways presented in ◘ Fig. 4.1, it is obvious that both pharmacological treatment strategies currently available (Che-I and NMDA-Rec-antagonism) mainly reflect treatments which act at the end of the neuropathological pathways of AD. Future goals of treatment which are more close to the underlying neuropathology are modulation of secretase-activity and immunization affecting amyloid-precursor protein (APP) and amyloid pathways, modulation of GSK-3 and CDK5 and the consequent disturbances such as reduction of



◘ **Fig. 4.1.** Schematic etiopathological model of Alzheimer's disease including therapeutic approaches (under research and established) at different sites 1–9

oxidative stress, inflammatory processes and intracerebral cholesterin modulation.

In addition, factors related to environmental effects (cognitive stimulation and training, nutrition factors, behavior and activity) have to be included into therapeutic strategies.

Therefore, treatment of AD requires always an integrative therapy which includes pharmacologic treatment as well as non-pharmacologic treatment strategies.

Pharmacotherapy of Alzheimer's Disease

Cholinesterase Inhibitors (Che-Is)

Three different Che-Is are currently available: donepezil, rivastigmine and galantamine. Due to the common main mechanism of action, the augmentation of cholinergic neurotransmission by inhibition of the cholinesterase, the difference between all three is marginally (Doody et al. 2001). While rivastigmine and donepezil predominantly act on muscarinic receptors of the cholinergic system, galantamine exerts its action – in addition to the inhibition of the cholinesterase – by an allosteric modulation of nicotinergic receptors.

Differences are found concerning half-life, which is longest for donepezil (about 70 h) and shortest for rivastigmine (1–2 h). Furthermore, donepezil and galantamine are metabolized via the cytochrom-P450 complex, which is not the case for rivastigmine. Galantamine affects the 2D6, donepezil the 2D6 and 3A4 subunit (Cummings 2004).

The elimination of the substance is merely by the kidney for rivastigmine and galantamine, while donepezil is eliminated by kidney and faeces (Cummings 2004).

Major side effects of all Che-Is are nausea, dizziness, diarrhea and headache. For rivastigmine vomiting may frequently occur, in particular at the beginning of treatment (Hogan et al. 2008, ◘ Table 4.1).

Selection of Che-Is. The application of a cholinesterase inhibitor is a treatment option for most patients with mild to moderate AD. The decision to initiate a therapy should be based first on the diagnosis and the evaluation of the relative benefits and risks of the therapy. However, treatment should not be started without an evaluation of the wishes and expectations of the patient itself and the caregiver (Clegg et al. 2002).

The choice of a cholinesterase inhibitor is commonly based on factors such as ease of use, tolerability, adverse effects, interactions with other medication and costs. In addition, physicians' familiarity in prescribing the specific agents may play a role. It is important to stress that the available data are insufficient to allow a conclusion about the relative effectiveness (Hogan et al. 2008).

Effectiveness of Che-Is. The application of Che-Is is recommended by a number of guidelines from societies of different countries (e.g. Raina et al. 2008) for mild and moderate AD. This recommendation is based on evidence from a substantial number of randomized trials. A recently published review which included 43 placebo-controlled trials (24 of donepezil, 10 of galantamine, 9 of rivastigmine) with a total number of 13,717 participants have shown consistent benefits, albeit modest and of debatable clinical significance concerning cognitive abilities and global clinical state (Hogan et al. 2008; Raina et al. 2008).

However, only 5 studies (4 on donepezil, 1 on rivastigmine) had drug interventions of 52 weeks and more. Due to the long duration of symptomatology in Alzheimer's disease (5 to 10 years) a much longer observation period is required (Raina et al. 2008).

Besides this shortcoming (lack of controlled long term studies), dropout rate and handling of missing data are further drawbacks of these trials. In general, dropout rate is higher in patients treated with Che-I than under placebo treatment. An interpretation of study results becomes problematic, if dropout rates are higher than 20%, (Unnebrink et al. 2001).

Although Che-Is are well tolerated in general, the dropout rates were significantly higher in treatment groups than in placebo groups exceeding the critical mark of 20% (Raina et al. 2008). Referring to this, the application of the last observation carried forward method (LOCFM) which is commonly applied in dealing with missing data in these trials and which assumes that patients remain stable from the time they drop out of the study and that dropout rates are randomly distributed in all groups tends to an exaggeration of the benefit of dementia therapies in general and in particular in trials assessing the effectiveness of specific pharmacological interventions such as Che-I treatment (Hills et al. 2002).

The randomized controlled studies of Che-Is reveal consistent statistically positive results, which, however, were modest and of debatable clinical relevance. Another uncertainty is the duration of the beneficial effects, as most studies were only performed for 26 weeks or less (Hogan et al. 2008). There are studies of long-term treatment with Che-Is (up to 5 years). These studies were open-label or observational studies (Seltzer 2007) and therefore evaluation of the response is not possible.

Memantine

Memantine has been introduced in AD therapy in 2003. Due to its different pharmacological approach it represents an alternative to Che-Is. Memantine is a non-competitive NMDA-receptor antagonist which protects the neuron of increased pathological stimulation by glutamate leading to an improved synaptic learning function.

Main side effect of memantine is dizziness, in addition confusion and agitation may occur, while nausea and diarrhea are less frequent than in Che-Is (◘ Table 4.1).

Although memantine has shown some efficacy in mild AD, it is licensed for the application of moderate and in contrast to Che-Is also for severe AD (Areosa et al. 2005).

Based on its action on a common principle of synaptic learning it should be effective also in other disorders with cognitive impairment and underlying glutamatergic dysfunction, such as vascular dementia (Erkinjuntti et al. 2004).

If a patient does not respond to Che-I treatment, memantine can be applied due to its different pharmacological profile. In addition, also combination therapy with memantine and a Che-I would be rational from a perspective of pharmacology because of the different mechanisms of action (Tariot et al. 2004a).

Table 4.1. Medications approved for the treatment of core-symptoms of Alzheimer disease (modified after Hogan et al. 2008)

Drug	Starting dose	Titration	Contraindications, warnings and precautions	Most common adverse effects	Metabolism via Cytochrome P450
Cholinesterase Inhibitors (Che-I)					
Donepezil	5 mg once daily	– If well tolerated, increase dose to 10 mg once daily after at least 4–6 weeks – Maximum dose is 10 mg/d	– Contraindicated in patients with known hypersensitivity to drug or piperidine derivatives, and those with conduction abnormalities (except right bundle-branch block) or unexplained syncope – Use with caution in patients at risk of ulcers (monitor for gastrointestinal bleeding), those with a history of seizures, asthma or chronic obstructive pulmonary disease, and older patients with low body weight – Use may exaggerate the effects of succinylcholine-type muscle relaxants	– Nausea: 11% – Diarrhea: 10% – Headache: 10% – Insomnia: 9% – Pain: 9%	– 3A4/2D6 Interact. potential high
Galantamine (extended release)	8 mg once daily in the morning, preferably with food	– After 4 weeks, increase dose to 16 mg once daily (initial maintenance dose) – If initial maintenance dose is well tolerated, consider increasing to 24 mg once daily after at least 4 weeks – Maximum dose is 24 mg/d	– Contraindicated in patients with known hypersensitivity to drug, those with conduction abnormalities (except right bundle-branch block) or unexplained syncope, and those with severe hepatic or renal impairment – Monitor body weight if weight loss is of concern (more common among women and patients with low body weight) – Use with caution in patients at risk of ulcers (monitor for gastrointestinal bleeding) and those with a history of seizures, asthma or chronic obstructive pulmonary disease – Use will likely exaggerate the effects of succinylcholine-type muscle relaxants	– Nausea: 17% – Dizziness: 10% – Headache: 8% – Injury: 8% – Vomiting: 7%	– 2D6 Interact. potential high

▼

Table 4.1. *Continued*

Drug	Starting dose	Titration	Contraindications, warnings and precautions	Most common adverse effects	Metabolism via Cytochrome P450
Rivastigmine (oral)	1.5 mg twice daily (in the morning and at night), with food	▬ If well tolerated, increase dose to 3 mg twice daily after at least 2 weeks ▬ If well tolerated, increase dose to 4.5 mg twice daily and then to 6 mg twice daily, after at least 2 weeks each time ▬ If treatment is interrupted for more than several days, reinitiate starting dose and titrate as above ▬ Maximum dose is 6 mg twice daily	▬ Contraindicated in patients with known hypersensitivity to drug, those with conduction abnormalities (except right bundle-branch block) or unexplained syncope, and those with severe hepatic impairment ▬ Monitor body weight if weight loss is of concern (more common among women) ▬ Use with caution in patients at risk of ulcers (monitor for gastrointestinal bleeding), those with renal impairment (monitor closely), and those with a history of seizures, asthma or chronic obstructive pulmonary disease ▬ Use will likely exaggerate the effects of succinylcholine-type muscle relaxants	▬ Nausea: 37% ▬ Vomiting: 23% ▬ Dizziness: 19% ▬ Diarrhea: 16% ▬ Headache: 15%	▬ No CYP450-metab. Interact. potential low
***N*-methyl-D-aspartate (NMDA) receptor antagonist**					
Memantine	5 mg once daily, in the morning	▬ If well tolerated, increase in weekly increments of 5 mg to maintenance dose of 10 mg twice daily	▬ Contraindicated in patients with known hypersensitivity to drug and those with severe renal impairment ▬ Use with caution in patients with cardiovascular disease or a history of seizures ▬ Conditions that raise urinary pH (e.g., renal tubular acidosis, urinary tract infection with *Proteus* bacteria) can reduce elimination of the drug in urine ▬ Monitor patients ophthalmic condition periodically ▬ Do not combine with related drugs such as amantadine, ketamine and dextromethorphan	▬ Dizziness: 17% ▬ Constipation: 6% ▬ Confusion: 6% ▬ Headache: 6% ▬ Hypertension: 3%	▬ No CYP450-metab. Interact. potential low

The combination therapy seems to be safe, well tolerated and may provide additional benefits in patients not responding to a monotherapy. This already has been shown in patients with moderate and severe AD (Tariot et al. 2004; Dantoine et al. 2006), although a recently published study did not reveal a benefit of an additional application of memantine (Porsteinsson et al. 2008).

The evaluation of effectiveness of memantine treatment in AD deals with the same problems as Che-I treatment (see above). This addresses predominantly the debatable clinical significance of statistically significant results. However, it has to be stressed that all these studies include a substantial number of responders, who clearly profit from the applied drug. It is a requirement for the future to find predictors (clinical or neurobiological) which patients will respond to memantine (and also Che-Is).

Application of Che-Is and memantine: Besides side effects, interaction profile and contraindications, which are decisive for the application of Che-Is and memantine starting doses, titration regimens and therapy evaluation strategies are important to know (◘ Table 4.1).

In addition, physicians should be able to communicate realistic treatment expectations to patients and family members.

If pharmacotherapy is initiated, patients should be followed carefully for the development of adverse effects and should be re-evaluated concerning treatment response after 3 or at least 6 months. This re-evaluation has to include the assessment and interpretation of cognitive and functional abilities by specific, reliable and valid measures such as the CERAD-test battery (Hogan et al. 2008).

These evaluations should cover more than only brief cognitive tests such as the Mini-Mental-State Examination because they are too insensitive for the assessment of subtle benefits or worsening (Bowie et al. 1999).

Therefore, therapy should be evaluated at a healthcare professional with the required expertise.

Stabilization of or improvement in target symptoms or domains are required for the continued coverage of Che-I therapy. Target symptoms are personally meaningful manifestations of dementia that are measurable and potentially responsive to therapy. The evaluation of treatment response should be based on the patient's cognition, behavior and daily functioning with additional information of the caregiver (if available) on these domains.

Pharmacotherapy of dementia should be terminated if the patient

a) decides to stop,
b) refuses to take medication,
c) shows no response on therapy,
d) experiences intolerable side effects,
e) has co-morbidities that make continued use either unacceptably risky or futile (Hogan et al 2008).

If pharmacotherapy is stopped, the patient should be monitored carefully over the first weeks for evidence of a significant decline. If this occurs, consideration should be given to reinstall previously administered pharmacological therapy (Hogan et al. 2008).

Nootropics

Besides treatment with Che-I and memantine there are further drugs with cognitive enhancing properties, the class of nootropics which includes substances, such as piracetam, nimodipine and ginkgo biloba.

For all of these substances positive results concerning improvement of cognitive abilities have been reported (Möller 1993; Winblad 2005). However, compared to Che-Is and memantine much less patients have been studied in randomized controlled trials. Therefore, a definitive proof of the efficacy of these drugs in AD is still missing (Evans et al. 2004).

There are studies showing positive effects of Ginkgo biloba in mild and moderate AD either alone or in combination with Che-Is and other nootropic agents, which showed a good tolerability and safety (Man et al. 2008). However, methodological shortcomings in the designs of the studies limit the interpretation of the results. According to the Austrian society of Alzheimer, Ginkgo biloba can be applied in mild to moderate AD, in case of intolerability or inefficacy after an unsuccessful change between Che-I or change to memantine (Alf et al. 2006).

Nonpharmacological Therapy

Nonpharmacological approaches to AD include behavioral strategies, such as physical activity, nutrition, ergotherapy and specific cognitive training techniques. Generally it can be said that psychological and neuropsychological therapies can be applied in the early stage of AD, while ergotherapeutic approaches are proposed in the middle stage of AD to train and keep abilities of daily living (Hüll et al. 2008).

Physical Activity

In the past years increased evidence emerged that regular physical exercise can protect the brain. The association between low risk of dementia and physical activity may be explained by increased cerebral circulation, lower levels of brain inflammation and of insoluble brain amyloid-beta protein.

This is supported by epidemiological studies which show that subjects with increased physical activity, such as walking, present with a lower risk for developing AD (Colcombe et al. 2003). In addition, subjects who had completed an exercise program showed greater frontal effects (PET) and greater cognitive efficacy of the brain compared to controls (Colcombe et al. 2004).

Animal studies which show that active laboratory animals have more hippocampal neurons than inactive animals, support this association (Gage 2002).

Socialization

It could be shown that limited social network (Fratiglioni et al. 200) and social disengagement are risk factors for cognitive impairment in the elderly independent from depressive symptoms (Bassuk et al. 1999; Glass et al. 2006). Predominantly emotional support is associated with lower blood levels of cortisol and better cognitive health (Kahn and Rowe 1998).

Dietary Supplements

Curcumin (a component of curry) fish oil (omega-3 fat) and phosphatidylserine have shown at least short-term benefits for people with age-related memory loss (Ng et al. 2006; MacDaniel et al. 2003; Freund Levi et al. 2006). Curcumin seems to have anti-amyloid and anti-inflammatory properties (Garcia-Alloza et al. 2007).

Concerning multi-vitamins, which can be beneficial for elderly people, who may not absorb all nutrients effectively, there is no definitive evidence that these dietary supplements have brain-protective or memory-enhancing effects (Hathcock 1997).

Brain Fitness

There are some hints that mental training can help the brain to become more efficient (Small et al. 2006). This has been shown in a study in which older people were taught a series of skills to improve cognitive performance and by a parallel effect on brain metabolism assessed by FDG-PET (Small et al. 2009).

However, these findings do not prove that crossword puzzles and other cognitive games will prevent AD or help to slow the decline of an already beginning AD. AD patients can learn some helpful strategies »memory helpers«, however certain mnemotechniques and »brainjogging« did not show any beneficial effects (Werheid and Thöne 2006).

Ergotherapy

There is one study which showed that ergotherapeutic intervention leads to an improvement in abilities of daily living and to a better quality of life in patients and caregivers (Graff et al. 2006, 2007). At least part of the topics mentioned under this section (non-pharmacological therapies. e.g. physical activity, socialization, dietary supplements) may be included into self-management programs of AD (Mountain 2006)

Interventions for Behavioral and Psychological Symptoms (BPSD)

The assessment of a patient with mild to moderate dementia should include an evaluation of behavioral and neuropsychiatric symptoms.

For the assessment of a significant presence of behavioral and neuropsychiatric symptoms the Neuropsychiatric Inventory (NPI) a brief informant-based rating scale can be used in clinical practice (Kaufer et al. 2000).

The most common psychopathological states and behavioral symptoms in AD are depression, insomnia and anxiety. In addition, in moderate and severe dementia the presence of agitation and psychosis may become problematic.

Depressive Symptoms

Depressive symptoms are common in patients with beginning AD and can range from mild symptoms to depressive disorder.

Moreover, depression is the major differential diagnosis of beginning AD. Clinically significant depressive symptoms should be treated. Treatment should include a non-pharmacologic and a pharmacologic approach. If an antidepressant is applied, the preferred choice should be a substance without or minimal anticholinergic activity, such as selective serotonin-reuptake inhibitors (SSRIs), as anticholinergic effects may worsen cognitive performance, predominantly in elderly subjects and patients with dementia (Lebert 2003).

Anxiety

For the treatment of anxiety non-pharmacologic interventions which include basic management of behavior and specific psychotherapeutic interventions should be considered first. If a psychotropic drug for treating anxiety is used, the risks have to be taken into account (e.g. sedation, disinhibition, depression, falls, incontinence, parkinsonism and akathisia). In particular, benzodiazepines have to be applied only with great caution in elderly patients (Wiegand et al. 2003).

There are some reports that the application of a Che-I might lead to an improvement of anxiety (Hermann et al. 2005). Therefore, if AD is diagnosed, the application of a Che-I should be considered first.

Insomnia

Insomnia is very common among patients with AD and often not recognized even by the next relatives (Rocamora et al. 2005). In addition, insomnia may additionally worsen cognitive performance and worsen abilities of daily living. Therefore, clinically significant sleep disturbances should be treated.

Non-pharmacologic approaches which include sleep hygiene, daytime activities, daily walking should always be used first. Furthermore, increased exposure to daylight or to artificial bright light may help to restore the disturbed circadian rhythm and consequently improve night-time sleep (Campell et al. 1993).

If a pharmacological treatment is required, substances with anticholinergic effects and long half-life with potential hangover (in particular benzodiazepines) should be avoided (Wiegand et al. 2003). For short-term treatment non-benzodiazepines, such as zolpidem and zopiclone, can be applied, if long-term treatment is necessary, sleep-inducing antidepressants without or low anticholinergic properties such as mirtazapine and trazodone should be used (Hemmeter and Thum 2007). In addition, as melatonin secretion also seems to be disturbed in AD patients (Cardinall et al. 2002), the application of recently available melatonin agonists (ramelteon) may be a further option (Roth et al. 2005).

Agitation and Psychotic Symptoms

Agitation and psychotic symptoms emerge in particular in middle and late stages of AD. The application of neuroleptics is guided by the side effects of the substance. Anti-psychotics with low anticholinergic properties and a low potential for extrapyramidal symptoms, such as melperon, pipamperon, can be applied. In addition, also quetiapine, risperidone and olanzapin have shown good efficacy (Tariot et al. 2004b). However, due to reports of an increased incidence for cerebral ischemias under atypical neuroleptics in dementia, the FDA released a warning message (FDA 2005; Miller 2007). Therefore, atypical anti-psychotics should be applied only with great caution and good monitoring of the patient, although they have shown a good efficacy in treating psychotic symptoms and agitation.

Conclusion

There is no causal therapy of Alzheimer's dementia currently available. Pharmacologic treatment strategies are still based on modulation of cholinergic and glutamatergic neurotransmission. Cholinesterase inhibitors and memantine, which represent this approach, have been extensively studied and have shown positive effects concerning slowing of the disease progression, improved abilities of daily living and enhanced quality of life for a certain time, not in all, but in the majority of patients. All other therapies – either pharmacological or non-pharmacological – are based on a much lower level of evidence, although possible beneficial effects may occur.

There are recommendations for non-pharmacological therapies, which have to be applied in combination with the pharmacological treatment, such as physical activity, brain fitness and others and should become part of self-management programs. In addition, clinically significant behavioral and psychological symptoms of AD should be consequently treated.

This integrative therapeutic strategy will provide the chance to improve quality of life of Alzheimer's patients for a longer time.

Nevertheless, intensive research focusing on disease-modifying mechanisms, such as of amyloid and non-amyloid neuropathology, is required. These approaches actively under study are promising, although they still carry major problems, such as autoimmune responses and cerebrovascular events – in case of immunotherapy, which have to be solved first.

References

Alf C, Bancher C, Benke T, Berek K et al. (2006) Konsensusstatement »Demenz« der Österreichischen Alzheimer Gesellschaft, update 2006. Neuropsychiatrie 2006; 20: 221–231

Areosa SA, Sherriff F, McShane R (2005) Memantine for dementia. Cochrane Database Syst Rev 3: CD003154

Bassuk SS, Glass TA, Berkman LF (1999) Social disengagement and incident cognitive decline in community-dwelling elderly persons. Ann Intern Med 131: 165–173

Bowie P, Branton T, Holmes J (1999) Should the Mini Mental State Examination be used to monitor dementia treatments? Lancet 354: 1527–1528

Campbell SS, Dawson D, Anderson MW (1993) Alleviation of sleep maintenance insomnia with timed exposure to bright light. J Am Geriatr Soc 8: 829–836

Cardinali DP, Brusco LI, Liberczuk C, Furio AM (2002) The use of melatonin in Alzheimer's disease. Neuro Endocrinol Lett Suppl 1: 20–23

Clegg A, Bryant J, Nicholson T, McIntyre L, De Broe S, Gerard K, Waugh N (2002) Clinical and cost-effectiveness of donepezil, rivastigmine, and galantamine for Alzheimer's disease. A systematic review. Int J Technol Assess Health Care 18: 497–507

Colcombe SJ, Erickson KI, Raz N, Webb AG, Cohen NJ, McAuley E, Kramer AF (2003) Aerobic fitness reduces brain tissue loss in aging humans. J Gerontol A Biol Sci Med Sci 58: 176–180

Colcombe SJ, Kramer AF, Erickson KI et al. (2004) Cardiovascular fitness, cortical plasticity, and aging. Proc Natl Acad Sci USA 101: 3316–3321

Cummings JL (2004) Drug therapy: Alzheimer's Disease. N Engl J Med 351: 56–67

Dantoine T, Auriacombe S, Sarazin M, Becker H, Pere JJ, Bourdeix I (2006) Rivastigmine monotherapy and combination therapy with memantine in patients with moderately severe Alzheimer's disease who failed to benefit from previous cholinesterase inhibitor treatment. Int J Clin Pract 60: 110–118

Doody RS, Stevens JC, Beck C et al. (2001) Practice parameter: management of dementia (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology. Neurology 56: 1154–1166

Erkinjuntti T, Román G, Gauthier S, Feldman H, Rockwood K (2004) Emerging therapies for vascular dementia and vascular cognitive impairment. Stroke 35: 1010–1017

Evans JG, Wilcock G, Birks J (2004) Evidence-based pharmacotherapy of Alzheimer's disease. Int J Neuropsychopharmacol 7: 351–769

FDA Public Health Advisory: Deaths with Antipsychotics in Elderly Patients with Behavorial Disturbances. www.fda.gov/cder/drug/advisory/antipsychotics.htm.

Fratiglioni L, Wang HX, Ericsson K, Maytan M, Winblad B (2000) Influence of social network on occurrence of dementia: a community-based longitudinal study. Lancet 355: 1315–1319

Freund-Levi Y, Eriksdotter-Jönhagen M, Cederholm T et al. (2006) Omega-3 fatty acid treatment in 174 patients with mild to moderate Alzheimer disease: OmegAD study: a randomized double-blind trial. Arch Neurol 63: 1402–1408

Gage FH (2002) Neurogenesis in the adult brain. J Neurosci 22: 612–613

Gaines JM, Miller KJ, Parrish JM et al. (2007) Effects of a healthy aging intervention program on older adults: The Memory Fitness Study. Poster presented at: National Gerontological Nursing Association's 22nd Annual Conference; October 18–21, 2007; Orlando, FL

Garcia-Alloza M, Borrelli LA, Rozkalne A, Hyman BT, Bacskai BJ (2007) Curcumin labels amyloid pathology in vivo, disrupts existing plaques, and partially restores distorted neurites in an Alzheimer mouse model. J Neurochem 102: 1095–1104

Glass TA, De Leon CF, Bassuk SS, Berkman LF (2006) Social engagement and depressive symptoms in late life: longitudinal findings. J Aging Health 18: 604–628

Graff MJ, Adang EM, Vernooij-Dassen MJ, Dekker J, Jönsson L, Thijssen M, Hoefnagels WH, Rikkert MG (2006) Community based occupational therapy for patients with dementia and their care givers: randomized controlled trial. BMJ 333: 1196–1201

Graff MJ, Vernooij-Dassen MJ, Thijssen M, Dekker J, Hoefnagels WH, Olderikkert MG (2007) Effects of community occupational therapy on quality of life, mood, and health status in dementia patients and their caregivers: a randomized controlled trial. J Gerontol A Biol Sci Med Sci 62: 1002–1009

Hathcock JN (1997) Vitamins and minerals: Efficacy and safety. Am J Clin Nutr 66: 427–437

Hemmeter UM, Thum A, Krieg JC (2007) Altersinsomnie (Insomnia in the elderly). Somnologie 11: 84–98

Herrmann N, Gill SS, Bell CM, Anderson GM, Bronskill SE, Shulman KI, Fischer HD, Sykora K, Shi HS, Rochon PA (2007) A population-based study of cholinesterase inhibitor use for dementia. J Am Geriatr Soc 55: 1517–1523

Hills R, Gray R, Stowe R et al. (2002) Drop-out bias undermines findings of improved functionality with cholinesterase inhibitors. Neurobiol Aging 23 (Suppl 1): S89

Hogan DB, Bailey P, Black S et al. (2008) Diagnosis and treatment of dementia: 5. Nonpharmacologic and pharmacologic therapy for mild to moderate dementia. CMAJ 179: 1019–1026

Huell M, Voigt-Radloff S (2008) Nichtpharmakologische Behandlungsmethoden bei Demenzen. Nervenarzt 79 (Suppl 3): 159–164

Kahn RL, Rowe JW (1998) Successful aging. Pantheon, New York

Relkin NR (2008) Current state of immunotherapy for Alzheimer's disease. CNS Spectr 13 (Suppl 16): 39–41

Kaufer DI, Cummings JL, Ketchel P, Smith V, MacMillan A, Shelley T, Lopez OL, DeKosky ST (2000) Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. J Neuropsychiatry Clin Neurosci 12: 233–239

Lebert F (2003) Serotonin reuptake inhibitors in depression of Alzheimer's disease and other dementias. Presse Med 32: 1181–1186

Man SC, Durairajan SS, Kum WF, Lu JH, Huang JD, Cheng CF, Chung V, Xu M, Li M (2008) Systematic review on the efficacy and safety of herbal medicines for Alzheimer's disease. J Alzheimers Dis 14: 209–223

Gail A (2006) Mountain Self-management for people with early dementia, An exploration of concepts and supporting evidence. Dementia 5: 429–446

McDaniel MA, Maier SF, Einstein GO (2003) Brain-specific nutrients: a memory cure? Nutrition 19: 957–975

Miller LJ (2007) The use of cognitive enhancers in behavioral disturbances of Alzheimer's disease. Consult Pharm 22: 754–762

Möller HJ (1993) Therapy of dementing diseases: value of calcium antagonists. Fortschr Med 111: 437–440

Ng TP, Chiam PC, Lee T, Chua HC, Lim L, Kua EH (2006) Curry consumption and cognitive function in the elderly. Am J Epidemiol 164: 898–906

Porsteinsson AP, Grossberg GT, Mintzer J, Olin JT; Memantine MEM-MD-12 Study Group (2008) Memantine treatment in patients with mild to moderate Alzheimer's disease already receiving a cholinesterase inhibitor: a randomized, double-blind, placebo-controlled trial. Curr Alzheimer Res 5: 83–89

Raina P, Santaguida P, Ismaila A, Patterson C, Cowan D, Levine M, Booker L, Oremus M (2008) Effectiveness of cholinesterase inhibitors and memantine for treating dementia: evidence review for a clinical practice guideline. Ann Intern Med 148: 379–397

Rocamora R, Thum A, Giesler M, Haag A, Becker A, Dodel R, Penzel T, Krieg J, Hemmeter U (2005) Schlafstörungen bei degenerativen Demenzen. Somnologie 9: 139–147

Roth T, Stubbs C, Walsh JK (2005) Ramelteon (TAK-375), a selective MT1/MT2-receptor agonist, reduces latency to persistent sleep in a model of transient insomnia related to a novel sleep environment. Sleep 28: 303–307

Seltzer B (2007) Is long-term treatment of Alzheimer's disease with cholinesterase inhibitor therapy justified? Drugs Aging 24: 881–890

Small GW, Silverman DH, Siddarth P et al. (2006) Effects of a 14-day healthy longevity lifestyle program on cognition and brain function. Am J Geriatr Psychiatry 14: 538–545

Small GW, Siddarth P, Burggren AC et al. (2009) Influence of cognitive status, age, and APOE-4 genetic risk on brain FDDNP positron-emission tomography imaging in persons without dementia. Arch Gen Psychiatry 66: 81–87

Tariot PN, Farlow MR, Grossberg GT, Graham SM, McDonald S, Gergel I; Memantine Study Group (2004a) Memantine treatment in patients with moderate to severe Alzheimer disease already receiving donepezil: a randomized controlled trial. JAMA 291: 317–324

Tariot PN, Profenno LA, Ismail MS (2004b) Efficacy of atypical antipsychotics in elderly patients with dementia. J Clin Psychiatry 65 (Suppl 11): 11–15

Unnebrink K, Windeler J (2001) Intention-to-treat: methods for dealing with missing values in clinical trials of progressively deteriorating diseases. Stat Med 20: 3931–3946

Werheide K, Thöne-Otto AIT (2006) Kognitives Training bei Alzheimer Demenz. Nervenarzt 77: 549–557

Wiegand MH (2003) Drug treatment of sleep disorders in the elderly. Internist (Berl) 44: 1187–1192

Winblad B (2005) Piracetam: a review of pharmacological properties and clinical uses. CNS Drug Rev 11: 169–182

4.3 An Alternative Description: Alzheimer's Disease as a Biographical Phenomenon

Ulrich Kropiunigg

The Medium is the Message

Alzheimer research already has its own biography. After a short »psychological« period in the mid 1930s, concern with Alzheimer's disease (AD) is now moving toward biomedicine. Ballenger speaks of a »biomedical deconstruction of senility« that began to develop in the 1970s and a later nosological establishment of AD, as it is understood today (Ballenger 2006). The first step was the correlative link between plaques and tangles and clinical manifestations in the brain (Tomlinson et al. 1970) – this work became trend setting. The integration of AD and senile dementia finally led to a quantitative revaluation – 1.2 million cases were estimated in the US – for a now economically profitable area of research (Ballenger 2006). Theories of »hippocampal shrinkage,« the »cholinergic hypothesis,« and genetic studies, which prompted the inclusion of the β-amyloid precursor protein, followed (for a review see Hodges 2006).

This scientific paradigm unfortunately shifts every other view of AD. In his essay *Does social medicine still matter in an era of molecular medicine?* Leon Eisenberg speaks of a »demise« of bio-psycho-social medicine and critically asks himself: »Shall we inter social medicine?« (Eisenberg 1999). In my opinion, however, it is far less about a false methodological approach than it is about the failure of economic qualities. The life sciences have inserted themselves into the market-oriented units of industry and research, whereas the tabooed »idealistic« approaches have not.

A second factor of influence that adds to the repression of holistic approaches to AD research is the scientific paradigm – which I in no way want to criticize in its basic authority. This factor deals far more with the unintentional consequences, such as the neglect of research into stressors from life experiences and the emphasis on experimental research on stress done in the laboratory. As a category for arbitrary pressures from so-called stressors, stress does mark the molecular processes. It does, however, have far-reaching consequences when personal responsibility is delegated to technical feasibility. What sorts of conclusions must an AD patient draw when the descriptions of the disease amount to molecular-biological malfunction, genetic determinancies, and as-yet undiscovered causes? Illness and cure appear to be independent of individuals from this point of view. These views disregard that the mind »is supervenient upon the neurophysiological; each mental event is also a neurophysiological event, under another description« (Kitwood 1987b).

This problem also presents itself to doctors who treat and who are themselves passive recipients of scientific research insofar as they do not do their own research. Thure von Uexküll argues that »the crisis of medicine [is] a crisis of its philosophy (…), which proscribes one-sided models and concepts to the doctor for his empiricism« (2001, my translation). When AD is thus described solely by molecular-biological categories, it affects the practitioner's actions and experiences, which are then directly transmitted to the patients. In other words, a scientifically grounded treatment derives from a scientific explanation. A world is thus constructed out of scientific theories following the dictum »the medium is the message« (McLuhan 1964), in which both the relationship between patient and doctor (as von Uexküll underscores) and the patient's existential relationship to him/herself and the world gets lost. Even Ludwig Wittgenstein relativised his reductionist explanation of the world, although he did not want to overstep this boundary in his philosophy: »We feel that, even when all *possible* scientific questions are answered, our life questions have not been touched« (Wittgenstein 2003, italics in original, my translation). Just as Antonio Damasio (2003) demonstrated with the tear apparatus, the »physiological stress apparatus« is mostly complete at birth; the occasions for its activation, however, whether psychological or material, are very different over the course of life.

Unintended Disclosures

The common answer to the question of what AD is, which falls under the heading »What happens in the brain?« shows three brain-organic topoi: plaques, tangles, and the neurotransmitter system. These standard paradigms are followed by the widely accepted statement that there is no recent cure for the disease. Explanations beyond this biomedical framework are scrupulously avoided. One seeks explicit indications of psychogenetic risk factors in vain, although convivial social activities, an active lifestyle, and staying mentally fit are recommended. A Mayo Clinic website suggests the following: »Staying engaged in social activities with friends, family and others/Engaging in intellectually stimulating activities/Eating a 'heart' healthy diet (…)/Participating in regular physical activity« (Lunde 2008). Long-term marital conflicts, personal oppression and the like are not named. As Tom Kitwood writes: »The main caring agencies concerned with senile dementia […] have a theoretical stance that is largely shared with the neuropathological research program« (Kitwood 1987b).

I therefore ask if we, with the aid of biographical literature that is not necessarily subject to scientific methodological rigor, could fill this gap? A new approach to development aid, in which novels and first-hand accounts replace empirical research (Lewis et al. 2008), could introduce an innovative shift in AD research.

There are numerous unintended biographical descriptions and diagnoses in literature. Of course, one must first find them and learn to read them from a certain perspective. In Elisabeth Forsythe's book *Alzheimer's Disease: The Long Bereavement,* she writes about her experiences with John, her husband who suffered from AD: »Increasingly it seems to me that illnesses cannot be isolated as though they are something quite separate from the people we are and John's dementia cannot be detached from the sort of person he was. I know, as a doctor, that somebody with AD could not write his own story but I wonder if John could have written his own story at any time in his life, even long before the dementia started« (Forsythe 1990). An extensive biographical description of John's childhood and their marriage follows. A choice of characterizations reads like a psychodynamic puzzle (■ Table 4.2). Not all indications, especially taken separately, would allow for a psychogenetic account of AD. But the clues are dense and a careful interpretation offers the picture of an »alienated life«, toward which the many »buts« point: innovative writer, but …; marries (late), but …; loving father, but .... In our investigation (Kropiunigg et al. 1999) we found many categories that could have been taken directly from Forsythe's »catalog.« A term that we identified as »pseudoactivity« or »active-unproductive,« she describes as such: »He seemed to be constantly active and apparently occupied but in the end achieving nothing« (Forsythe 1990). A further term that we called »quantitative orientation toward the family« (a substantially temporal but finally merely physical presence) can also be found: »… wants family life but without being committed to it.« John's detachment may derive from a foundational psychological irritation during childhood. His parents had separated, he was an only child, and his father – a renowned artist – died early; nonetheless John never discussed his father's death with his wife. »There were large parts of his life which were always completely *secret* and I believed they remained *hidden even from himself*. In an extraordinary way his death from Alzheimer's disease was a logical end to his *fragmented* and hidden life« (Forsythe 1990, italics added).

Marion Roach's biography *Another Name for Madness,* about her mother Allen (who suffered from AD), also shows typifications that can easily be linked to Forsythe's account of her husband John (see ■ Table 4.2 for a comparison; for a detailed analysis of Marion Roach's book see Kitwood [1987a]). The inability to deal more intimately with her husband Jim's death, the »invention« of a friend, and the failure of emotional closeness find their counterparts in John. The previously mentioned activity seems here to be a compulsion for self-assurance: »Her favorite expression was 'Be up. Be doing.' She was always up – and doing something – by six« (Roach 1985). Here, action seems to be the end in itself.

Susanne Hoffmann took a similar stance in her report *My Mother, Like a Child.* Not only had she always viewed her mother as eccentric and as

Table 4.2. Excerpts from two biographies (Forsythe 1990; Roach 1985). Keywords describing Allen Roach are taken from Tom Kitwood (1987a)

The life of John Forsythe	The life of Allen Roach
Breakdown of parents' marriage	Tomboy in her youth
Father died early, but he never spoke of it with his wife	Unable to give support to husband when he was dying of cancer
Innovative writer, but gave up ambitions to study engineering for more money as city broker. Successful, but acting a role. Desire to be conventional	Claimed to have a woman friend who influenced her strongly toward greater independence. This friend did not really exist
Solitary person, remained extraordinarily remote. Feelings of sadness over many years. Longing to return to his Scottish homeland	Hated physical contact, especially with women
Secret desire to be eccentric	Restless, tough, competitive (Be up. Be doing.)
Lived an alternative way of life	Woman of action rather than feeling
Married at 45, but remained emotionally distant in relationship	Marriage was lacking in affection and mutual validation
Wanted family life, but without being committed to it	Disidentified herself from pregnancy
Pleased with his children, but avoided any involvement	Projected her depression onto her older daughter, and took her to the doctor for »treatment«

living in a parallel universe, but peculiar behaviors such as »restlessness and absent-mindedness, for example, which are cardinal symptoms of dementia, belonged to my mother's *character set*. *Ever since I can remember*, she has twiddled her thumbs hectically, and could not sit still for ten minutes without suddenly jumping up and running around like a flea (Hoffmann 2008, my translation and italics). Further characteristics – unintentional etiologically relevant data, one may assume – concern her mother as a housewife (»The waste basket was highly visible in the middle of the room as a symbol of her untiring effort to achieve spotless cleanliness«) and as an abandoned wife: »[She] still insisted in public that he was only on a trip. She continued to find excuses for her husband's absence« (Hoffmann 2008, my translation).

At a time when AD first garnered a broader public interest, the view to this disease was not yet as infected by biological research and was more receptive to untarnished assessments. In his theoretical essay, Daniel Miller identifies AD patients as »conditioned to be average, [and] middle of the road,« as well as equipped with the disposition to »not [stick] your head out by looking like you know too much« (Miller 1995). It is amazing that Hoffmann also describes a scene in which one of her mother's guests »[preferred] to spend the afternoon chatting with someone at eye-level rather than one who was submerged [under the table, looking constantly for dropped pieces of cake]« (Hoffmann 2008, my translation).

Psychological resistance could be responsible for reports about patients in which one's own role as a close relative is not mentioned. It is understandable; simply the publication of an AD biography is a courageous step. However, one may not rule out the possibility that the relationships among the sick and their relatives must be marked by conflicts long before the outbreak of the disease. Indications of causal communicative disturbances in those with dementia can thus far only be found in a study by Barbara Gail Hanson (1989, 1991). Based on the constructivist theory, Hanson analyzed video clips of families with aged members, including 29 identified senile dementia patients.

She found that the dialogues generally ended to the disadvantage of the demented members, whose family members construed their statements as wrong – even if they were correct – and thereby marginalized them. Hanson (1989) concluded from this *definitional deficit* (as opposed to *definitional equality*): »I assert that it is in the families in which a member is excluded from the process of reality construction that symptoms of senile dementia, or other pathologies, will be promoted«. Hanson leaves open the question, however, of whether the process of »patienting« is simply a reaction of the relatives to the disease, or whether it is to be understood as a life-long experience within the family, and therefore as a mentally straining biographical attribute of long-term »ineffectiveness« in the familial construction of reality. I found only one other indication of conflicts that existed long before the onset of the disease in Bayer-Feldmann and Greifenhagen (1995).

This finding leads me back to another construction of reality: the scientific definition of AD and its influence on the affected patients and their caregivers. Not everyone who comes in contact with AD wants to engage with often painful psychological insights. The etiological and therapeutic uncertainty therefore easily allows for refuge in exonerating formulations, as I will demonstrate with the next pertinent book. Her mother's experiences with AD were the impetus for Isobelle Gidley's text *Alzheimer's. What it is, how to cope*, which she wrote with Richard Shears. Her mother does not appear except in the introduction, it does, however, offer a representative consolation: »Whoever you are, whatever you do, no matter what you eat, whatever the colour of your skin, you are in the Alzheimer lottery« (1988). The interviews with AD patients could have elicited alternative beliefs. See, for example, the characterization of a model suffering from AD: »Rita [Young] was always called 'vague' by the family. She seemed content to drift in her own dream world [...]«. But the two authors get caught on the symptoms of the manifest disease. It is therefore not surprising that in the second edition of their book, they make the effort to write an addendum in which they celebrate the Aluminum theory as »one tremendous step forward.«

The distancing from biographies is a particular characteristic of AD research. Although autobiographical approaches in empirical research periodically reappear and Tom Kitwood's research (Kitwood and Bredin 1992) is highly welcomed, this is not reflected in consequent reports. The biographies' possible contents (psychological trauma or stress) recede behind the formal demands to only know the autobiography to the extent that it can help to understand the actual situation of AD patients and what empathetic bedside manners require (Keady et al. 2007). Trevor Adams, for instance, lauds Kitwood's work with a »critical but appreciative review,« mentioning his many accomplishments – and his depiction of a »moral vacuum« within the standard paradigm of AD research –, but he does not follow Kitwood's explorations into psychological and social »causes« and calls his methodological assumptions »rather naïve« (Adams 1996).

Compensation and the Fragile Self

Regardless to which theories of the course of life and aging one adheres, they all indicate the necessity to overcome life experiences through the repeated interactions by which one grows (Erikson 1981; Havighurst 1953) or experience »entropy« (Schroots 1996). Upbringing, education, and naturally and potentially stressful life experiences like entering school, choosing a partner, marriage, divorce, changing jobs, unemployment, mental and bodily illness and much more pose challenges and determine whether there will be a physically and mentally successful aging process.

Psychological causes of psychosomatic illnesses – including AD – might therefore already be found »deep down« in the early years of any biography (Kropiunigg 1989). Pedro Caneiro's studies show an enduring effect of early non-cognitive skills; even the mother's level of education can affect the life course: »[T]he effect of maternal education follows the children into adulthood« (Carneiro et al. 2007). Furthermore, depression at age eleven makes one very likely to become an underachiever and report depression at age 42 (Carneiro et al. 2007) – a risk factor often found in AD (Devanand et al. 1996; Kokmen et al. 1991; Shalat et al. 1987; Speck et al. 1995; Wilson et al. 2002).

Recent empirical research that deals with the biographies of AD patients is rare (examples are: Bauer 1997; Bauer et al. 1994; Kitwood 1990b; Kropiunigg 1999a,b). I refer here to the results and the psychoanalytic interpretations of a Viennese study, in which the lifestyles of 50 AD patients were compared with those of 90 surgical patients through questionnaires, semi-structured interviews, and a risk protocol (for details see Kropiunigg et al. 1999).

The biography of AD patients hints toward life-long irritations in the areas of work and family, which I relate back to a fragile self (»adapted self« in the words of Kitwood 1990) and compensation in the areas of being and doing (cf. Erlich and Blatt 1985). Five potential pathogenic factors were found: an active-unproductive working style, living with a dominant partner, a merely quantitative attitude toward work, a lacking sense of self-esteem, and not working in the desired career. A qualitative orientation in work and family was protective. The results of a similar study by Bauer and colleagues speak to the relevance of our results. With the exception of two findings (sociability, early childhood trauma) their study found strikingly similar results. They describe AD patients as conflict-avoiders, submissive, overworked, without meaningful career motivation, and unable to assert themselves in a partnership (Bauer et al. 1995). As an illustration of the biographical approach I will therefore analyze the above empirical findings from the perspective of psychoanalysis, in this case Individual Psychology (Adler 1972 [1912]; Lattmann and Wuchterl 1992).

Childhood

Data from our AD patients could not be identified straining factors during childhood as risk factors. Lack of parental support and an emotionally negligent parental home could be found both in the AD group – one patient was never recognized by his father (to whom his mother stood in a servile relationship), as a legitimate son, although everyone in the neighborhood knew about it – as well as in the control group of surgical patients: the illegitimate daughter of a maid and a farmer, who had to live in her maternal grandmother's house with fifteen other children, only began to experience a somewhat happy life with her third stepfather.

Career

A clear pattern indicating a compensatory dynamic can be seen in career choice. The AD patients entered their future jobs with far higher personal aspirations than did the control group. They had their eye on a demanding job, which they never achieved for a variety of reasons; at the end they engaged in comparatively simple activities. The example of the »unrecognized genius« illustrates this especially clearly: after completing high school university remains unattainable for financial reasons. During the Second World War he is in the *Luftwaffe* and gains a certain sense of self-esteem by discovering engine failures that others then have to repair. After the war he first works with the public radio, then switches to a private firm, where he is quickly downgraded to an area with low responsibility. He quits and starts his own electronics store, which goes bankrupt when the technological advances in the industry confuse him. He was briefly married to a noble, then to a saleswoman at a newspaper stand, which he continuously referred to as a »bookstore.« At the end of his career path he is a consultant for household appliances.

This example shows a fierce desire for higher achievements. In terms of Individual Psychology it resembles a means of safeguarding by which he – as in the *Luftwaffe* – must retreat to a theoretical or less demanding position and avoid the reality check of practice. But he then suffers from lifelong corrections by reality. This mental tension, which can also be seen in other AD patients, lies in neither giving up nor reacting flexibly. The fictional goal is constantly vivid in the background and forces him into a role – as we will see in other examples – of compensatory ceremonial fulfillment of life tasks. Although this goal may not be attainable in the future, it can also be activated in backward-looking fantasies – as in the case of a housewife who still lives with her mother-in-law and proudly speaks of the times in which she was a beloved teacher (despite her lack of formal education). These patterns of loss and compensation may also occur by coincidence and force a person into a new role as happened to a successful salesman. Due to unforeseen political downfalls in countries where he had made deals, his career came to a sudden halt. His wife soon forced him to run the household and care for his chronically ill mother-in-law, while she began a successful career relatively late in life. Eight years later he was diagnosed with AD.

Quantity and Quality

When desired goals are not reached or their substantial bases disappear, compensatory behavior will emerge, as Individual Psychology underscores. Of the three defined working habits (passive-unproductive, active-productive and active-unproductive), AD patients show an active-unproductive working style. They are constantly busy, without even coming close to realizing their goals. Being inundated with work seems to be their primary interest. Finally, as their untiring efforts remain without substantial success, quantity replaces quality. This »wrong« compensation psychodynamically describes a balancing effort: what lacks in quality (satisfaction) is compensated for by effort. I will illustrate this compensation with the case of a general practitioner: He absolutely wanted to become a university radiologist, but had to give up this career goal for financial reasons. The son of a »female general« became a maniacally working doctor with a huge clientele, who additionally did the bookkeeping for his wife's and sister's businesses. When his daughter established a medical practice, he again took over the accounting. Only when he further desired to take over bookkeeping for his brother was he stopped. He often dreams of running and his catchphrase is »Ready? Go!« One must suspect that this lifestyle is marked more by readiness for the achievement of others' wishes than autonomous decisions. Only in quantitative variables – many patients, many tasks – is there apparent satisfaction, which is actually a compensation and serves the sustainability of the fragile self. Since the goals cannot be attained – on the one hand the satisfaction of motherly demands (by the female general) and on the other the originally desired yet unattainable career –, a frustrating endeavor is established, identified in our interviews as »active-unproductive behavior.« Thus, a life without felt and experienced success enhances the possibility of chronic stress.

A comparable behavior is not found among surgical patients (controls). Even when they experience unfavorable conditions, they remain positive and could be described as »active-productive.« They clearly have a more qualitative point of view toward work, and if this is not possible, they sometimes find solace in the motto »Work is good for money, and money is good for the family.«

AD patients mainly see the quantitative aspect of work. Their directing fiction leads them to seek recognition through grand effort and constant activity. If success remains elusive, feelings of failure and psychological stress inevitably appear. An AD patient, in contrast to her brothers, was not allowed to attend university, was her husband's explicit second choice, and from that point on worked around the clock both at home and in her husband's workshop, who for his part played the *pater familias* – with his own interests that he did not share with his wife. In the end she did love to »serve« her husband and his business, in order to – as counter-fiction clearly shows – »succeed through humility and submission« (Adler 1972).

Self-Esteem

A lack of any stable self is evident in AD patients' former lives. While the control group remembers instances of resistance and assertiveness (like the woman who as a student in a convent school resisted the nun's orders to bow before the crucifix), one cannot find even hints of such actions among the AD protocols. Miller (1995) renders this a social conditioning »to be average, [and] middle of the road.« Minimal latitude remains in which the person can move with a fragile self and which must be continuously reconstructed through compensation. Since they do not know how to defend themselves and to therefore avoid conflict, they become tangled up in the plans and intentions of others à la longue. Joachim Bauer describes the premorbid AD personality as »unsure of one's own self, dependent, in need of guidance and support« (Bauer et al. 1994, my translation). They presumably borrow an ephemeral identity through surrender and self-sacrifice; a fragile self that must be continuously reconstructed through a heroic compensatory fight: they don't give up, but in place of a qualitative life there is merely a »quantitative« one. Interesting gender differences can be seen here. Men more often strive for societal recognition and are known as »helping hands« around the neighborhood. In the workplace they act according to the motto: »First in the morning, last in the evening.« Women, on the other hand, mutate into willing housewives – a euphemism which in some cases might better be described as »house slaves.« Both strategies serve the formation of a fragile self in equal measure. One woman thereby became subject to the needs of others. She married »because of a child,« got a defamatory divorce, had to clear out the apartment, and left her son with his father. When the son got sick with asthma she returned, cared for the child, and accepted a sort of *mésalliance à trois* with her ex-husband and his new girlfriend. When the latter got pregnant, she once again had to leave the child and the apartment. Tom Kitwood describes a similar case of lifelong adaptation to a changeful family history. After the death of her husband and according to circumstance, Rose H. frequently moved in with her sister, her brother, or her married daughter, and always proceeded to make herself useful. »Rose's life was lived primarily on the basis of the adapted self« (Kitwood 1990).

Partnership

With such strong self-esteem problems it seems inevitable that the partnerships of later AD victims would be out of balance from early on. While cultural, entertainment, and sporting events are typical meeting places for later couples among the control group, AD patients meet their later partners »under special circumstances.« After the war, an AD patient thus found sanctuary in the parental home of his future wife; another female AD patient was only accepted as a wife after she had proven her fertility and then functioned as a »deliverer« of a male heir; a woman from an affluent background became the »financial backing« of her husband's risky and at times questionable business dealings. One main finding of our interviews concerns the pronounced dominance of the AD patient's partners. Later AD patients lack creative power in both their lives and their marriages. In the biographies of AD patients almost no qualitative interests can be detected; they instead let themselves be caught up with daily challenges imposed by their partners. While this might represent a psychological concession, it can also derive from the partner's dominant stance. I want to leave this question open. It is clear that in comparison to the control group, the healthy partner dominates life planning and interactions. Hanson's description of the exclusion from »reality construction« and Bauer's »verbal debasement in the years before AD« at least hint toward a chronic conflict, in which the healthy partner nolens volens takes on the leadership role (Bauer et al. 1995; Hanson 1989). In a study with caregivers of AD patients – conducted without any intentions concerning biographical meaning – phrases like »problematic partner relationship,« »giving up responsibility,« and »paternalism« unexpectedly appear. In regard to the relevance of empirical conclusions about risk factors drawn from questionnaires, it is interesting that one could only determine that premorbid »conflicts were the order of the day« through »careful inquiries« (Bayer-Feldmann and Greifenhagen 1995). It is to be assumed that the onset of AD and the following typical conflicts only show more clearly that which had always marked relationship patterns.

Being and Doing

Altogether, a picture of estranged and dominated persons emerges in AD patients' premorbid lives. They apparently do not participate in reality construction and neither gain a foothold in life nor do they develop a stable self. Instead, they fight a life-long battle for an ultimately fragile self with admirable energy. In terms of Erlich and Blatt (1985), any control over two fundamental modi of experience fails: that of being and that of doing. Through compensation they fall victim to overwork (men more often than women) or submission (counter-fiction; more often used by women) in the area of doing, while in the area of being they are constantly occupied with the maintenance of a fragile self, which is nurtured by the very act of doing. Vocationally and in the family they merely take on roles, which in the end – because they are not »lived« – remain only fragile. A somewhat satisfactory »goodness of fit« (Erlich and Blatt 1985) with their environment does not materialize. Instead, they compensate with untiring activity, suffer from not having achieved their dream career, or find gratification in a counter-fiction through subordination. Their heroic efforts cover up a disturbed sense of self-esteem, »since the deficient or partly atrophied sense of *being* found compensatory outlets in an increased and expanded emphasis on *doing*« (Erlich and Blatt 1985). In other words: compensation makes possible the constant perpetuation of a fragile self or a »fragile equilibrium,« as Kitwood defines it (1987a). It can be seen in characteristic sayings, like »Be up. Be doing« (Roach 1985) and the »Ready? – Go!« of the previously mentioned general practitioner. It is my impression that this deals with an unconscious desire for a firm being (be up!/ready?) and successful doing (be doing!/go!). The person is not unsure of both dimensions and is therefore unknowingly occupied Sisyphus-like with the construction of a fragile self. In Kitwood's analysis of Allen Roach this concept is pinpointed as follows: »[Allen] strives to validate herself through action« (Kitwood 1987a). Bauer gives a similar account of an unceasing effort to gain power over reality in his report of an AD patient in psychotherapy who is constantly on the lookout for a »new beginning« (Bauer 1997). Without a stable self on which to rely, only constant motion and repeated submission create the fragile certainty of being. It is as if being and doing required verbal reassurance and are therefore magically called upon. Love of work does not prompt these actions but rather the existential compulsion of being nothing without it. Kitwood speaks of a »fundamental ontological insecurity« (Kitwood 1987a). It is like a fight against annihilation, against which they fight with their compensatory fragile self, until this too is destroyed in dementia. These very subtle processes may only be detected by thorough introspection and analysis. Most empirical research will not do the work. Consider in this regard Bauer's findings from two years of psychotherapy. An AD patient who was not capable of asserting himself to his wife and his boss disclosed to him one day: »I like to put myself down. [...] I want to come up again. [...] My goal is to become more decisive, to defy my wife« (Bauer 1997). He has thus built himself a (temporarily not so) fragile self to help him in his efforts: »There is still a little dwarf in me who lets me say 'I don't know,' although I do know. In revenge I then let [the others] do *everything* [themselves]« (Bauer 1997, my translation, italics in original). Here too it cannot be assumed that this is not about a long-lived communicative pattern which has probably been refined over the course of growing symptom intrusions of AD.

There is no doubt that psychosocial stress affects bodily systems, including the brain (McEwen 2008; McEwen 2000; Sapolsky 1996), and does so even in spite of genes (Meaney 2001). But all these respective findings are not yet enough to state with assurance causal connections with AD. Those who work psychoanalytically will naturally see this differently and know why. Substantial insights can be won only after meticulous work on biographical material and its representation in the mind. Empirical studies derived from the methodology of natural sciences will hardly allow any deeper insight as to the level of »psychosocial risk factors.« On the other hand, it is somewhat risky to draw deep psychological conclusions from empirical data, as I have done here. It therefore remains to be hoped that more research will be done in the future using the same or an equivalent approach to the one I have outlined here with references to Tom Kitwood and Joachim Bauer. It is my opinion that it is far more necessary – and challenging – to deal with AD as a psychosomatic phenomenon rather than merely presenting the (thoroughly valuable) somatopsychic descriptions of the manifest illness. Especially biographical patterns that potentially solidify into risk factors will sensitize us to the somatic dangers of our behavior when psychophysiologically integrated stressors go far beyond stimulation and pressure for »reorganization in the brain« (Huether et al. 1996) and instead cause unwanted damage. Health education, however, specifically for those with AD, potential AD patients and their relatives, currently consists primarily of generalized deductions of scientific findings from animal studies, the laboratory and from assessing abstract risk factors like depression, anxiety or aggression – to name a few. The deeper causes of AD, however, remain to be unveiled for a better self-management or self-care of the disease. We must therefore go beyond plaques, tangles, transmitters, and surface phenomena like the »history of depressive episodes« and look into the many conscious and unconscious coping styles of humans. Otherwise, we will indeed be in Isobelle Gidley's AD lottery, which leaves wide open who will or will not contract AD. Self-management therefore demands a paradigm that allows for the inclusion of an analysis of the self and its two main dimensions of being and doing. AD research has long been in great need of scientists who will write the next chapter in AD's own biography, in which self-management is taken seriously and provides sound patterns derived from psychoanalysis.

References

Adams T (1996) Kitwood's approach to dementia and dementia care: a critical but appreciative review. J Adv Nurs 23: 948–953

Adler A (1972) Über den nervösen Charakter. Fischer, Frankfurt am Main

Ballenger JF (2006) Progress in the history of Alzheimer's disease: The importance of context. J Alzheimer's Dis 9: 5–13

Bauer J (1997) Möglichkeiten einer psychotherapeutischen Behandlung bei Alzheimer-Patienten im Frühstadium der Erkrankung. Nervenarzt 68: 421–424

Bauer J, Bauer H, Teising M (1994) Psychosomatische Aspekte der Alzheimer-Demenz (pp. 47–61). In: Hirsch R (Ed.) Psychotherapie bei Demenzen. Steinkopff, Darmstadt

Bauer J, Qualmann J, Bauer H (1994) Psychosomatische Aspekte bei der Alzheimer Demenz und bei vaskulären Demenzformen (pp. 214–228). In: Heuft G, Kruse A, Nehen H-G, Radebold H (Eds.) Interdisziplinäre Gerontopsychosomatik. MMV Medizin Verlag, Vieweg

Bauer J, Stadtmuller G, Qualmann J, Bauer H (1995) Premorbid psychological processes in patients with Alzheimer's disease and in patients with vascular dementia. Z Gerontol Geriatr 28: 179–189

Bayer-Feldmann C, Greifenhagen A (1995) Group work with relatives of Alzheimer patients – a systemic approach. Psychother Psychosom Med Psychol 45: 1–7

Carneiro P, Crawford C, Goodman A (2007) The impact of early cognitive and non-cognitive skills on later outcomes. Centre for the Economics of Education London School of Economics, London

Carneiro P, Meghir C, Parey M (2007) Maternal education, home environments and the development of children and adolescents. IZA Institute for the Study of Labor, Bonn

Damasio AR (2003) Der Spinoza-Effekt: Wie Gefühle unser Leben bestimmen. List, München

Devanand DP, Sano M, Tang MX, Taylor S, Gurland BJ, Wilder D, Stern Y, Mayeux R (1996) Depressed mood and the incidence of Alzheimer's disease in the elderly living in the community. Arch Gen Psychiatry 53: 175–182

Eisenberg L (1999) Does social medicine still matter in an era of molecular medicine? J Urban Health 76: 164–175

Erikson HE (1981) The life cycle completed. Norton, New York

Erlich HS, Blatt SJ (1985) Narcissism and object love. The metapsychology of experience. Psychoanal Study Child 40: 57–79

Forsythe E (1990) Alzheimer's Disease. The long bereavement. Faber and Faber, London

Gidley I, Shears R (1988) Alzheimers. What it is, how to cope. Unwin, London Sydney Wellington

Hanson BG (1989) Definitional deficit: a model of senile dementia in context. Fam Process 28: 281–289

Hanson BG (1991) Parts, players, and »patienting«: The social construction of senile dementia. Family Systems Medicine 9: 267–274

Havighurst RJ (1953) Developmental tasks and education. David McKay, New York

Hodges JR (2006) Alzheimer's centennial legacy: origins, landmarks and the current status of knowledge concerning cognitive aspects. Brain 129: 2811–2822

Hoffmann S (2008, Nov.) Meine Mutter, wie ein Kind (pp. 48–53). Chrismon, Hansisches Druck- und Verlagshaus, Frankfurt am Main

Huether G, Doering S, Rüger U, Rüther E, Schüssler G (1996) Psychische Belastungen und neuronale Plastizität. Z Psychosom Med 42: 107–127

Keady J, Ashcroft-Simpson S, Halligan K, Williams S (2007) Admiral nursing and the family care of a parent with dementia: using autobiographical narrative as grounding for negotiated clinical practice and decision-making. Scand J Caring Sci 21: 345–353

Kitwood T (1987a) Dementia and its pathology: in brain, mind or society? Free Associations 8: 81–93

Kitwood T (1987b) Explaining senile dementia. Free Associations 10: 117–140

Kitwood T (1990) Understanding senile dementia – a psychobiographical approach. Free Associations 19: 60–76

Kitwood T, Bredin K (1992) Towards a theory of dementia care: personhood and well-being. Ageing Soc 12: 269–287

Kokmen E, Beard CM, Chandra V, Offord K-P, Schoenberg BS, Ballard DJ (1991) Clinical risk factors for Alzheimer's disease: a population-based case-control study. Neurology 41: 1393–1397

Kropiunigg U (1989) Kindheit und Erziehung bei psychosomatisch Kranken. Psychother Psychosom Med Psychol 39: 168–172

Kropiunigg U (1999a) Alzheimer's Disease as a result of »wrong« compensation. J Indiv Psychol 55: 395–409

Kropiunigg U (1999b) Kompensation und ephemer-fragiles Selbst: eine individualpsychologische Analyse der Alzheimer Krankheit. Z Individualpsychol 24: 186–202

Kropiunigg U, Sebek K, Leonhardsberger A, Schemper M, Dal-Bianco P (1999) Psychosoziale Risikofaktoren für die Alzheimer Krankheit. Psychother Psychosom Med Psychol 49: 153–159

Lattmann UP, Wuchterl K (1992) Der Topos der Kompensation bei Alfred Adler – Anmerkungen aus der Sicht der philosophischen Anthropologie. Z Individualpsychol 17: 3–18

Lewis D, Rodgers D, Woolcock M (2008) The fiction of development: literary representation as a source of authoritative knowledge. J Dev Studies 44: 198–216

Lunde A (2008) Lifestyle strategies may slow or prevent decline. Mayo Clinic medical information and tools for healthy living: http://www.mayoclinic.com/health/alzheimer/AZ99999

McEwen BS (2008) Central effects of stress hormones in health and disease: Understanding the protective and damaging effects of stress and stress mediators. Eur J Pharmacol 583: 174–185

McEwen BS (2000) Effects of adverse experiences for brain structure and function. Biol Psychiatry 48: 721–731

McLuhan M (1964) Understanding Media: The Extensions of Man. McGraw-Hill, New York

Meaney MJ (2001) Nature, nurture, and the disunity of knowledge. Ann N Y Acad Sci 935: 50–61

Miller DW (1995) The psychobiological nature of reality with a theory about Alzheimer's. Advances 9: 69–76

Roach M (1985) Another name for madness. Houghton and Mifflin, Boston

Sapolsky RM (1996) Why stress is bad for your brain. Science 273: 749–750

Schroots JJF (1996) Theoretical developments in the psychology of aging. The Gerontologist 36: 742–749

Shalat SL, Seltzer B, Pidcock C, Baker EL Jr (1987) Risk factors for Alzheimer's disease: a case-control study. Neurology 37: 1630–1633

Speck CE, Kukull WA, Brenner DE et al. (1995) History of depression as a risk factor for Alzheimer's disease. Epidemiology 6: 366–369

Tomlinson BE, Blessed G, Roth M (1970) Observations on the brains of demented old people. J Neurol Sci 11: 205–242

von Uexküll T (2001) Körper-Sein, Körper-Haben – Der Hintergrund des Dualismus in der Medizin. Psychother Psychosom Med Psychol 51: 128–133

Wilson RS, Barnes LL, Mendes de Leon CF et al. (2002) Depressive symptoms, cognitive decline, and risk of AD in older persons. Neurology 59: 364–370

Wittgenstein L (2003) Logisch-philosophische Abhandlung. Tractatus logico-philosophicus. Suhrkamp, Frankfurt am Main

Caregivers Care with Alzheimer's Disease, Prevention of Caregivers Burn-Out

Aleksandra Milićević-Kalašić

Introduction

Alzheimer's disease (AD) is the most common cause of dementia and a major cause of morbidity and mortality in the elderly, affecting together with other related dementias (ADRD) about 24 millions people around the world. Since most people with Alzheimer's disease continue to live in their own homes, there is an increase in the number of people with dementia living in the community cared for by family caregivers (Ferri et al. 2005; Henderson and Jorm 2000).

Care-giving is an emotional, physical and at times financial burden. While caring can be rewarding, the strains and responsibilities of the role can have an impact on the carer's own psychological and physical health. The chronic stress of providing in-home care to a loved one with dementia is associated with significantly higher levels of psychological morbidity, depression, stress, burden, long term grief reactions and premature mortality than people who are not caregivers or those who are caring for the physically ill (Proctor and Testad 2005; Sanders et al. 2008; Mahoney et al. 2005; Shulz and Beach 1999). Average annual informal costs was estimated at $ 25,381 per patient, increasing from $ 20,589 at baseline to $ 43,030 in year 4 of the longitudinal study (Zhu et al. 2006).

Patient/Caregiver Dyad

The needs of the caregivers and of the person with dementia are inevitably intertwined and can sometimes conflict and change over time. So it is very important to understand the individual needs of caregivers and the person with dementia and monitore them in due time to provide appropriate support over time. Brief psychosocial intervention in dementia care is not enough to address the ongoing changes in families (Proctor and Testad 2005).

Clinicians should consider the dynamics between patients and caregivers when managing BPSD (behavioral and psychological symptoms of dementia) or neuropsychiatric symptoms of dementia as caregivers characteristics are associated with these disturbing behavioural changes occurring in 90% of cases at some time (Sink 2006; Ballard 2005).

On the other hand, it is well known that caregiver's stress is the product of an interaction of care-related stressors, the resources available to families and psychosocial variables. An abundance of literature on caregivers of individuals with dementia has been written since mid-1980s trying to explain what's happening during the process of care-giving and how it effects (predominantly negative) their physical and mental health (Proctor and Testad 2005; Mahoney et al. 2005; Sink et al. 2006; Haley 1997; Dunkin and Anderson-Hanley 1998; Croog et al. 2006; Italiano et al. 2003 ; Kanel et al. 2006; Mannion 2008; Milićević Kalašić et al. 2001).

Caregiver Burden and Consequences

Caregivers suffer from the burden of household chores and are exposed to BPSD such as depression, anger, agitation, wandering and paranoia in their care recipients. They also face the progressive deterioration of the personality or the »loss of self«, suffering and death of a loved one (Haley 1997; Dunkin and Anderson-Hanley 1998).

Total caregiver/patient problem burden was also most strongly positively associated with caregiver anger-resentment toward the patient, followed by caregiver concerns about own time restriction and limitation of social life.

Care-giving is associated with unhealthy life style and behaviors such as increased alcohol consumption, unhealthy diet, use of tobacco and disturbed sleep and with a variety of health problems and conditions (headaches, nervousness, insomnia, and decreased tolerance for pain, weight loss or gain, drowsiness). A recent meta-analytic review found that caregivers of a family member with dementia had elevated stress hormones (e.g. cortisol) and suppressed antibody production in comparison to non-caregivers. The findings suggest that poor sleep was associated with higher plasma IL-6 and D-dimer levels and reveal a mechanism that may explain how disturbed sleep might be associated downstream with cardiovascular risk (Italiano et al. 2003; Kanel et al. 2006; Mannion 2008).

Negative impact of care-giving on their social life and associations appeared to have particular marked effects on caregiver's depressive symptoms and anxiety scores. The fact, that caring for a person with dementia places the caregiver at greater risk of experiencing serious psychological disorders such as depression has been well documented in many studies. Prevalence rates of depressive symptoms among caregivers range from 28% to 55% (Mahoney et al. 2005; Sink et al. 2006; Haley 1997; Dunkin and Anderson-Hanley 1998; Croog et al. 2006; Italiano et al. 2003; Kanel et al. 2006; Mannion 2008; Milićević Kalašić et al. 2001; Schulz et al. 1995). It is very interesting that caregivers with a history of clinically significant depression are not necessarily more prone to depressive symptoms when care-giving responsibilities are high (Neundorfer et al. 2006).

Gender Differences in the Experience of Burden

The greatest proportion of caregivers (about 70%) of patients with dementia consists of women, they experience higher level of burden when compared with men caregivers and this increases their vulnerability for depression. Gender differences have been reported in the ways people use to cope with several stressors of care giving, suggesting that men receive more informal support than women (Sink et al. 2006; Haley 1997; Dunkin and Anderson-Hanley 1998; Croog et al. 2006; Milićević Kalašić et al. 2001; Hibbard et al. 1996; Russell 2007; Papastavrou et al. 2007).

Prevention of Caregivers' Burn-out

Finding better ways to support family caregivers is a major public health challenge. Everything previously mentioned should be used in achieving this goal. Several studies reviewed the evidence of the impact of programs designed to prevent the negative consequences of care-giving for a person with dementia. Interestingly, combined care programs addressing both the persons with dementia and their caregivers have been shown to be most effective with respect to the caregiver. Care professionals also should take in consideration subgroup of caregivers with individual risk profiles and demands at different stages of illness. Besides it would be valuable to know how technology can support people with dementia and their caregivers and what requirements should be considered regarding their function and design. Staff should be trained under sustained supervision (Proctor and Testad 2005; Sink et al. 2006; Milićević Kalašić et al. 2001; Brodaty et al. 2003; Smits et al. 2007; Cook et al. 2008; Belle et al. 2006; Granello and Fleming 2008; Cahill et al. 2007; Aminzadeh et al. 2007; Gwyther 2006).

Early detection of signs of carers' stress is a crucial first step in helping them to accept help and to learn how to cope with some of the demands of the role. Many of the caregivers are socially isolated and there is great variation in what caregivers know about available services and support and as well how reluctant are they to engage with them.

Disclosing the diagnosis should be seen as part of a process of supporting the patient and the caregivers, which requires more than one visit. Understanding of the experience of people with dementia and their caregivers at the critical point of diagnosis disclosure is of a great importance in designing supportive interventions to maximize adaptive coping responses. It is considerably important that information is given in an empathic and sensitive way.

By using *available community respite resources*, such as a daycare and possibly nightcare services, caregivers can use relief time to meet their personal health needs for relaxation and sleep. Community programs need to be made known to the caregiver, and access to these resources should be discussed with the caregivers on referrals. Identified unmet needs of patient/caregiver dyad should give direction in developing services in order to help patients and carers in the way they need it.

Education about dementia should not be delivered in a prescriptive way, but should focus on the caregivers's individual understanding. Unfortunately, single educational interventions for caregivers of patients of dementia have been only modestly successful in reducing burden or nursing home placement (Sink et al. 2006).

Psychological and social interventions incorporate a diverse set of approaches, including stress management, education about dementia, problem-solving and behaviour management. Mental healthcare professionals have multitask roles, not only to have the necessary skills to detect and manage caregivers' stress but also to promote well-being in caregivers through education about how to access help and manage stress effectively.

When mental health problems are identified, appropriate interventions need to be developed to help caregivers meet their health needs. Caregivers whose mental health problems are more severe should be referred to a *mental health specialist*.

Caregivers also need to be given the opportunity to talk about care-giving stressors and their reaction to what is happening to them as they care for their impaired relatives. They should be encouraged to join a local Alzheimer's Association support group or a clinic-based support group or to communicate their care-giving questions online.

Support groups for caregivers provide social contact and emotional support which can help to alleviate feelings of isolation and promote well-being. Psychosocial interventions should be offered to address changing needs of followed dyads: a post-diagnostic counseling group will be most helpful for those who has to adjust to a diagnosis of dementia, behavior management would be of a great value for family members of patients who exibit neuropsychiatric symptoms (up to 90% in some period of time) and intervention focusing on issues of loss and bereavement may be most effective at later stages in care-giving.

Caregivers should be counseled about stressors (including sleep disruption), effective techniques for care giving, methods of appraising their own health needs, and healthy living strategies. Interventions focused on realistic appraisal may help alleviate some of the fear or quilt that frequently stops caregivers from seeking help sooner and from using helpful care-giving appliances, such as adult diapers except as a last recourse. Discussion about providing patient care, accompanied by practical advice and transitional guidelines on what to expect at various phases of ADRD, may also assist the caregiver in his/her role and may help them to feel more in control of their situation and lessen the burden of care-giving.

Technology and knowledge can help but spirituality, faith, and religious ritual seem to help exhausted families find meaning and purpose in adversity, an anchor for identity and a foundation for coping with change, loss, uncertainty, and the limits of control (Proctor and Testad 2005; Sink et al. 2006; Milićević Kalašić et al. 2001; Brodaty et al. 2003; Smits et al. 2007; Cook et al. 2008; Belle et al. 2006; Granello and Fleming 2008; Cahill et al. 2007; Aminzadeh et al. 2007; Gwyther 2006).

References

Aminzadeh F, Byszewski A, Molnar FJ, Eisner M (2007) Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. Aging and Mental Health 11: 281–290

Ballard C (2005) Drugs used to relieve behavioural symptoms in people with dementia or an unacceptable chemical cosh? Psychogeriatr 17: 4–12

Belle SH, Burgio L, Burns R, Coon D, Czaja SJ, Gallagher-Thompson D et al. (2006) Enhancing the quality of life of dementia caregivers from different ethnic or racial groups. Ann Intern Med 145: 727–738

Brodaty H, Green A, Koshera A (2003) Meta analysis of psychosocial interventions for caregivers of people with dementia. JAGS 51: 657–664

Cahill S, Macijauskine J, Nygard AM, Faulkner JP, Hagen I (2007) Technology in dementia care. Technology and Disability 19: 55–60

Cook EM, Elston C, Gardiner E, Agar S, Silver M, Win T, Wang M (2008) Can training community mental health nurses to support family carers reduce bahavioural problems in dementia? An exploratory pragmatic randomised controlled trial. Int J Geriatr Psychiatry 23: 185–191

Croog SH, Burleson, Sudilovsky A, Baume RM (2006) Spouse caregivers of Alzheimer patient: problem responses to caregiver burden. Aging and Mental Health 10: 87–100

Dunkin JJ, Anderson-Hanley C (1998) Dementia caregiver burden; a review of the literature and guidelines for assessment and intervention. Neurology 51(Suppl 1): S53–S60

Ferri CP, Prince M, Brayne C et al. (2005) Global prevalence of dementia: A Delphi consensus report, Lancet 366: 2112–2117

Granello PF, Fleming MS (2008) Providing counseling for individuals with Alzheimer's disease and their caregivers. Adultspan Journal 7: 13–25

Gwyther LP (2006) Spirituality and caring for older family members. South Med J 99: 1180–1181

Haley WE (1997) The family caregiver's role in Alzheimer's disease. Neurology 48 (Suppl 6): 25–29

Henderson AS, Jorm AF (2000) Definition and epidemiology of dementia: a review. In: Maj M, Sartorius N (eds) Dementia. Wiley, Chichester

Hibbard J, Neufeld A, Harrison MJ (1996) Gender differences in the support networks of caregivers. J Gerontol Nurs 22: 15–23

Italiano PP, Zhang J, Scanlan JM (2003) Is care giving for persons with dementia and related cognitive disorders hazardous to one's physical health? Psychological Bulletin 129: 946–972

Kanel R, Dimsdale JE, Ancoli-Israel S, Mills PJ, Patterson TL, McKibbin CL, Archuletta C, Grant I (2006) Poor sleep is associated with higher plasma proinflammatory cytokine interleukin-6 and procoagulant marker fibrin D-dimer in older caregivers of people with Alzheimer's disease. J Am Geriatr Soc 54: 431–437

Mahoney R, Regan C, Katona C, Livingstone G (2005) Anxiety and depression in family caregivers of people with Alzheimer's disease. Am J Geriatr Psychiatry 13: 795–801

Mannion E (2008) Alzheimer's disease: the psychological and physical effects of the caregiver's role. Part 1 and 2. Nursing Older People 20: 27–38

Milićević Kalašić A, Marković Žigić D, Kosic T, Vlašić M (2001) Home based assessment for carers of patients with dementia. Int Psychogeriatr 13 (Suppl 2): 272-S

Neundorfer MM, Mc Clendon, Smyth KA, Strauss ME, Mc Callum TJ (2006) Does depression prior to care giving increase vulnerability to depressive symptoms among caregivers of persons with Alzheimer's disease? Aging and Mental Health 10: 606–615

Papastavrou E, Kalokerinou A, Papacostas SS, Tsangari H, Sourtzi P (2007) Caring for a relative with dementia: family caregiver burden. J Adv Nurs 58: 446–457

Proctor R, Testad I (2005) Carer stress-overview. In: Burns A (ed) Standards in dementia care. Taylor & Francis London New York, S 241–247

Russell R (2007) Men doing »Women's work«: Elderly men caregivers and the gender construction of care work. J Men's Studies 15: 1–18

Sanders S, Ott C, Kelber S, Noonan P (2008) The experience of high levels of grief in caregivers of person with Alzheimer's disease and related dementia. Death Studies 32: 495–523

Schulz R, O'Brien AT, Bookwala J, Fleissner K (1995) Psychiatric and physical morbidity effects of dementia care giving: Prevalence correlates and causes. Gerontologist 35: 771–791

Shulz R, Beach SR (1999) Caregiving as a risk factor for mortality. The Caregiver Health Effects Study. JAMA 282: 2215–2219

Sink K, Covinsky K, Barnes D, Newcomer R, Yaffe K (2006) Caregivers characteristics are associated with neuropsychiatric symptoms of dementia. J Am Geriatr Soc 54: 796–803

Smits CHM, De Lange J, Droes RM, Meiland F, Vernooij-Dassen M, Pot AM (2007) Effects of combined intervention programs for people with dementia living at home and their caregivers: a systematic review. Int J Geriatr Psychiatry 22: 1181–1193

Zhu CW, Scarmeas N, Torgan R, Albert M, Brand T, Blacker D, Sano M, Stern Y (2006) Clinical characteristics and longitudinal changes of informal cost of Alzheimer's disease in the community. JAGS 54: 1596–1602

6

Psychological Aspects of Promotion of Self-Management

Dorothee Karl

Self-Perception and Self-Concept

Self-perception and the self-concept resulting from it constitute key elements in preservation, restoration, or improvement of health, meaning a person's physical, mental, and cognitive capabilities and resources. This being so, an individual's self-perception and self-concept form the roots of self-management which, in turn, is shaped and influenced by both inter-personal and intra-personal factors.

To achieve self-regulation, individuals must begin by minutely analysing their motivations, objectives, and values to gain active control over them. The point is to become consciously aware of the individual process of change and control it to serve a specific purpose. The emphasis here is on the self-management of individuals and, consequently, on their active, responsible role throughout the process of illness and/or recovery.

This calls for a large measure of personal initiative and responsibility, self-organisation, and self-motivation. All these expressions are subsumed under the term self-management. According to Kanfer et al. (2000), self-management calls for a great deal of self-responsibility on the part of the individual as well as for a great measure of self-regulation and self-development. In this context, the term self-regulation means »that persons direct their behaviour towards objectives set by themselves« (Kanfer et al. 2000). On the one hand, this means that persons set their own objectives, while on the other, self-regulation implies that individuals plan their own way towards an objective relatively freely and independently, and proceed accordingly. Thus, people can control their actions as directed by their personal style and/or personality. Together with a large measure of autonomy, the option to choose one's own way constitutes an important motivational support factor (Deci and Ryan 1993).

One of the prerequisites for the development of self-regulation is self-observation (Kanfer et al. 2000; Bandura 1991). The starting point is to break with routines and automatisms and focus on a particular behaviour that is to be influenced. Registered in the context of the prevailing situation, observed behaviour is then compared against internal expectations and personal objectives. In this context, self-observation serves two purposes: self-diagnosis and self-motivation. Systematic self-observation yields important information about one's own person and its impact, enabling one to control one's behaviour more thoroughly (Bandura 1991). The self-motivating effect arises from the fact that one tends to set oneself more and more difficult objectives if one keeps one's own actions under close observation (Bandura and Cervone 1983).

People who understand their own role in this way become »experts on themselves« who, however, can never proceed beyond a subjectively coloured image of objective reality. For this reason, constant critical examination is of extreme importance for identifying successful approaches to self-management. This scientific method is also known as induction. Inductive reasoning implies forming a general theory from observed perceptions (Bortz and Döring 2002).

According to Harter (1990), people assess themselves in terms of their cognitive and physical capabilities, their acceptance of other people who are important to them, and their social acceptance (manners, morals, humour, responsibility). This assessment is always based on idealised concepts of these terms of reference which people store in their minds. The greater the discrepancy that emerges after this test between achievements on the one hand and ideals and/or the desired state of affairs on the other, the weaker a person's sense of self-worth will be. The test itself is fed by two sources: One is to compare one's own performance at two different points in time (temporal comparison), the other is based on measuring oneself by standards set by others and on comparing one's own performance with that of others (social comparison). The quality of a person's sense of self-worth is of fundamental importance for personal development and stability as well as for the ability to cope with challenges, forming an important protective resource because it reflects the extent to which individuals control their own reinforcements as well as their ability to influence themselves actively.

Persons with a positive sense of self-worth will view problems as challenges to be tackled with assurance of ultimate success. Moreover, coping with a problem successfully will confirm and/or reinforce their positive self-assessment. Conversely, persons with a weak sense of self-worth are particularly vulnerable because they expect little of their own competence and tend to be fearful of failures, for which they feel more strongly responsible than for their successes. These discrepancies in the way in which people experience, perceive, and attribute matters cause differences in the manner in which they behave and digest information that affect their performance (Jerusalem 1991; Meyer 1994).

The primary objective of promoting self-management is to support individuals in consciously observing their own process of change and directing it towards specific objectives, with emphasis on man's role as an active, responsible being.

Past experience provides an important individual reference system for self-management. However, such experience not only consists of feelings that are restricted to and emerge from a specific event but also of impressions that develop with a view to future scenarios that might be triggered by the event itself or by future actions. The way in which people deal with the content of such an experience-generating event depends on their intentions (Echterhoff 1992). Thus, a specific self-purpose might induce individuals to expect progress or other positive benefits with regard to their own quality of life.

In this context, it is apposite that Dieckmann (1994) should emphasise that »self-activity implies self-concern«.

Motivation and Stereotyping

In the health sector, negative societal stereotypes occur frequently which, for example, ascribe to elderly and chronically ill people characteristics such as inflexibility, lack of strength, or »pig-headedness« (Kolland 2005). Among other things, these stereotypes negatively influence the motivation to act responsibly. »When we are offended, we are no longer capable of acting constructively« (Koper 2006).

Faulty perception (e.g. Rosenthal effect, halo effect, contrast errors, projections; Herkner 2001; Hobmair 2003; Zimbardo 2004) which results in a negative image of the other may have the primary consequence of causing deficits in the image of the self, and the secondary consequence of negatively influencing the course of a disease.

A special phenomenon encountered in some elderly people is that this group of persons employs various adaptation strategies, such as subadaptation to promote the sense of self-worth (avoiding subjects that threaten the self-worth), temporary self-deprecation (referring to health problems), and self-stereotyping to conceal supposed deficiencies (Mayer 2002).

Studies addressing the subjective self-assessment of personal health found that the risk of illness increases with age (Nacelle 1992; Federal Statistical Office 1991). It is striking that this self-assessment is accompanied by a feeling of loneliness as well as a willingness to accept handicaps as something that is normal for one's age and must be lived with (Svanborg et al. 1988).

An individual's physical well-being as well as his attitude towards his own ageing process are greatly influenced by mental functional capacity (Ruoppila and Suutama 1994; Ilmarinen and Tempel 2002). In human beings, the term mental functional capacity describes the ability to perform various tasks that require intellectual and other forms of mental effort (Ilmarinen and Tempel 2002).

People may fall ill, or their performance may decline, because they mismanage their own resources. Realistically judging one's own resources may occasionally be rendered impossible by situational characteristics such as stress or conflicts with others.

Despite the psychological pressure exerted by stereotypical assumptions it is generally thought that greater experience improves peoples' ability to assess various situations in their lives, the challenges relating to them, and their own options to cope with these situations (Ilmarinen and Tempel 2002). Moreover, it is postulated that experienced people will be more mature in terms of social competence, reject uncontrolled behaviour patterns, and suggest more useful patterns instead (Ilmarinen and Tempel 2002).

Furthermore, many older people are distinguished by feeling more satisfied with themselves and leading positive lives as well as by understanding, circumspection, serenity (Bundesverband der Unfallkassen 2002, October 07), and marked self-responsibility.

The contradiction between increasing satisfaction on the one hand and the growing fear of failure on the other (Ilmarinen and Tempel 2002) shows that generalising statements regarding the increase in inter-individual differences in old age are unjustifiable.

To a large extent, the quality of self-management depends on an individual's experience with his perceived resources and the implementation of his action strategies in various situations.

The quality of self-management has therefore lifelong effects on the individual development.

Approaches to Improve Self-Management

As described in the beginning, potentials that exist objectively are rendered subjective by external and internal evaluation processes. This may partially explain why peoples' performance may fall short of or exceed their capabilities as they appear from objective medical data. Thus, misjudging one's own state of health may lead to excessive physical strain if it is overestimated and to laxness or reactant behaviour if one's own physical potentials are underestimated.

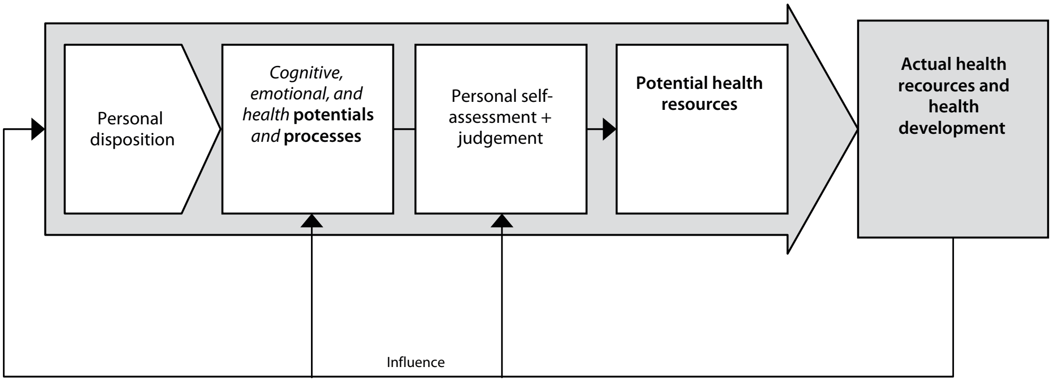
Discriminating between potential and actual health resources shows the importance of external influences on individual development. Individual perceptions of the relation between health-oriented behaviour input and the state of health anticipated intrinsically and/or extrinsically (target compliance) are produced by a highly complex fabric of conditions that is influenced by many factors. Ultimately, these factors decide about the extent to which individuals are prepared to promote their own health responsibly. This decision is preceded by implicit and explicit processes (◘ Fig. 6.1).

Therefore, endeavours to re-orient the public-health system so as to support improvements in self-management should give consideration to the personal level of development of the individual.

The roots of a health-conscious mode of living that aims to preserve and promote health and performance may be planted in childhood (Semmer and Richter 2004).

The cognitive input for developing a holistic approach to promote self-management competences will expand as more material becomes available to compare objective and subjective data. Measurements of the sustainability of the effects of self-management strategies should include cognitive, physiological, and mental aspects in their overall consideration and assessment. The next step should be to investigate whether these effects differ significantly in strength between specific groups of persons (typologies), symptoms, behavioural strategies, or developments.

Consequently, the aspect of subjectiveness should be given greater consideration in the selection and development of methodologies.



◘ **Fig. 6.1.** Influencing facts of the self-concept (Karl 2009)

References

Bandura A (1991) Social cognitive theory of self-regulation. Organizational Behavior and Human Decision Processes 50: 248–287

Bandura A, Cervone C (1983) Self-evaluative and self-efficacy mechanisms governing the motivational effects of goal systems. J Pers Soc Psychol 45: 1017–1028

Bortz J, Döring N (2002) Forschungsmethoden und Evaluation für Human- und Sozialwissenschaftler. 3. überarb. Aufl. Springer, Berlin Heidelberg New York

Bundesverband der Unfallkassen (2002, Oktober 07) Forschung für die Praxis – Erwerbsarbeit und Alter: Neue Anforderungen zur Integration älterer Arbeitnehmer. URL www.unfallkassen.de/pdf/FFDP12002.pdf

Deci EL, Ryan RM (1993) Die Selbstbestimmungstheorie der Motivation und ihre Bedeutung für die Pädagogik. Zeitschrift für Pädagogik 39: 177–186

Dieckmann B (1994) Der Erfahrungsbegriff in der Pädagogik. Deutscher Studien Verlag, Weinheim

Echterhoff W (1992) Erfahrungsbildung von Verkehrsteilnehmern. Forschungsbericht der Bundesanstalt für Straßenwesen. Verlag Mainz, Aachen

Harter S (1990) Causes, correlates, and the functional role of global self-worth: A life-span perspective. In: Sternberg RJ, Kolligan J Jr (eds) Competence considered. Yale University Press, New Haven, CT, pp 67–97

Herkner W (2001) Sozialpsychologie, 2. Aufl. Huber, Bern

Hobmair H (2003) Psychologie, 3. Aufl. Bildungsverl. EINS, Troisdorf

Ilmarinen J, Tempel J (2002) Arbeitsfähigkeit 2010 – Was können wir tun damit, Sie gesund bleiben? VSA-Verlag, Hamburg

Jerusalem M (1991) Allgemeine Selbstwirksamkeit und differentielle Streßprozesse. Psychologische Beiträge 33: 388–406

Kanfer FH, Reinecker H, Schmelzer D (2000) Selbstmanagement-Therapie, 3., überarb. Aufl. Springer, Berlin Heidelberg New York

Karl D (2009) »Arbeitsfähigkeit« ein ganzheitlicher, integrativer Ansatz (in Vorbereitung)

Kolland F (2005) Bildungschancen für ältere Menschen. Ansprüche an ein gelungenes Leben. Lit Verlag, Wien

Koper T (2006) Den »Silberschatz« heben – aber wie? Personalführung 7: 69–73

Meyer W-U (1994) Das Konzept von der eigenen Begabung. Huber, Bern

Mayer A-K (2002) Alt und Jung im Dialog. Programm PVU Psychologie Verlags Union, Weinheim Basel Berlin

Nacelle G (1992) Zwischen Arbeit und Rente. Maro Verlag, Augsburg

Ruoppila I, Suutama T (1994) Psychological changes and ageing. In: Kuusinen J, Heikkinen E, Huuhtanen P et al. (eds) Ageing and Work. WSOY & Finnish Institute of Occupational Health, Helsinki

Semmer N, Richter P (2004) Leistungsfähigkeit, Leistungsbereitschaft und Belastbarkeit älterer Menschen. In: von Cranach M, Schneider H-D, Ulrich E, Winkler R (Hrsg) Ältere Menschen im Unternehmen. Haupt Verlag, Bern, S 95–116

Statistisches Bundesamt (Hrsg) (1991) Im Blickpunkt: Ältere Menschen. Metzler-Poeschel, Stuttgart

Svanborg A (1988) The health of the elderly population: results from longitudinal studies with age-cohort comparisons. In: Evered D, Wehlan J (eds) Research and the ageing population. Wiley, Chichester, pp 3–16

Zimbardo P (2004) Psychologie, 7. Aufl. Eine Einführung. Springer, Berlin Heidelberg New York

Self-Management Programs

Sabine Bährer-Kohler, Eva Krebs-Roubicek, Olusola T. Ephraim-Oluwanuga

7.1 Management and Self-Management Programs for Chronic Disease – Tools, Transformation and Promotion

Sabine Bährer-Kohler, Eva Krebs-Roubicek

Introduction

A PubMed search for the above terms yields a total of more than 200,000 papers over the past 30 years that relate to self-management. Surprisingly, only a few publications address

- self-management and dementia,
- guidelines for self-management and dementia, or
- scales of self-management and dementia.

To select, analyze and present the state of the art in this field is not easy, especially because it is difficult to differentiate between data concerning self-care, self-management, educational programs and coping programs worldwide.

Even though Redman (2007) did develop a standard dataset to facilitate describing the effectiveness of existing programs, there is still no program comparison. This is why it is difficult to assess the effectiveness of single interventions.

On the other hand, self-management for people with a chronic disease is now widely recognized as a necessary part of treatment interventions that try to improve the coping ability of patients and their caregivers.

The aim of those interventions is to arrange highly effective conditions which are essential components of chronic disease care (WHO 2005).

Important topics of patient education in coping with chronic disease include

- self-management,
- skills,
- self-efficacy,
- health status, self-rated health,
- health behavior,
- social/role activities and limitations,
- coping abilities,
- quality of life,
- locus of control,
- better communication between patients and health providers,
- health distress,
- health care utilization (outpatient visits, times hospitalized, and days in hospital),
- perceived self-efficacy and
- socio-economic factors.

These interventions aim for the following:

- Improved health status, self-rated health,
- Improved health-related quality of life,
- Improved health behavior,
- Improved control of chronic disease,
- Improved locus of control,
- Acceptance of social/role and activity limitations,
- Decreased health care utilization (outpatient visits, times hospitalized, and days in hospital).

Models

Lorig (2000) describes how self-management models have changed in general. It seems important to implement programs based on background models like the following.

The *healthcare model* is characterized by:

- education on health matters and empowerment to enable people to adopt an active role in managing their own health status,
- emphasis on a preventive lifestyle, early diagnosis,
- tailored care and self-management of (chronic) diseases.

The *medical model* describes the approach to illness that is dominant in Western medicine. It aims to identify medical treatments for diagnosed symptoms and syndromes and treats the human body as a very complex mechanism. Thus, the medical model still largely presumes that the role of the healthcare professional is to diagnose and prescribe, whereas it is the role of the patient to comply (Medical Model 2008).

The *public health model* has been very effective in preventing problems ranging from childhood diseases to those caused by smoking, but it has not been effective in stopping the increase in chronic conditions that are largely related to aging.

The Chronic Care Model (CCM) of the U.S. Department of Health and Human Services Health Resources and Services Administration integrates different aspects across a broad range. The CCM comprises six interrelated components that support high-quality health care for people living with a chronic disease (adapted from Wagner 1998):

- community resources,
- health system organization of health care,
- self-management support,
- delivery system,
- decision-making support,
- clinical information systems.

The *level-of-connectedness model*: A number of models have been proposed to describe the processes of appraisal and coping in the early stage of dementia. With regard to gender differences, Dijkhuizen et al. (2006) identified three higher-order themes out of ten that are important to women:

- connectedness,
- protective strategies,
- adjustment.

This model places coping in an interpersonal framework, whereby a woman's ability to maintain a sense of self is inherently dependent on the readiness of others to facilitate connectedness. This provides a focus for possible further development of psychosocial interventions that consider well-being in an interpersonal context.

The models mentioned above as examples of existing models form the basis for further steps to develop self-management programs.

Self-Management Programs

Chronic disease self-management education programs aim to empower patients by providing information, skills and techniques to improve self-care and doctor–patient interaction, with the ultimate goal of improving the quality of life.

The roles of healthcare professionals, physicians, nurses, social workers and patients are changing (Holman and Lorig 2004). The health professional will be more of a partner, consultant, interpreter of symptoms and a resource person, offering suggestions for treatment. The patient monitors symptoms, reports on them and tries to manage the disease on a day-to-day basis.

Recent evidence suggests that patients with effective self-management skills make better use of the healthcare professionals' time and display enhanced self-care (Barlow et al. 2000). Systematic reviews of the effectiveness of many self-management programs indicate benefits for patients with conditions such as diabetes and hypertension. The educational interventions with the greatest health impact are those with a flexible approach to both delivery and program content (Australian Government 2006).

To explore barriers to engagement by healthcare professionals it is necessary to consider the uncertainty of the benefits of self-management programs and the limited local evidence on the impact of such programs on the patients' self-care abilities (Kennedy et al. 2004).

Seven-Phase Self-Management Program

This program is based on a seven-phase model (Kanfer et al. 2006, 1996, 1991, 1988) with semi-structured interviews addressing knowledge, self-management skills, positive health behavior, increased self-confidence, health status and quality of life, focusing on the following aspects:

1. Establishing favorable starting conditions
2. Building up motivation to change issues
3. Analyzing behavior and the operative model of conditions
4. Agreeing on therapy goals
5. Planning, selecting and realizing specific methods
6. Evaluating the therapeutic success
7. End of therapy.

The Self-Management Program of Lorig and Holman

The Chronic Disease Self-Management Program for several diseases (CDSMP) was developed at Stanford University by professors Halstead Holman and Kate Lorig (2004).

The Chronic Disease Self-Management Program consists of a workshop of two and a half hours held once a week for six weeks in community settings such as senior citizens' centers, churches, libraries and hospitals. People with a variety of chronic health problems can participate. The workshops are facilitated by two trained leaders, of which one is a non-health professional with a chronic disease (http://patienteducation.stanford.edu/programs/cdsmp.html).

The following aspects are included:

1. Techniques to deal with problems such as frustration, fatigue, pain and isolation
2. Exercises for maintaining and improving strength, flexibility, and endurance
3. Appropriate use of medication
4. Communicating effectively with family, friends and health professionals
5. Nutrition
6. Methods of evaluating new treatments.

Further Programs

A search of PUBMED in September 2008 revealed nineteen publications on chronic disease self-management programs of which, however, none dealt with Alzheimer's disease. The latest publication was about cancer survivors (Wilson 2008).

But a *worldwide search for* **CDSMP and Alzheimer's disease** was successful, e.g. in Kentucky, USA. In 2005, Educational Television aired a series described by Dr. Wayne Tuckson as follows: »Health issues related to aging and caring for the elderly are increasingly critical as the number of Americans living to the age of 85 and beyond continues to skyrocket. This program looks at two Louisville projects: Staying Alive: How to Be an Effective Caregiver and Living Well Workshops: Chronic Disease Self-management Program (CDSMP), a six-week series of free workshops that teach techniques to deal with chronic conditions and aging. The program also explores the Nun Study at the University of Kentucky, which gives some clues about the causes and prevention of Alzheimer's disease«.

The *CDSMP and older people* – four examples:

- In the US, the Maryland Department of Aging received grants in 2007 for the Maryland Disease Self-Management Program (DSMP) to empower older people. As introduced, the program was based on three years of evidence (2008).
- The Ohio Department of Aging (ODA) received a grant for prevention programs based on evidence. Regional programs include Chronic Disease Self-Care Management, Physical Activity and Fall Prevention. Chronic Disease Self-care implements the Stanford Chronic Disease Self-Management Program (CDSMP) in four regions of Ohio. Over a period of three years 113 CDSMP courses are planned, reaching 1165 older adults (2006).
- The Chinese Community Center (CCC) at Town Park, Houston, USA works with senior citizens using the chronic disease self-management program (2008).
- Moreover, the Department for the Aging in New York is engaged in evidence-based health programs as documented in their newsletter of August 2008.

Introduction to the Variety of Self-Management Programs

To illustrate the variety of self-management programs, documenting different aspects of those programs related to specific diseases may be helpful.

Aspects of Self-Management in Coronary Heart Disease

These programs include certain aspects that will be described below. Up to now, traditional studies focused on improving physiological features, such as left ventricular function or coronary graft potency. However, increasing attention has been directed toward health status outcomes as being equally – if not more – important for the well-being of patients with cardiac disease (Pilote et al. 2002).

Little is known about the determinants of health status in patients with cardiovascular disease, especially about the extent to which the heart state is determined by psychological versus physiological measurements of cardiac function (Lesman-Leegte et al. 2006). Depressive symptoms are prominent among patients due to heart failure, as documented by Norra et al. (2008), and they are associated with a poorer prognosis, particularly increased morbidity and mortality.

Some authors hypothesize that cardiac-oriented self-management could be associated with changes in health status, defined as the individual degree of wellness or illness due to the burden caused by cardiac symptoms, physical limitations, quality of life and overall health within the broader population of outpatients with established coronary heart disease (Sarkar et al. 2007).

Jovicic et al. (2006) examined the effects of interventions based on the model of self-management for health outcomes for patients with heart failure. The objective of this study was to determine the effectiveness of self-management interventions on hospital readmission rates, mortality and health-related quality of life in patients diagnosed with heart failure. The outcomes of primary interest were the number of general hospital readmissions, hospital readmissions due to heart failure, and mortality. Secondary outcomes were treatment compliance and quality of life scores. The authors included six randomized trials in their review and concluded that self-management programs targeting patients with heart failure lead to a decrease in overall hospital readmissions.

Aspects of Self-Management Programs in Diabetes

During the last years, some important work has been performed for patients suffering from diabetes, e.g. Renders et al. (2002) tried to improve the management of diabetes mellitus in primary-care, outpatient and community settings. The authors documented that »multifaceted professional interventions and organizational interventions that facilitate structured and regular review of patients were effective in improving the process of care. The addition of patient education to these interventions and the enhancement of the role of nurses in diabetes care led to improvement in patient outcomes and the process of care.«

Kaissi et al. (2006) found that the Assessment of Chronic Illness Care (ACIC) tool tailored to diabetes management can be used to examine structural dimensions in primary-care clinics.

Nutting et al. (2007) documented that the introduction of elements of a chronic care model is associated with higher-quality care for diabetes.

Aspects of Self-Management Programs in Depression

The self-management program for depression now in use is based on the following aspects: there is a growing interest in self-management programs for patients suffering from depression which emphasize the patients' central role as a partner in managing their illness. Patients suffering from depression enrolled in the self-management program experience statistically significant improvements in their health status, health behavior and self-efficacy. Additionally, the use of self-management programs was associated with fewer emergency department visits (Lorig et al. 2001). As both efficacy trials and »real-world« studies suggest their effectiveness, healthcare providers should consider the use of self-management programs in treating patients with depression (Ritter et al. 2001).

MacNaughton (2003/2006) developed a depression toolkit: information and resources for the effective self-management of depression, including resources for building self-management skills. The main foci are: »Core self-management skills vs. illness-specific skills and the self-care depression program with overcoming inactivity, challenging negative thinking habits, solving problems effectively, reducing the risk of relapse.«

Aspects of Self-Management Programs in Arthritis

Osborne et al. (2007a,b) evaluated the Arthritis Self-management Course (ASMC) in a nationwide context. »ASMC is a 6 weeks group educational program lasting for two hours designed to assist people with chronic illness to manage better their condition. Measures of program effectiveness include health status and service utilization. Data were collected on 3 occasions: before intervention (baseline) and 6 months and 2 years after the program.«

Lorig et al. (2005) compared in a study the relative effectiveness of the two programs (ASMC and CDMSP – Chronic Disease Self-management Program) for individuals with arthritis and summarized that »the disease-specific ASMC should be considered first where there are sufficient resources and participants. However, both programs had positive effects, and the CDSMP should be considered a viable alternative.«

Detailed Aspects of Management and Self-Management of Dementia in Several Countries and Suggestions of the WHO

USA. A general approach to management in individuals suffering from dementia is documented by the East Texas Geriatric Education Center, USA (2008).

1. »Optimize function and quality of life and capitalize on remaining strengths
2. Address specific causes of impaired function and cognition, and triggers of behavioral symptoms
3. Manage functional deficits
4. Address psychosocial issues
5. Address socially unacceptable/disruptive behavioral symptoms
6. Address related ethical studies
7. Manage related complications, other existing conditions, or adverse reactions«.

Australia. The main office of the Southern Division of General Practice (SDGP 2008) in Australia published a chronic disease management program on the management and care of patients with dementia. They underlined that courses for caregivers are held regularly throughout the state, providing information and opportunities for discussion and support as well as advice on the NSW Action Plan on Dementia 1996–2001.

The purpose of one of those projects was »to provide general practitioners with a resource for the care of people with dementia that encourages early intervention, ongoing management throughout the course of the disease and partnership with carers and other service providers.«

Canada. The chronic disease management of the Chronic Disease Management Initiative (CDMI 2008) in British Columbia documented that »health care emphasizes helping individuals to maintain independence and to keep as healthy as possible by prevention, early detection, and management of chronic conditions, such as congestive heart failure, asthma, diabetes, dementia and other debilitating illnesses. Chronic conditions impose challenges for those affected, their families and care providers. A patient's ability to follow medical advice, accommodate lifestyle changes and access resources are all factors that influence successful management of an ongoing illness.« In a survey performed 2001 by physicians in British Columbia, chronic disease was identified as a priority in developing specific disease management methods for

- diabetes,
- depression,
- rheumatic disorders, osteoarthritis and
- dementia.

United Kingdom. In the UK, an attempt to integrate the Expert Patients Program (EPP), an adaptation of the Stanford University chronic disease self-management program, into the National Health Service (NHS) that was begun in 2002 has met with limited success (Bury et al. 2005). It was anticipated that the EPP would be a valuable option in the healthcare setting to help professionals and patients to better manage their chronic conditions (Donaldson 2003). The course for the future has been outlined in a recent UK government white paper (UK Department of Health 2006) which describes how chronic disease management can promote self-care and the empowerment of patients, including dementia patients, in a primary health service setting.

World Health Organization. The World Health Organization suggested how patients suffering from a chronic disease might manage their condition. Various hypotheses about prevention have since then been advanced. The absence of proof does not mean that these hypotheses and clinical impressions have to be disregarded. Rather, they should be borne in mind and accepted or rejected when relevant evidence is at hand. Time will distinguish fact from fiction. At the moment, everyone should practice the approved methods of health protection and promotion, such as healthy eating, regular exercise and abstaining from tobacco and alcohol. Although not directly linked to the prevention of Alzheimer's disease, good health in youth is a prerequisite of good health in old age. Family members should be aware of early warning signs which may suggest that one of the older members may be on the verge of developing Alzheimer's disease or another form of cognitive decline. Early diagnosis and early intervention can be beneficial both to the patient and the family. Families and others will benefit by joining self-help groups or support groups, as these are well known to provide social and psychological support to members. If there is no support group in the area, families may wish to start a new group (WHO 2009).

Recent studies like McIlvane et al. (2008) state with regard to persons with mild cognitive impairment and their caring partners »that PWMCI (persons with MCI) and partners are likely to minimize the threat of AD and to perceive that conversion is controllable and preventable with health promotion activities.« Connor et al. (2008) described a specific case management involving activities associated with mastery and relationship strain for dementia caregivers. He concluded that assessing the specific needs of caregivers and persons with dementia leads to improvement in the caregivers' sense of mastery, and that more work is needed to determine whether this increase is sustained over time and can reduce the need for institutionalization.

General Remarks on Implementing Chronic Disease Self-Management

A current study (Francis et al. 2007) investigates the sharing healthcare initiative in Australia with regard to the translation of different models of chronic disease self-management into health and community service contexts in Australia. »Four intervention models were accepted: (1) the Stanford Chronic Disease Self-Management course; (2) generic disease management planning, training and support; (3) tailored disease management planning, training and support, and (4) telephone coaching. Participants in the projects showed improvements in self-management practices, but those receiving Model 3, flexible and tailored support, and Model 4, telephone coaching, reported the greatest benefits.« The results were comparable with those of the Australian Government (2006).

Results of a Meta-Analysis

Contrary to other studies, a meta-analysis of self-management interventions across a variety of chronic conditions of Jordan and Osborne (2007) based on data of Chodosh et al. 2005 and Warsi et al. 2003/2004 shows no effect on arthritis. However, benefits were observed in diabetes and hypertension (◘ Table 7.1).

◘ **Table 7.1.** Effects of self-management interventions (modified after Jordan and Osborne 2007)

Condition	No. of studies	Interpretation
Diabetes	50	No effect (4), small effect (13), small to moderate benefits (13), clinically important benefits (20)
Osteoarthritis: pain	14	No effect
Osteoarthritis: function	12	Small benefits
Arthritis: pain	33	No effect
Arthritis: disability	29	No effect
Hypertension: systolic blood pressure	20	Clinically significant reduction (13), small to moderate benefit (7).
Hypertension: diastolic blood pressure	21	Clinically significant reduction (13), no effect (8).

Tools/Scales for the Examination of Self-Management and Self-Care

The most important evaluation of an effect of self-management seems to be the subjective estimation of such effect. The following supportive examples should provide practical input and help to evaluate the importance of specific measures for specific questions (◘ Table 7.2).

Aspects of the Transformation of Self-Management and Chronic Disease

Several studies were found which deal with the adaptation of models of self-management and chronic disease for use by the general population. There is, however, no evidence-based guideline for the feasibility and efficiency of self-management models of chronic diseases and their possible adaptation to the general population. Such a guideline could be useful to inform public health authorities and interested parties in a convenient manner about several chronic diseases. This is especially important as the cost benefit of the developed and validated models is not being highlighted at present.

For diabetes (e.g. Piatt et al. 2006), the authors translated the Chronic Care Model into the community, deriving their results from a randomized controlled trial of a multifaceted diabetes care intervention. Norris et al. (2002) documented increasing diabetes self-management education in

◘ **Table 7.2.** Measurements

Name of tool, information	Author, source, information
Self-management behaviors e.g. Exercise, cognitive symptom management, mental stress management/relaxation Communication with physicians **Self-efficacy e.g.** Chronic disease self-efficacy (original scales), 6-item chronic disease self-efficacy **Health Status e.g.** Self-rated health, illness intrusiveness rating, fatigue visual numeric, energy/fatigue, health distress, CES-D (depression), CES-D 10-item (depression), and social/role activity limitations **Health Care Utilization** Visits to providers, visits to providers (diabetes) **Education** Years of education **Diabetes-specific Scales e.g.** Diabetes self-efficacy	The tools used by Lorig et al. (2008) are documented at http://patienteducation.stanford.edu/research/
Health Education Impact Questionnaire (heiQ)	In 2004, Osborne conceived, developed and implemented the Health Education Impact Questionnaire (HEIQ), a national quality assurance and monitoring system for chronic self-management education programs
Coping Inventory for Stressful Situations (CISS)	The Coping Inventory for Stressful Situations is a self-report measure of emotion-, task- and avoidance-oriented coping. Endler et al. (1999), CISS: Coping inventory for stressful situations. New York. MHS.
SF-36, SF12- Short Form 36 Health Survey	By Bullinger and Kirchberger (1998a,b) with self-assessment sheet (time window 4 weeks, 1 week), extraneous assessment sheet (time window 4 weeks, 1 week), interview sheet (time window 4 weeks, 1 week). See also Ware et al. (1992).

▼

Table 7.2. *Continued.*

Name of tool, information	Author, source, information
Diabetes Self-Management. Questionnaire	The Palo Alto Medical Foundation Diabetes Self-Management Questionnaire. Diabetes Self-Management Questionnaire. This questionnaire helps to understand how to manage diabetes and how you can be helped. www.pamf.org/diabetes/DiabetesSelfMgtQuest.pdf.
The Chronic Pain Coping Inventory, CPCI	The Chronic Pain Coping Inventory (CPCI) by Jensen et al. 1995 was developed to assess eight behavioral coping strategies targeted in multidisciplinary pain treatment (guarding, resting, asking for assistance, task persistence, relaxation, exercise/stretch, coping, self-statements and seeking social support)
The Stroke Self-Efficacy Questionnaire	The Stroke Self-Efficacy Questionnaire by Jones et al. 2008 measures individual confidence in functional performance after a stroke
Diabetes Mellitus type II Self-Efficacy Scale	By Bijl et al. (1999). Addresses the psychometric properties of diabetes management
Battery for Health Improvement (BHI)	By Disorbio and Bruns (2008) For: Individuals 18–65 years old, especially those in rehabilitation. 217 multiple-choice items
Illness Perceptions Questionnaire-Revised	By Moss-Morris et al. (2002). The revised illness perception questionnaire (IPQ-R) uses eight different illness groups to validate the IPQ-R, including HIV, multiple sclerosis, asthma and type-II diabetes
Measurement of patient outcome in arthritis	By Fries et al. 1980. Measurement of patient outcome in arthritis. The paradigm measures outcomes by five separate dimensions: death, discomfort, disability, drug (therapeutic) toxicity, and dollar cost. These outcome dimensions may be quantified in interviews or through patient questionnaires
The health assessment questionnaire: status and review	By Ramey et al. (1992). The Health Assessment Questionnaire (HAQ) was originally developed in 1978 by James F. Fries. The HAQ is used in two different formats, the Short HAQ or the Full HAQ
GHQ- General Health Questionnaire	By Goldberg (1989). GHQ General Health Questionnaire. The General Health Questionnaire (GHQ) has been translated into 38 languages, a testimony to its validity and reliability. The GHQ is easy to use
WHO Qol 100-Quality of life Questionnaire	By Angermeyer et al. (2000). The WHO QOL-100 is a generic, patient-completed measure of health-related quality of life that was simultaneously developed at 15 sites worldwide. Domains: physical health, psychological health, level of independence, social relationships, environment, spirituality/religion/personal beliefs
WHO Qol BREF-Quality of life Questionnaire	BREF: Short version By Angermeyer et al. (2000). WHO QOL-BREF is a useful alternative to the WHO QOL-100 in evaluating quality of life in terms of physical, psychological and environmental domains of life quality

community settings, and Siminerio and co-workers described deploying a chronic care model to implement and sustain diabetes self-management training programs.

Evidence-based guidelines for the management e.g. of coronary heart disease are documented in the publications of the Finnish Medical Society Duodecim (2006).

Also the American College of Physicians (2007) is trying to develop and implement evidence-based guidelines and support those guidelines through provider education and reminders. They support an increase of interaction between generalists and specialists for patients with chronic disease. The Health Science Institute of Chicago postulated that it was necessary to compare the traditional emergency model with the chronic care model of integrated, evidence-based, consumer-focused care, and to teach consumers, family members, and community chronic care partners how to support evidence-based healthcare services.

There are various evidence-based care guidelines. A few of the more popular ones were found e.g. in: Agency for Health Care Research & Quality, National Guideline Clearing House, Institute for Clinical Systems Improvement, Rand Corporation, National Institutes of Health (NIH), American College of Cardiology, American Diabetes Association.

General-purpose evidence-based health promotion standards have been published by National Guideline Clearinghouse Centre for Disease Control & Prevention, Canadian Task Force on Preventative Health Care, American Academy of Family Physicians: Summary of policy recommendations for periodic health examinations, revised 2003.

So there are numerous successful interventions worldwide, showing that promoting and encouraging patient's self-management and involving them in decision-making improves their compliance and well-being.

Several programs have been widely used up to now, the most popular being the Chronic Disease Self-Management Program model by Lorig et al. (1993) which is based on patient education. This program is currently being disseminated nationwide in the United States by the Kaiser system. In 1994, it was introduced in Australia, a guide to implementation was published in 2007 by the Australian Department of Health, and the program has recently been adopted by the National Health Service in Britain.

In Canada, the Chronic Disease Self-Management Program was implemented by the University of Victoria's Centre on Aging as a pilot program in the Yukon in 1998 and has since become a permanent government-funded program.

Aspects of Promotion of Self-Management in Chronic Disease

Next to guidelines, there are other options to achieve a transformation to self-management in coping with chronic diseases. One of these options is using the media, where it is important to create new and use already existing websites, focused databases, and print media. Further options to introduce the subject to interested persons include radio and television programs, newspaper advertisements, and films. In addition, regional, national and global platforms may be created through symposiums, congresses, and other meetings that offer opportunities for personal exchange and networking among those concerned, organizations, associations, research institutes, and funding agencies. In all this, it is important that those involved should cooperate continuous, focusing on, among other things, the development of innovative evaluation tools, concepts, and programs to promote self-management of chronic diseases.

Summary

Chronic disease self-management education programs aim to empower patients worldwide through providing information and teaching skills and techniques to improve self-care and doctor-patient interaction as well as to reduce the importance of socioeconomic factors, but always with the ultimate goal of improving the quality of life of the individual.

There is a variety of management and self-management programs for chronic disease.

Tasks for the future include promoting an international and interdisciplinary exchange on self-management, defining self-management, implementing this definition and documenting a standard dataset to facilitate the description of the effectiveness of existing programs for purposes of comparison. Another objective is to find better solutions for the transformation of and participation in the programs.

As self-management is only one component of chronic disease care, establishing formal regional alliances and networks across the healthcare continuum would facilitate primary health care reform and generate opportunities to integrate other prevention and care initiatives for chronic diseases, including Alzheimer's Disease.

References

American College of Physicians (2007) www.acponline.org

Angermeyer M, Kilian R, Matschinger H (2000) WHOQOL-100 und WHOQOL-Bref. Hogrefe, Göttingen

Australian Government Department of Health and Aging (2006) COAG health services – promoting good health, prevention and early intervention. Fact sheet. Commonwealth Government, Canberra

Australian Government Department of Health (2007) Chronic Disease Self-Management – A Guide to Implementation 2007. Source 2008: www.canningdivision.com.au/CDGP%20Documents/Practice%20Resources/Chronic%20Disease%20manual.pdf

Barlow JH, Turner AP, Wright CA (2000) A randomized controlled study of arthritis self-management program in the UK. Health Educ Res 15: 665–680

Bijl JV, Poelgeest-Eeltink AV, Shortridge-Baggett L (1999) The psychometric properties of the diabetes management self- efficacy scale for patients with type 2 diabetes mellitus. Journal Adv Nurs 30: 352–359

Bullinger M, Kirchberger I (1998a) Fragebogen zum allgemeinen Gesundheitszustand SF 36, Fremdbeurteilungsbogen, Selbstbeurteilungsbogen, Interviewbogen. Hogrefe, Göttingen

Bullinger M, Kirchberger I (1998b) Fragebogen zum allgemeinen Gesundheitszustand SF 12, Fremdbeurteilungsbogen, Selbstbeurteilungsbogen, Interviewbogen. Hogrefe, Göttingen

Bury M, Ink D (2005) The HSJ debate. Self-management of chronic disease doesn't work. Health Serv J 115: 18–19

Chinese Community Center – CCC (2008) www.ccchouston.org

CDMI Chronic Disease Management Initiative in British Columbia (2008) http://www.health.gov.bc.ca/cdm/cdminbc/index.html

Chodosh J, Morton SC, Mojica W, Maglione M, Suttorp MJ, Hilton L, Rhodes Sl, Shekelle P (2005) Meta-analysis: chronic disease self-management programs for older adults. Ann Intern Med 143: 427–443

Connor KI, McNeese-Smith DK, Vickrey BG, van Servellen GM, Chang BL, Lee ML, Vassar SD, Chodosh J (2008) Determining care management activities associated with mastery and relationship strain for dementia caregivers. J Am Geriatr Soc 56: 891–897

Department for the Aging (2008) Modernization News, New York

Dijkhuizen van M, Clare L, Perace A (2006) Striving for connection. Dementia 5: 73–94

Disorbio JM, Bruns D (2008) Battery for Health Improvement-2 [BHI-2]. http://www.pearsonassessments.com/tests/

Donaldson L (2003) Expert patients usher in a new era of opportunity for the NHS. BMJ 326: 1279–1280

East Texas Geriatric Education Center, USA (2008) www. etgec.utmb.edu/dementia/management.html.-ETGEC

Endler NS, Parker JDA (1999) CISS: Coping inventory for stressful situations. MHS, New York

Finnish Medical Society Duodecim (2006) Coronary heart disease (CHD): symptoms, diagnosis and treatment. EBM Guidelines. Evidence-Based Medicine. Wiley Interscience, Helsinki

Francis CF, Feyer AM, Smith BJ (2007) Implementing chronic disease self- management in community settings: lessons from Australian demonstration projects. Aust Health Rev 31: 499–509

Fries J, Spitz P, Kraines R, Holman H (1980) Measurement of patient outcome in arthritis. Arthritis Rheum. 23: 137–145

Goldberg DG (1989) GHQ (General Health Questionaire). Schweizerische Rundschau Medizin 78: 219–227

Health Science Institute in Chicago (2007) www.of the Science Institute Chicago

Holman H, Lorig K (2004) Patient self- management: A key to effectiveness and efficiency in care of chronic disease. Public health report 119, USA

Jensen MP, Turner JA, Romano JM, Strom SE (1995) The Chronic Pain Coping Inventory: development and preliminary validation. Pain 60: 203–216

Jones F, Partridge C, Reid F (2008) The stroke self-efficacy questionnaire: measuring individual confidence in functional performance after stroke. J Nurs Healthcare Chronic Illness 17: 244–252

Jordan JE, Osborne RH (2007) Chronic disease self-management education programs: challenges ahead. MJA 186: 84–87

Jovicic A, Holrovd-Leduc JM, Strauss SE (2006) Effects of self-management intervention on health outcomes of patients with heart failure: a systematic review of randomized controlled trials. BMC Cardiovasc Disord 11-2: 43

Kaissi AA, Parchman M (2006) Assessing chronic illness care for diabetes in primary care clinics. J Comm J Qual Patient Saf 2: 318–323

Kanfer FH, Schefft BK (1988) Guiding the process of therapeutic change. Research Press, Champaign

Kanfer FH, Gaelick-Buys L (1991) Self-management methods. In: Kanfer FH, Goldstein AP (eds) Helping people change, 4th edn. Pergamon, New York, pp 305–360

Kanfer FH, Reinecker H, Schmelzer D (1996) Selbstmanagement-Therapie. Ein Lehrbuch für die klinische Praxis, 2. Aufl. Springer, Berlin Heidelberg New York

Kanfer FH, Reinecker H, Schmelzer D (2006) Grundlagen der Selbstmanagement-Therapie, 2. Aufl. Berlin, Springer Heidelberg New York

Kennedy A, Gately C, Rogers A (2004) National evaluation of the expert patient program. Manchester UK. National Primary Care Research and Developmental Centre. http: www.npcrdc.ac.uk/

Lesman-Leegte I, Jaarsma T, Veldhuisen van DJ (2006) Psychological distress and cardiovascular disease. Eur Heart J 27: 1123

Lorig K, Mazonson P, Holman HR (1993) Evidence suggesting that health education for self- management in patients with chronic arthritis has sustained health benefits while reducing health care costs. Arthritis Rheum 36: 439–446

Lorig K (2000) Self-management education: context, definition, and outcomes and mechanisms. Chronic Disease Management Conferences, conference contribution, Sydney

Lorig KR, Ritter P, Stewart AL, Sobel DS, Brown BW Jr, Bandura A, Gonzalez VM, Laurent DD, Holman HR (2001) Chronic disease self-management program: 2-year health status and health care utilization outcomes. Med Care 39: 1217–1223

Lorig K, Ritter PL, Plant K (2005) A disease – specific self-help program compared with a generalized chronic disease self-help program for arthritis patients. Arthritis Rheum 53: 950–957

Macnaughton E (2003/2006) Depression toolkit, Information and Resources for effective self-management of Depression – Pilot-version 2002, BC Partners for Mental Health and Addictions Information. Source 2008: www.heretohelp.bc.ca

McIlvane JM, Popa MA, Robinson B, Houseweart K, Haley WE (2008) Perceptions of illness, coping, and well-being in persons with mild cognitive impairment and their care partners. Alzheimer Dis Assoc Disord 22: 284–292

Medical Model (2008) Source: http://en.wikipedia.org/wiki/Medical_model 2008

Moss-Morris R, Weinman J, Petrie KJ, Horne R, Cameron LD, Buick D (2002) The revised illness perception questionnaire (IPQ-R). Psychol Health 17: 1–16

NHS – National Health Service of England (2008). http://www.alzscot.org/pages/policy/dementiaepidemic.htm Dementia Epidemic.

Norra C, Skobel EC, Arndt M, Schauerte P (2008) High impact of depression in heart failure: early diagnosis and treatment options. Int J Cardiol 125: 220–231

Norris S, Nichols P, Caspersen C, Glasgow R, Engelgau M, Jack L Jr, Snyder S, Carande-Kulis V, Isham G, Garfield S (2002) Increasing diabetes self-management education in community settings. A systematic review. Am J Prev 22 (4 Suppl): 39–66

Nutting PA, Dickinson WP, Dickinson LM, Nelson CC, King DK, Crabtree BF, Glasgow RE (2007) Use of chronic care model elements is associated with higher-quality care for diabetes. Ann Fam Med 5: 14–20

Ohio Department of Aging ODA (2006). http://www.goldenbuckeye.com/advocacy/updates/lu_2006_10.html)

Osborne RH, Elsworth GR, Whitfield K (2007a) The Health Education Impact Questionnaire (heiQ). An outcomes and evaluation measure for patient education and self-management interventions for people with chronic conditions. Patient Education and Counseling 66: 192–201

Osborne RH, Wilson T, Lorig KR, McColl GJ (2007b) Does self- management lead to sustainable health benefits in people with arthritis? A 2-year transition study of 452 Australians. J Rheumatol 34: 1112–1127

Piatt GA, Belalcazar LM, Swank PR (2006) Translating the chronic care model into the community: results from a randomized controlled trial of a multifaceted diabetes care intervention. Diabetes Care 29: 2761–2762

Pilote L, Lauzon C, Huynh T et al. (2002) Quality of life after acute myocardial infarction among patients treated at sites with and without on-site availability of angiography. Arch Intern Med 162: 553–559

Ramey D, Raynauld J, Bries J (1992) The health assessment questionnaire 1992: status and review. Arthritis Care Res 5: 119–129

Redman BK (2007) Accountability for patient self-management of chronic conditions; ethical analysis and a proposal. Chronic Illness 3: 88–95

Renders C, Valk G, Griffin S et al. (2002) Interventions to improve the management of diabetes mellitus in primary care, outpatient and community settings In: The Cochrane Library, Issue 3. Oxford: Update Software

Ritter PL, Stewart AL, Kaymaz H, Sobel DS, Block DA, Lorig KR (2001) Self-reports of health utilization compared to provider records. J Clin Epidemiol 54: 136–141

Sarkar U, Sadia A, Whooley MA (2007) Self-efficacy and health status in patients with coronary heart disease. Findings from the Heart and Soul Study 69: 306–312

SDGP (2008) The Chronic Disease Management program and there the management and dementia Care of Patients with Dementia Sir Mark Oliphant Building, Bedford Park SA 5042, Australia. Source: http://www.sdgp.com.au/

Siminerio L, Piatt G, Emerson S, Ruppert K, Saul M, Solano F, Stewart A, Zgibor J (2006) Deploying the chronic care model to implement and sustain diabetes self-management training programs. The Diabetes Educator 32: 253–260

UK Department of Health (2006) Source: http://www.library.nhs.uk

U.S. Department of Health and Human Services Health Resources and Services Administration (2006). http://hab.hrsa.gov/publications/march2006/

U.S. Maryland Department of Aging (2008). www.mdoa.state.md.us/AnnualReport/AR07/7Grants07.pdf

Wagner EH (1998) Chronic disease management: What will it take to improve care for chronic illness? Effect Clin Pract 1: 2–4

Ware JE, Sherbourne CD (1992) A 36-item Short Form Health Survey (SF36): conceptual framework and item selection. Med Care 30: 473–483

Warsi A, LaValley MP, Wang PS, Avorn J, Solomon DH (2003). Arthritis self-management education programs: a meta-analysis of the effect on pain and disability. Arthritis Rheumatism 48: 2207–2213
Warsi A, Wang PS, LaValley MP, Avorn J, Daniel H, Solomon DH (2004) Self-management Education Programs in Chronic Disease. A Systematic Review and Methodological Critique of the Literature. Arch Intern Med 164: 1641–1664
WHO (2005) Preventing chronic disease, a vital investment: WHO global report. WHO, Geneva
WHO (2009) http://www.searo.who.int/
Wilson PM (2008) The UK Expert patients program: lessons learned and implications for cancer survivors' self-care support programs. J Cancer Surviv 2: 45–52

7.2 Tools of Self-Management and Their Application in Low-Resource Treatment Settings

Olusola T. Ephraim-Oluwanuga

Self-management methods have already been described by other authors in this book. The goal of this sub-chapter is to examine how applicable they are in low-resource treatment settings, such as are found in many developing countries of the world. According to DeMonaco and von Hippel, self-management is defined as:

1. engaging in activities that protect and promote health;
2. monitoring and managing symptoms and signs of illness;
3. managing the impact of illness on functions, emotions, and interpersonal relationships; and
4. adhering to treatment regimens.

An important reason for encouraging the use of self-management methods is that if patients are to benefit from earlier detection of chronic diseases, they need to take responsibility for and actively engage in self-management.

Patient self-management tools have been defined as Technologies used by consumers to deal with their health issues outside formal medical institutions. Self-management tools could range from simple check lists or questionnaires to internet tools or tools which involve the use of mobile phones (Armstrong and Powell 2008). According to Barret (2005), self-management tools can be categorized as:

- Subordinate: Tools such as video monitoring or home-surveillance sensor systems, provide limited patient discretion beyond agreement to use the tools.
- Structured: These are tools that provide more active self-management, but in highly defined ways. Examples range from sound and text reminders from a table-top appliance or perhaps a personal digital assistant or telephone, along with the patient's ability to transmit data, for example, blood pressure readings.
- Collaborative: This category covers those tools that have been the most thoroughly examined and embraced by disease management theorists. These include decision support aids, online interventions, chronic disease management aids, and patient education materials.
- Autonomous: As the name suggests, tools for autonomous roles do not require regular participation or input from professionals. Internet sites such as Diets and home heart defibrillators are examples of this category of tools.

Self-management is not an entirely new concept, as people with health conditions have always had to participate in their treatment to some extent, however minimal. What is new is the emphasis on structure in self-management, which clearly defines roles and responsibilities of healthcare workers, patients and their domestic caregivers. Structured self-management requires that specific information is given to patients about their health conditions and what they are required to do to participate in the treatment.

Neither self-management methods nor tools currently enjoy wide use in the formal health sector in low-income countries, which is the subject in consideration here. The major reason for this is lack of awareness. Most healthcare workers are not aware of self-management tools, neither are most patients.

It has already been noted that self-management tools have not been widely used in the management of Alzheimer's disease, even in developed countries. The use of self-management methods or tools in countries with low resources concerning healthcare is even lower. This part of the chapter will be discussing the potential for the use of self-management methods and tools in Nigeria (an African country), as a typical example of a low-resource setting.

Nigeria as an Example of a Low-Resource Setting

Nigeria is a typical example of a low-resource setting in terms of health-service delivery. Factors which qualify Nigeria as a typical example of a low-resource setting include, low income, poor infrastructure and inadequate personnel–patient ratio.

Although the country is rich in natural resources, Nigeria has a per capita income of 640 US Dollars. The income is low and poverty is still widespread, with 60% of the population still living on one US dollar a day or less.

Infrastructure is poor with poor road network, inadequate primary healthcare facilities, unreliable supply of electricity and an inefficient but expensive telephone network.

Nigeria has a health personnel–patient ratio which is below internationally acceptable standards. According to the WHO ATLAS 2005 report, Nigeria has a psychiatrist-to-population ratio of 0.09:100,000 (130 psychiatrists to a population of 127 million people). According to this, it can be extrapolated that the geriatric psychiatrist–population ratio may be about 1:20 million. There are however more psychiatric nurses than all the other mental-health professionals available (4:100,000). The ratios of mental-health workers to population are shown in ◘ Table 7.3. These ratios place Nigeria as a low-resource setting in terms of mental-healthcare manpower.

All of these factors would necessitate the use of self-management methods to save cost. However, it is a paradox that the same factors would hinder the optimal use of self-management methods. This is because self-management methods require close communication with healthcare providers, all of which are dependent on the afore-mentioned inadequate infrastructure.

◘ **Table 7.3.** Table showing ratio of mental healthcare workers to population in Nigeria (data from the WHO ATLAS 2005 Survey of Mental Health)

Mental healthcare personnel	**No. per 100,000 population**
Psychiatrists	0.09
Neurosurgeons	0.009
Psychiatric nurses	4
Neurologists	0.02
Psychologists	0.02
Social workers	0.02

What Self-Management Methods are Available in Nigeria?

According to the literature, there is very little formal use of self-management methods in Nigeria or in other African countries. A study was found, which evaluated the use of self-management methods in type-2 diabetics in Nigeria (Yussuff et al. 2008). There was no study found documenting use of self-management methods amongst people with mental health or neurological disorders.

However, self-management methods are very much in use in the traditional medicine sector. There appears to be greater engagement between the practitioners of African traditional medicine and their patients than between the patients and practitioners of orthodox Western-style medicine. This has been documented in the older literature (e.g. Odejide et al. 1977). Traditional medicine encourages the patients to actively prepare their own herbal remedies, prepare and apply poultices and sometimes, alter the quantity of traditional medication used, by monitoring their own symptoms.

Alzheimer's Dementia in Nigeria

Nigeria, like many developing countries, has a relatively young population. Therefore the little resources available for health are largely devoted to matters affecting the health of younger people. Very little attention is being paid to the health problems of the elderly.

In Nigeria, the age-adjusted prevalence rate of dementia is 2.29% and of Alzheimer's disease 1.41%. This is low, compared with 6.4% in African Americans in Indianapolis USA (Hendrie et al. 1995) or 6.6% in those above 65 in the UK (MRC CFA Study 1998).

Most of the patients with Alzheimer's disease may not receive medical attention as dementia is culturally regarded as part of the normal aging process by a large part of the society. If they are seen in hospital, most of the drugs in the treatment of Dementia are not available in the country. The only available drug is donepezil, a cholinesterase inhibitor, which is not affordable to most of the patients. Only about 10% of those who have dementia or any mental-health condition receive treatment.

The concept of nursing home care is not yet culturally acceptable in Nigeria, and for a population of 140 million, there are probably not up to 250 beds available in fewer than 10 nursing homes in the country. Even then, the conditions in the nursing homes are poor, as they are not well funded (Baiyewu, Adeyemi and Ogunniyi 1997). There is a need to train health workers for the care of the elderly. Although it is assumed that the elderly in African countries are much respected and looked after by their offspring, this is not always true.

Baiyewu et al. (1997) noted a poor attitude towards the elderly, even amongst health workers.

Home visits by health workers are very rare, restricted largely to children. Except for those who can afford to pay for it as an extra service in the private sector, the elderly do not receive home visits.

The state of mental-health services outlined above could mean that self-management is of great potential use for people with Alzheimer's disease and their caregivers in Nigeria. These people are already being cared for at home, but what is required is to put them in contact with the health system and teach them and their caregivers self-management methods which have the potential to greatly reduce the burden of illness and improve their quality of life.

Self-Management Tools and Alzheimer's Disease in Nigeria

An example of potentially useful tools of self-management suitable for Alzheimer's disease patients would be the Lorig's tools (Lorig 2008). Lorig's tools include self-management behavior, self-efficacy, health status healthcare utilization, education and diabetes-specific scales. These scales are short-item questionnaires which could be used if adapted and translated into the major Nigerian languages.

Although these tools are currently being used in the care of diabetes, they could be adapted for use in Alzheimer's disease. Adaptation will be necessary because some of the tools are diabetic-specific. There are some items which may not be relevant to Alzheimer's disease within each of the groups, which could be omitted.

Also, because of the mental state in Alzheimer's disease, some of the items in Lorig's tools may have to be administered by caregivers, i.e. caregivers make their assessments and observations and answer the questions on patients' behalf.

In addition, some items may not be culturally relevant in the African setting but they could still be useful if replaced by similar concepts.

Taking the self-management behavioral aspects as a group, we may examine their relevance to self-management of Alzheimer's disease. Self-management behavior tools include exercise, cognitive symptom management, mental stress management/relaxation and communication with physicians.

For example, exercises such as cycling and aerobics are not highly relevant to elderly Nigerians, because they are only very rarely employed by them and skiing does not take place at all. However, these exercises can be substituted by other forms of exercise, e.g. taking a walk around their neighborhood, climbing stairs within their house, etc.

The cognitive symptom management items may be relevant, especially for patients who were familiar with those concepts previously. Otherwise they would have to be taught to the patients and their caregivers who could reinforce the teaching. The ability to manage their cognitive symptoms would be beneficial to patients with Alzheimer's disease because in the early stages of the disease, the awareness of the loss of memory is clear and expectedly distressing. In a country lacking the social support of a robust mental health workforce, tools of self-management are useful and should be promoted.

Promotion of tools of self-management should be done by healthcare workers and by patients' caregiver groups or consumer associations. For this to happen, self-management tools need to be understood by these healthcare workers themselves. Therefore, there should be presentations and training about self-management tools within professional associations and in health institutions. For example, nurses associations should be a target group for such awareness training. A point in favor of Lorig's tools is that they can be taught and supervised by nurses, and nurses are available in every community in the country. This means that once the Lorig tools gain acceptance by nurses, they have a potential for wide use in the country.

There should also be public-health enlightenment campaigns to raise awareness within the public. This could begin when there is a critical mass of healthcare workers who are trained in the use of self-management tools, so if they are demanded by patients, service and support will be available.

Potential Benefits of Use of Self-Management Tools in Low-Resource Settings

Self-management is a way of helping the health service to manage the increasing numbers of patients with long-term chronic conditions, which will emerge, according to the World Health Organization projections in the 2005 report on Preventing Chronic diseases (WHO 2005).

According to Dewar (2006), older persons may rely on, and even prefer, to introduce self-care techniques such as home remedies, massage, nonprescription analgesics, and cognitive techniques, such as distraction and rest to pain-relieving medications, exercises or physiotherapy (Jakobsson et al. 2003; Landsbury 2000; Tse et al. 2005). More investigation is needed into the approaches used by older persons and their preferred strategies particularly as older persons are frequently taking multiple prescription medications.

Healthcare givers need to have simple ways of monitoring compliance with self-management methods. The following list shows suggestions of such simple ways.

Possible Ways of Monitoring and Evaluation of Compliance with Self-Management Methods

- Asking questions of compliance in a non-threatening way to be sure the right instructions are followed.
- Keeping records – non-literate persons can keep records, e.g. putting a pebble in a jam jar each time a dose of medication is taken.
- Unannounced visits and checking amount of medication remaining.
- Testing urine/blood or other objective laboratory tests

Self-management methods may not be suitable for all patients. The focus on increasing self-reliance may not be acceptable to all. Thorne and Patterson (2001) in their study of self-management methods amongst diabetics found that some patients wanted more information and wanted to be told what to do. Accepting and taking responsibility for a disease such as diabetes can be difficult, and for patients who are not ready to do so, a patient-centered empowerment approach may not be appreciated. The same may be true of Alzheimer's disease. The symptoms of Alzheimer's disease, especially the key symptom, which is memory loss, may make it difficult for a patient to use self-management tools.

Moreover, many patients in the Thorne and Patterson study were not inclined to do the homework everyday. Many patients found the daily records arduous and time-consuming, suggesting that they may not have fully profited from this element of the course.

Caregivers who are already burdened may also not be willing to take up the additional tasks involved in self-management and its oversight in a condition such as Alzheimer's disease.

The following list shows of some of the factors that could improve compliance with self-management methods.

Factors That Could Improve Compliance with Self-Management Methods

- Education of patients and caregivers
- Adapting the DOTS method (already widely used in tuberculosis patients), whereby a member of the household or some other person may supervise the treatment or a role pay of what is done at home is repeated during a clinic visit.
- Constantly offering encouragement to patients and their caregivers.
- Gently but firmly correcting mistakes when they occur.

Barriers to Use of Self-Management Tools in Nigeria

Lack of Policy

The foundational barrier to the use of self-management tools in mental healthcare or in the care of the elderly in Nigeria is the lack of effective policy. Policy is the background to effective planning and organization, which is the key to efficient deployment of resources, even when those resources are inadequate. There is no policy for the health of the elderly and although there is a mental health policy, it is outdated and does not cover concepts such as promotion of self-management.

Since there is no policy, there is no formal framework to teach or promote self-management and this results in lack of awareness and lack of skilled manpower to teach and supervise it.

Lack of Awareness

There is very little awareness of structured self-management methods for chronic illnesses in Nigeria. Literature search found some work done in the use of self-management methods in the care of diabetes. There was no literature regarding the care of elderly or in mental illness. The reason for the lack of awareness is not far-fetched. A community survey on health and mental well-being by Gureje and Lasebikan (2006) showed that less than 10% of people in the community who had mental health problems had ever consulted any orthodox or traditional medical practitioner or priest. Therefore, considering the apparent lack of knowledge, evidenced by the scanty literature and the high level of unmet need for care, it could be projected that only a very tiny fraction, if any of those who suffer from chronic mental illnesses such as Alzheimer's disease would have any access to self-management methods.

Lack of Skilled Manpower to Teach and Supervise the Use of Self-Management Tools

The poor health personnel–population ratios have been alluded to earlier. Lack of skilled manpower could be considered as a barrier. This is because although methods of self-management are usually not complex and the tools are quite often easy to use, there is still a need for the methods to be taught formally to those who require them, in order to obtain the optimum benefit from their use. Healthcare workers constitute the majority of skilled workers available to teach these methods, yet, they remain largely unaware of self-management methods.

This may be due in part to the medicalization of illnesses in the society. The majority of patients seen in the formal medical sector for chronic illnesses are not put in contact with social workers, psychologists or home-visitor nurses.

As mentioned earlier, psychiatric nurses are a group of professionals at whom self-management methods should be specifically targeted. They are more in number and available in every part of the country. If engaged appropriately, they may be the best group of professionals to rely upon for widespread use of self-management methods and tools in Nigeria.

Lack of the Right Quality of Partnerships

Self-management methods require partnerships. Most of these partnerships already exist but may need to be strengthened or redefined or both. For example, patient–health worker partnerships need to be redefined. There is still a paternalistic attitude of health workers towards patients in most parts of Africa. But self-management methods entail patient empowerment and regard for patients as personal experts concerning their health conditions and how it affects them. At the present time, neither the health workers nor the patients usually have such an opinion.

The WHO 2000 World Health Report devoted to health systems rated Nigeria 149th out of 191 member nations in terms of health-system responsiveness. Health-system responsiveness is a measure of how the system performs relatively to non-health aspects, meeting, or failing to meet, the population's expectations of how it should be treated by providers of health services, whether preventive or curative. Elements of health responsiveness include respect for dignity and access to social support networks which are important if self-management methods are to be effectively used. It follows therefore that considerable re-education will be required to alter the current situation. This re-education is a daunting but not insurmountable challenge.

Patient–caregiver partnerships for the elderly in Nigeria as they stand currently are also a barrier to widespread use of self-management tools. Most of the elderly in Nigeria were never employed in the formal sector of the economy and they therefore do not draw pensions. This would leave such economically disadvantaged elderly as weak partners to the caregivers for the purpose of joint managers of their health.

The life expectancy in Nigeria is lower than in the developed countries, and this causes a cultural acceptance of disability in the elderly. Symptoms of illness may not be taken seriously by the elderly themselves or by their caregivers. Therefore to involve the elderly and/or their caregivers in symptom monitoring as part of self-management could meet with cultural resistance.

Factors Related to the Patient

Some of the limitations of self-management are defined by the condition of the patient. Patients may be unable to understand or carry out instructions due to their mental state or due to illiteracy.

The diagnosis may preclude self-management. For example, hazardous medication may not be entrusted to the hands of a psychotic or suicidal patient.

Lack of insight on the part of the patient may cause him to regard treatment unnecessary or demand that it should be discontinued.

Recommendations and Conclusions

Given the high prevalence of chronic illnesses amongst the elderly, the large unmet need for care in low-resource health settings and the impact upon patients, families and the healthcare system, the promotion of self-management tools is desirable in low-resource settings.

It is a fact that self-management methods are not suitable in all cases and for all patients but if well designed and appropriately supervised, self-management methods can provide effective care for patients with chronic conditions and improve their outcomes.

Where successful, self-management empowers the patients and may facilitate stabilization of the patient's condition and recovery.

Patient–caregiver partnerships also need to be strengthened to enhance the use of self-management methods, particularly for the elderly. The important partnerships necessary to initiate and support self-management are not yet properly introduced and they need to be so, if self-management methods are to be promoted effectively.

People with Alzheimer's disease and their caregivers can benefit from the use of self-management methods and tools of self-management (e.g. Lorig).

It is recommended that self-management methods should be promoted first by educating the healthcare workers and policy makers about them. This would be followed by education and training of already qualified healthcare workers and the inclusion of self-management methods in the curricula of healthcare workers' training in their various institutions. Nurses, the most abundant and widespread members of the mental health-work force, should be specifically targeted and involved in the promotion and use of self-management methods and tools.

Self-management methods may also be taught as life skills to youth and children, so that they will be disposed to accepting them and educating their elders about them.

The best way to assess the benefit of the use of self-management methods is to monitor and evaluate their use properly, once they have been introduced. This will require research, which will require funding, a resource which is often in short supply in developing countries. However, whatever little funds are devoted to such research, it is expected that the results will prove to be of value.

Self-management methods clearly will involve societal reorientation about healthcare delivery in low-resource settings. Patients, caregivers, health workers and policy makers all need to be persuaded that self-management methods will, on the long term, improve outcomes and reduce burden of chronic illnesses such as Alzheimer's and many others. The task is daunting, but with all hands on deck, taking small but determined steps at a time, it is an achievable possibility.

References

Armstrong N, Powell J (2008) Preliminary test of an internet-based diabetes self-management tool. J Telemed Telecare 14: 114–116

Baiyewu O, Adeyemi JD and Ogunniyi AO (1997) Psychiatric Disorders in Nigerian Nursing Home Residents. International Journal of Geriatric Psychiatry 12: 1146–1150

Baiyewu O, Ikuesan BA, Bella AF, Adeyemi JD, Bamgboye BA, Jegede RO (1997) Attitude to aging in different Groups in Nigeria. International Journal of Aging and Human development 44:283–292

Barrett MJ (2005) Patient self-management tools: An overview. critical mass consulting. www.chcf.org/topics/view.cfm?itemID=111783 (Accessed 12 October 2008)

Bode C, de Ridder DTD, Bensing JM et al. (2006) Preparing for aging: development, feasibility and preliminary results of an educational program for midlife and older based on proactive coping theory. Patient Educ Couns 61: 272–278

DeMonaco HJ, von Hippel E (2007) Reducing medical costs and improving quality via self-management tools. PLoS Med 4: e104

Dewar A (2006) Assessment and management of chronic pain in the older person living in the community. Austr J Adv Nurs 24: 33–38

Gureje O, Lasebikan VO (2006) Use of mental health services in a developing country. Results from the Nigerian survey of mental health and well-being. Soc Psychiatry Psychiatr Epidemiol 41: 44–49

Hendrie HC, Osuntokun BO, Hall KS, Ogunniyi AO, Hui SL, Unverzagt FW, Gureje O, Rodenberg CA, Baiyewu O, Musick BS 1995. Prevalence of Alzheimer's disease and dementia in two communities: Nigerian Africans and African Americans. Am J Psychiatry 152: 1485–1492

Jakobsson U, Hallberg IR, Westergen A (2003) Pain management in elderly persons who require assistance with activities of daily living: a comparison of those living at home with those in special accommodations. Eur J Pain 8: 335–344

Landsbury G (2000) Chronic pain management: A qualitative study of elderly people's preferred coping strategies and barriers to management. Disab Rehab 22: 2–14

Lorig K (2008) Research instruments Developed, Adapted or Used by the Stanford Patient Education research center. http://patienteducation.stanford.edu/research/download.html. Accessed October 28 2008

MRC CFAS (1998) Cognitive function and dementia in six areas of England and Wales: the distribution of MMSE and prevalence of GMS organicity level in the MRC CFA Study. Psychol Med 28: 319–335

Naim RM (2006) Views and news self-management tools: technology for patients. www.sghgroup.com/sghmj/Articles/Self_management_Tools.pdf (Accessed October 28, 2008)

Odejide AO, Olatawura MO, Sanda A, Oyeneye A (1977) Traditional healers and mental illness in the city of Ibadan. Afr J Psychiatry 3: 99–106

Thoolen B, de Ridder D, Bensing J, Gorter K and Rutten G 2008 Beyond Good Intentions: the development and evaluation of a proactive self-management course for patients recently diagnosed with type 2 diabetes: Health Educ Res 23: 53–61

Thorne SE, Paterson BL 2001. Health care professional support for self-care management in chronic illness: insights from diabetes research. Patient Educ Couns 41:81–90.

Tse M, Pun S, Benzie I (2005) Pain relief strategies used by older people with chronic pain: an exploratory survey for planning patient-centred intervention. J Clin Nurs 14: 315–320

Warsi A, Wang PS, LaValley MP et al. (2004) Self-management education programs in chronic disease: a systematic review and methodological critique of the literature. Arch Intern Med 164: 1641–1649

WHO Project ATLAS (2005) Resources for Mental Health. World Health Organisation, Geneva

Self-Management

Alexander Kurz, Cathy Greenblat, Francoise Guillo-Ben Arous, K. Jacob Roy

8.1 Self-Management of Patients with Alzheimer's Disease

Alexander Kurz

Introduction

Alzheimer's disease (AD) is one of the most common chronic diseases in the older segment of the population (Heron 2007; Von Renteln-Kruse 2001). The cardinal clinical feature is dementia, a gradually progressive intellectual decline which significantly interferes with the individual's personal, social and occupational roles. At first glance, this pattern of symptoms appears to be incompatible with the concept of patient self-management. People with AD might neither have sufficient insight into their own condition nor appropriate capacities to participate in the management of their illness (Feinberg and Whitlatch 2001). However, the construct of dementia as it is laid out in the current psychiatric classification systems encompasses states of less severe cognitive impairment in which affected individuals have the ability to comprehend medical treatment strategies, to choose among different options, to cooperate with physicians, and to plan their own future (Vernooij-Dassen and Olde-Rikkert 2004). As the disease progresses, however, the person's capacity for self-management will decrease and the decisions on medical treatment as well as the organisation of care must be taken over by the physician and family members (Lai and Karlawish 2007). Since many disease-management decisions need to be made at a time when the affected individual can no longer participate in or contribute, the pro-active component of self-management is more important in AD than in other chronic diseases. It can take several forms, including advance directives and designating a proxy or legal representative who will decide on behalf of the patient. Moreover, since AD significantly impairs self-care, activities of daily living and the ability to live alone in the community, the range of management decisions is broad. It includes counselling and support of care-providing family members or other informal carers, selecting an appropriate living environment, regulating participation in activity programs or utilisation of day centres and other community facilities, and providing guidance on end-of-life decisions (Kaufer 2001). The present article discusses the prerequisites of self-management in people with AD and outlines the goals and components of self-management in this particular group of patients.

Prerequisites of Self-Management in Patients with AD

Early Diagnosis and Disclosure

Since individuals with AD can only engage in self-management at the early clinical stage of their illness, a timely diagnosis is required (Wilkinson and Milne 2003). General practitioners are usually the first physicians to see and assess patients with possible dementia, and therefore have a key role in the early identification and subsequent management (Van Hout et al. 2006). However, general practitioners are often reluctant to disclose the diagnosis of dementia, particularly at early stages. According to surveys among physicians, less than half of the patients are told their diagnosis, and the diagnosis is more often disclosed to caregivers than to patients (Cahill et al. 2006; Gély-Nargeot et al. 2003; Kaduszkiewicz et al. 2007; Van Hout et al. 2006). Most people with dementia, on the other hand, wish to be told their diagnosis (Jha et al. 2001). Disclosure of diagnosis is a process that takes time and is best conducted in a supportive setting. A diagnosis should be shared over a number of sessions, and the physician needs to go at the patient's pace (Wilkinson and Milne 2003).

Decision-Making Capacity

In order to participate in medical decisions patients need to have insight into their problems, be able to acquire and memorise new information, and have the capacity to make decisions. In people with early AD, disease insight may be reduced but is not completely lost (Kalbe et al. 2005). With adequate support of encoding and recall, they also retain the ability to learn new information (Fernandez-Ballesteros et al. 2005). Decision-making capacity is defined by the abilities to comprehend the meaning of information (understanding), to recognise how information applies to oneself (appreciation), to compare options and infer the consequences of choices (reasoning), and to express a choice (Karlawish 2008). Persons with early AD may well retain sufficient capacity to make a decision about treatments. In these individuals there is relative preservation of the abilities to choose and reason, compared to the abilities to understand and appreciate. Therefore, it is of particular importance to make sure that the person with AD correctly understands the information given and adequately applies it to their personal situation. Decision-making capacity is associated with the preservation of insight, and persons with preserved awareness of their diagnosis are highly likely to retain capacity to make decisions about their care (Karlawish 2008). More specifically, people with early AD usually can convey a clear treatment choice (Moye et al. 2006) and can consistently respond to preferences and their own involvement in decisions about daily living (Feinberg and Whitlatch 2001).

Communication

Disturbance of language is common in patients with AD and it becomes more severe as the disease progresses (Blair et al. 2007). Patients may present with word-finding difficulty, empty vocabulary, cirumocutions, problems with topic maintenance, digressions, tangentiality, and perseveration of ideas (Müller u. Buendouzi 2005). Disturbance of verbal expression is accompanied by decrement in semantic processing (Emery 2000). Therefore, AD presents a challenge to communication which changes over time and needs to be met by equally dynamic skills and strategies. Recommendations for communication between physicians and individuals with AD include quiet environment, avoidance of distraction, patience, use of repetition and clarification to enhance patient comprehension, encoding, and recall.

Goals of Self-Management in People with AD

The general goal of self-management is to support patients in living the best possible quality of life with their chronic condition (Bodenheimer et al. 2002). Research on quality of life in dementia has shown that patients have a more positive appraisal of their lives, roles and relationships than family carers and healthcare professionals might expect (Cahill et al. 2006). Surveys among people with dementia have demonstrated that being in contact with family and friends, keeping active, feelings of belonging, being able to make decisions independently, and being useful are major contributors to happiness and self-esteem (Dröes et al. 2006; Kurz et al. 2008; Van der Roest et al. 2007). Within a self-management program for individuals with AD patients should therefore adopt strategies which help them maintain their functional abilities, level of activity, and a social network for as long as possible. They need to make the best use of available treatment options (Farlow and Pejovic 2008) and take full advantage of preserved abilities.

Components of Self-Management in People with AD

At the early stage of their illness, people with dementia are capable of engaging in key components of self-management (Markwick et al. 2002). They can acquire knowledge of their condition, agree on a treatment plan with their physician, share in medical decision-making, and adopt lifestyles and daily routines that reduce the impact of the illness on their emotional, social and physical life.

Obtaining Information About the Disease

In order to successfully cope with the many challenges of AD, patients and family members or other carers must be informed about a number of disease-related issues. These refer to the signs, symptoms and course of AD; the progressive limitations on daily living and social roles it causes; the moderate effects of current pharmacological treatments; realistic expectations from medications; the potential side effects of these medications and how; the most frequent neuropsychiatric symptoms such as depression, agitation, apathy, or sleep disorder (Volicer and Hurley 2003). Patients and carers must also be aware of the importance of general medical care and prevention including nutrition, skin care, toileting schedules, and dental care (Blass and Rabins 2008). As an essential part of self-management education individuals with AD and their carers need to understand that quality of life and psychological well-being is not directly determined by disease-related measures such as severity of cognitive impairment or limitation on activities of daily living, but can be modified by activity, social interaction, and living arrangement (Banerjee et al. 2008). Finally, the importance of establishing a care plan and future planning needs to be emphasised.

Maintaining Cognitive and Functional Ability

Antidementia drugs are used to improve and preserve cognitive ability and everyday functioning in AD. At the early clinical stage, the cholinesterase inhibitors are the only approved class of compounds (Hogan et al. 2008). Their clinical effects can be summarised as a temporary delay in the progression of symptoms (Raina et al. 2008). This has two important consequences for the management of the disease. First, treatment must be initiated early in order to maintain cognition and functioning at the highest possible level. Second, the time gained at which patients can function at this level must be optimally used in terms of quality of life. Patients and family members or other carers must be aware of possible adverse events of cholinesterase inhibitors in order to be able to report such events to the physician. Monitoring of medication is important in solitary patient to ensure optimal adherence to the treatment plan (Smith et al. 2007). Several non-pharmacological interventions also have the potential of improving cognitive ability, everyday functioning, and quality of life. Wherever possible, people with AD and their carers should seek to combine such interventions with antidementia medications. For example, cognitive training and cognitive rehabilitation approaches can be beneficial if adjusted to individual needs and abilities (Sitzer et al. 2006). Occupational therapy focusing on enhancement of patient meaningful activities and caregiver coping behaviour has been shown to enhance the patients' daily functioning and quality of life (Graff et al. 2006, 2007). Furthermore, an individualised physical exercise program slows down cognitive loss (Kramer and Erickson 2007), reduces functional decline (Heyn et al. 2004; Rolland et al. 2007), and improves activities of daily living (Santana-Sosa et al. 2008). Recent evidence suggests that nutritional components which stimulate membrane formation and synapse formation improve cognitive ability (Van der Beek and Kamphuis 2008).

Enhancing Emotional Well-Being

Emotional well-being and quality of life of people with AD are much less closely associated with measures of disease the impact of behavioural interventions is greater on this part of the clinical symptoms than it is for cognitive ability and functional competence. According to availability and personal preference, patients can choose from a number of non-pharmacological interventions which have been shown to improve mood and psychological well-being (Burns et al. 2002). These include participation in pleasurable activities (Cohen-Mansfield 2001; Teri and Gallagher-Thompson 1991; Teri et al. 2003; Volicer and Hurley 2003), mental stimulation such as conversation, singing and dancing (Farina et al. 2006a,b; Livingston et al. 2005) as well as regular physical exercise such as walking (Williams and Tappen 2008). For other types of interventions, data on efficacy are less convincing, e. g. for music therapy (Livingston et al. 2005) and sensory stimulation (Burns et al. 2002). Counselling and problem-solving education of informal carers also has a beneficial effect on the emotional state of people with AD (Senanarong et al. 2004). When neuropsychiatric symptoms such as depression, agitation, or anxiety become severe they may require pharmacological treatment with antidepressants or antipsychotics (Volicer and Hurley 2003). People with AD and their carers should be informed about the effects and potential risks of these treatments (Blass and Rabins 2008). As part of the care plan they should determine under which circumstances these medications should be administered.

Dealing with Potential Dangers

Since AD impairs cognitive ability, visual perception, and motor function, it leads to reduced driver fitness, unsafe driving, and greater crash risk. Individuals with AD experience more accidents and perform more poorly on road tests than age-matched healthy controls (Grace et al. 2005). Driving ability may be significantly impaired at the early clinical stage of AD, but some patients can continue to drive safely for extended periods of time (Ott et al. 2008). On the basis of self-monitoring of driving practices or a formal driving evaluation, people with AD and their family or other carers should discuss whether driving habits can be adjusted to accommodate the disease (driving only during the day, avoiding highways, driving only in familiar environments) or whether driving needs to be given up altogether (Erten-Lyons 2008). Other safety issues that need to be considered include the administration of medication, electric or gas appliances in the home, likelihood of falls, and wandering away from home. Together with their family carers or other proxies, people with AD should determine which kind of assistive technology they wish to implement, e. g. automatic shutters for electricity or gas, electronic door locks, or tracking devices (Bharucha et al. 2008).

Planning Ahead

Individuals with AD will lose the ability of making decisions about the management of their illness as the disease progresses. Therefore, future planning is an essential part of self-management. People with AD should actively participate in designing a care network including family members, friends, and available care facilities, defining responsibilities and structures of co-operation. They should provide advance directives with regard to the environment in which they wish to live, to medical interventions they are willing to accept or not, and to end-of-life decisions. Pro-active planning may include participation in research by providing advance consent or by designating a proxy for research decision-making (Sachs 1994).

Summary

Alzheimer's disease (AD), the most common cause of progressive intellectual impairment in elderly adults, and patient self-management are not contradictory. At the early clinical stage of AD affected individuals have sufficient insight, reasoning ability and decision-making capacity to participate in the management of their illness. To take advantage of this ability, timely diagnosis and appropriate communication between people with AD, informal carers, and physicians are required. Self-management of AD has several components. Patients need to obtain comprehensive information about the disease and the available treatment options. They must understand that quality of life and psychological well-being are not tightly linked to the neurodegenerative process but can be modified by their own behaviour. To maintain they highest possible level of cognitive and functional ability people with AD should seek to combine medications with non-pharmacological interventions. They can adopt a number of behavioural strategies to preserve their emotional well-being. Dealing with potential dangers refers to driving and potential risks in and around the home. Since the decision-making capacity of people with AD is destined to decline over time, future planning is an essential part of self-management. This includes the design of a care network, advance directives on living arrangements, regulations regarding participation in medical research, and guidance on end-of life decisions.

References

Banerjee S, Samsi K, Petrie CD, Alvir J, Treglia M, Schwam EM, del-Valle M (2009) What do we know about quality of life in dementia? A review of the emerging evidence on the predictive and explanatory value of disease specific measures of health related quality of life in people with dementia. Int J Geriatr Psychiatry 24: 15–24

Bharucha AJ, Anand V, Forlizzi J, Dew MA, Reynolds CF, Stevens S, Wactlar H (2009) Intelligent assistive technology applications to dementia care: current capabilities, limitations and future challenges. Am J Geriatr Psychiatry 17: 88–104

Blair M, Marczinski CA, Davis-Faroque N, Kertesz A (2007) A longitudinal study of language decline in Alzheimer's disease and frontotemporal dementia. J Int Neuropsychol Soc 13: 237–245

Blass DM, Rabins PV (2008) In the clinic: dementia. Ann Intern Med 148: ITC4-1-ITC4-16

Bodenheimer T, Lorig K, Holman H, Grumbach K (2002) Patient self-management of chronic disease in primary care. JAMA 288: 2469–2475

Burns A, Byrne J, Ballard C, Holmes C (2002) Sensory stimulation in dementia. An effective option for managing behavioural problems. BMJ 325: 1312–1313

Cahill S, Clark M, Walsh C, O'Connell H, Lawlor B (2006) Dementia in primary care: the first surfey of Irish general practitioners. Int J Geriatr Psychiatry 21: 319–324

Cohen-Mansfield J (2001) Nonpharmacologic interventions for inappropriate behaviors in dementia. Am J Geriatr Psychiatry 9: 361–381

Dröes RM, Boelens-Van-Der-Knoop ECC, Bos J et al. (2006) Quality of life in dementia in perspective. An exploratory study of variations in opinions among people with dementia and their professional caregivers, and in literature. Dement Int J Soc Res Pract 5: 533–558

Emery VOB (2000) Language impairment in dementia of the Alzheimer type: A hierarchical decline? Int J Psychiatry Med 30: 145–164

Erten-Lyons D (2008) When should patients with Alzheimer disease stop driving? Neurology 70: e45–e47

Farina E, Mantovani F, Fioavanti R et al. (2006a) Efficacy of recreational and occupational activities associated to psychologic support in mild to moderate Alzheimer disease. A multicenter controlled study. Alzheimer Dis Assoc Disord 20: 275–282

Farina E, Mantovani F, Fioravanti R et al. (2006b) Evaluating two group programmes of cognitive training in mild-to-moderate AD: Is there any difference between a »global« stimulation and a »cognitive-specific« one? Aging Ment Health 10: 211–218

Farlow MR, Pejovic MLMV (2008) Treatment options in Alzheimer's disease: maximizing benefit, managing expectations. Dement Geriatr Cogn Disord 25: 408–422

Feinberg LF, Whitlatch CJ (2001) Are persons with cognitive impairment able to state consistent choices? Gerontologist 41: 374–382

Fernandez-Ballesteros R, Zamarron MD, Tarrega L (2005) Learning potential: a new method for assessing cognitive impairment. Int Psychogeriatr 17: 119–128

Gély-Nargeot MC, Derouesné C, Selmès J (2003) European survey on current practice and disclosure of the diagnosis of Alzheimer's disease. A study based on caregiver's report. Psychol Neuropsychiatr Viei 1: 45–55

Grace J, Amick MA, D'Abreu A, Festa EK, Heindel WC, Ott BR (2005) Neuropsychological deficits associated with driving performance in Parkinson's and Alzheimer's disease. J Int Neuropsychol Soc 11: 766–775

Graff MJL, Vernooij-Dassen MJM, Thijseen M, Dekker J, Hoefnagels WHL, OldeRikkert MGM (2007) Effects of community occupational therpy on quality of life, mood, and health status in dementia patients and their caregivers: A randomized controlled trial. J Gerontol 62A: 1002–1009

Graff MJL, Vernooij-Dassen MJM, Thijssen M, Dekker J, Hoefnagels WHI, Olde-Rikkert MGM (2006) Community-based occupational therapy for patients with dementia and their caregivers: randomised controlled trial. BMJ 333: 1196–1111

Heron M (2007) Deaths: leading causes for 2004. Natl Vital Stat Rep: 1–95

Heyn P, Abreu BC, Ottenbacher KJ (2004) The effects of exercise training on elderly persons with cognitive impairment and dementia: A meta-analysis. Arch Phys Med Rehabil 85: 1694–1704

Hogan DB, Bailey P, Black S et al. (2008) Diagnosis and treatment of dementia: 5. Nonpharmacologic and pharmacologic therapy for mild to moderate dementai. CMAJ 179: 1019–1026

Jha A, Tabet N, Orrell M (2001) To tell or not to tell – comparison of older patients' reaction to their diagnosis of dementia and depression. Int J Geriatr Psychiatry 16: 879–885

Kaduszkiewicz H, Wiese B, Van den Bussche H (2007) The management of dementia patients from the point of view of office-based general practitioners (GPs) and specialists – the results of an empirical investigation. Z Arztl Fortbild Qualitatssich 101: 15–20

Kalbe E, Salmon E, Perani D et al. (2005) Anosognosia in very mild Alzheimer's disease but not in mild cognitive impairment. Dement Geriatr Cogn Disord 19: 349–356

Karlawish J (2008) Measuring decision-making capacity in cognitively impaired individuals. Neurosignals 1: 91–98

Kaufer DI (2001) Long-term care in dementia: patients and caregivers. Clin Cornerstone 3: 52–62

Kramer AF, Erickson KI (2007) Captalizing on cortical plasticity: inflouence of physical activity on cognition and brain function. Trends in Cognitive Sciences 11: 342–438

Kurz A, Schulz M, Reed P, Wortmann M, Rodrigo J, von-Lützau-Hohlbein H, Grossberg G (2008) Personal perspectives of persons with Alzheimer's disease and their carers: A global survey. Alzheimer's Dement 4: 345–352

Lai JM, Karlawish J (2007) Assessing the capacity to make everyday decisions: A guide for clinicians and agenda for future research. Am J Geriatr Psychiatry 15: 101–111

Livingston G, Johnson K, Katona C, Paton J, Lyketsos CG (2005) Systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia. Am J Psychiatry 162: 1996–2021

Markwick M, Reece M, Battersby MW (2002) The Development and implementation of a generic assessment tool in chronic disease self-management. In: Health Outcomes 2002: Current Challenges and Future Frontiers, Canberra

Moye J, Karel MJ, Gurrera FJ, Azar AR (2006) Neuropsychological predictors of decision-making capacity over 9 months in mild-to-moderate dementia. J Gen Intern Med 21: 78–83

Müller N, Buendouzi JA (2005) Order and disorder in conversation: Encounters with dementia of the Alzheimer's type. Clin Linguist Phon 19: 393–404

Ott BR, Heindel WC, Papandonatos GD, Festa EK, Davis JD, Daiello LA, Morris JC (2008) A longitudinal study of drivers with Alzheimer's disease. Neurology 70: 1171–1178

Raina P, Santaguida P, Ismaila A, Patterson C, Cowan D, Levine M, Booker L, Oremus M (2008) Effectiveness of cholinesterase inhibitors and memantine or treating dementia: evidence review for a clinical practice guideline. Ann q 148: 379–397

Rolland Y, Pillard F, Klapouszczak A, Reynish E, Thomas D, Andrieu S, Rivière D, Vellas B (2007) Exercise program for nursing home residents with Alzheimer's disease: A 1-year randomized, controlled trial. J Am Geriatr Soc 55: 158–165

Sachs GA (1994) Advance consent for dementia research. Alzheimer Dis Assoc Disord 8: 19–27

Santana-Sosa E, Berriopedro MI, López-Mojares LM, Pérez M, Lucia A (2008) Exercise training is beneficial for Alzheimer's patients. Int J Sprots Med 29: 1–6

Senanarong V, Jamjumras P, Harmphadungkit K, Klubwongs M, Udomphanthurak S, Poungvarin N, Vannasaeng S, Cummings JL (2004) A counseling intervention for caregivers: effect on neuropsychiatric symptoms. Int J Geriatr Psychiatry 19: 781–788

Sitzer DI, Twamley EW, Jeste DV (2006) Cognitive training in Alzheimer's disease: a meta-analysis of the literature. Acta Psychiatr Scand 114: 75–90

Smith GE, Lunde AM, Hathaway JC, Vickers KS (2007) Telehealth home monitoring of solitary persons with mild dementia. Am J Alzheimers Dis Other Demen 22: 20–26

Teri L, Gallagher-Thompson J (1991) Cognitive-behavioural interventions for treatment of depression in Alzheimer´s patients. Gerontologist 31: 413–415

Teri L, Gibbons LE, McCurry SM et al. (2003) Exercise plus behavioral management in patients with Alzheimer disease: a randomized controlled trial. JAMA 290: 2015–2022

Van der Beek EM, Kamphuis PJ (2008) The potential role of nutritional components in the management of Alzheimer's disase. Eur J Pharmacol 585: 197–207

Van der Roest HG, Meiland FJ, Maroccini R, Comikjs HC, Jonker C, Dröes RM (2007) Subjective needs of peole with dementia: a review of the literature. Int Psychogeriatr 19: 559–592

Van Hout HP, Vernooij-Dassen MJ, Jansen DA, Stalman WA (2006) Do general practitioners disclose correct information to their patients suspected of dementia and their caregivers? A prospective observational study. Aging Ment Health 10: 151–155

Vernooij-Dassen M, Olde-Rikkert MGM (2004) Personal disease management in dementia care. Int J Geriatr Psychiatry 19: 715–717

Volicer L, Hurley AC (2003) Management of behavioral symptoms in progressive degenerative dementias. J Gerontol 58A: 837–845

Von Renteln-Kruse W (2001) Epidemiological aspects of morbidity in older age. Z Gerontol Geriatr 34: 1/10–11/15

Wilkinson H, Milne AJ (2003) Sharing the diagnosis of dementia – learning from the patient perspective. Aging Ment Health 7: 300–307

Williams CL, Tappen RM (2008) Exercise training for depressed older adults with Alzheimer's disease. Aging Ment Health 12: 72–80

8.2 Self-Management of Patients – Another Perspective

Cathy Greenblat, Francoise Guillo-Ben Arous, K. Jacob Roy

Introduction

Alzheimer's disease, constantly evoked, widely feared, constitutes »a major challenge to public health«. While it remains poorly understood, it is at last beginning to be shown in movies, for example in the West, but concrete situations, happy or extreme, linked to the disease are rarely photographed. We believe that good photographs can speak volumes and can throw light onto the various dimensions of this mind-crippling illness and of what we know about providing high quality dementia care.

Who knows the reality of everyday life with Alzheimer's? The disease is so often lived in secret, hidden in the interior of families or behind the walls of institutions. Is it possible to go through the door of an Alzheimer's unit or that of a palliative care unit and photograph? Can one wait, share, exchange, see, and then show what goes on, what one has seen and felt? To do so is extremely difficult and it has not often been done. The first challenge comes from the fundamental question of respect, then there is the need for patients' and/or their family member's consent as well as the right to the image, an extremely delicate set of questions in this type of illness. Then one must gain the active collaboration of the institution, which is rare. This visual approach, however, constitutes an authentic collaborative research effort between the photographer, the treatment team, and the patient and family. The results can serve as a tool for the improvement of the quality of care, because the photographic work will generate a new dimension of communication and foster reflection about practices and concepts of the disease. Photographs can also be an excellent pedagogic tool.

The relationship with patients puts the caregiver into a situation of constant learning as the patient teaches us about his illness. We also learn from the team that we train and from those with whom we collaborate, and we learn from other teams working in other countries. Photographers, too, help us to learn because their images forcefully move us to reflect upon images of ourselves and on interpersonal links. In the difficult and complex task of taking care of patients affected by Alzheimer's disease, enhancing self-image has a positive effect on patients. It also influences the ideas that caregivers develop of their roles and of their objectives.

Once medical and nursing responsibility has been accepted and an optimal treatment plan has been established, it is important, in fact it is of primary importance, to address the patient not simply as a sick person with symptoms, but as an individual. A more egalitarian relationship can then be created in which the caregiver's approach is fully professional but also natural. The sick person gives way to the individual, to a person better expressing his self, his desires, his opinions, his limitations, and his fantasies. In those institutions where the ethic of care respects these needs, it is easier for the photographer to penetrate the intimacy of relationships, to capture the signs and the non-verbal language of the body, the intensity of looks, and the profound humanity of the moments of care. Here we see some examples in the photographs taken by Cathy Greenblat in the USA, Europe, Japan, and India over the past several years, following publication of her important book of text and photos, *Alive with Alzheimer's*.

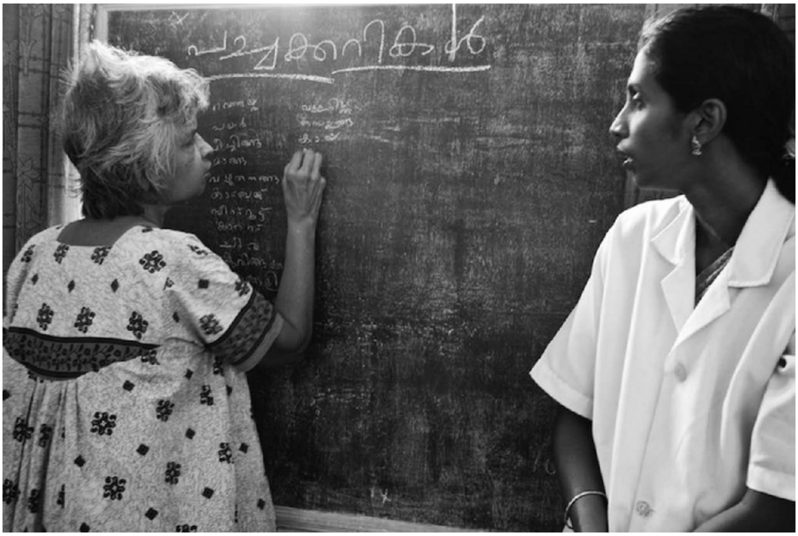
Photos and Commentary

Fig. 8.1. Music is foremost in this music therapy scene, contained in two concentric circles. Rolland and his daughter are at the heart of the space. He leans toward her, seeking her contact, her cheek, while her hands are positioned on his chest, around his heart. While his eyes are closed, his hearing and touch are completely awake. The three musicians redefine and delimit the affective space. They are on the physical periphery, but they contribute importantly by creating the music. Kate, a music therapist at an Alzheimer's hospital in the US, had formed a small »band« composed of 3 male residents, all with quite advanced AD. They named themselves »The Windjammers« and loved meeting, playing, feeling important, and joking about going »on tour«. Rolland was not playing this day, but he was clearly engaged with the music and his friends, as well as with his daughter who was visiting. A moment after this photograph was taken, she wiped away the tears that streamed down his face as he recognized a song

◘ Fig. 8.2. Jeanette continued to participate in the music therapy activities while she was on hospice care during the terminal stage of her illness. The powers of concentration of people with Alzheimer's disease are affected very early and they decline considerably during the course of the evolution of the illness. This happens even more in terms of the capacity to coordinate gestures in a logical sequence. Jeanette's face expresses a great precision and concentration. Her face shows so fully how she is seeking the sounds and the notes. Exploring and playing an instrument *alone* helps greatly in defining the individual's space

◘ Fig. 8.3. Good care demands strong physical proximity, getting close by approaching one another naturally, spontaneously, to transmit warmth and attention. Geetha, a trained volunteer at the ARDSI daycare centre in Cochin, India, has learned that and she has learned that good caregivers concentrate on the rhythm of the patient and his or her state of receptivity. The relational choice made by the patient is determined by the quality of the moment as well as by Geetha's knowledge and sensitivity. This woman was diagnosed with dementia at age 68 and was initially taken care of at home by family and domestic servants. Her aggressive behavior, however, became very problematic, and she was enrolled in the daycare centre where she chats and tells stories and benefits from trained staff members and volunteers who are understanding and kind

◘ Fig. 8.4. At a hospital north of Tokyo, the Directress, a doctor, gives her attention to many patients. She exudes warmth in each contact. Physical touch is not generally part of Japanese culture, but the training of doctors and nurses and aides emphasizes the positive effects of physical touch, and it appears very »natural« when it is employed. This photograph contrasts with and adds understanding to the preceding one. Patients often make a choice of a defiant and hostile attitude. What will come to pass is a more reserved, distant, less warm contact, than in the prior instance, but this patient broke into a warm smile in response to the doctor's tender touch



◘ Fig. 8.5. The staff at the Day Care Center in Cochin understand the need to find activities that are meaningful to the participants given both their backgrounds and their present capabilities. This woman, a former mathematics teacher likes to write numbers on paper or on the blackboard. Does this type of activity really favor the sensation of autonomy? Yes, if the patient, like this woman, finds in it old pleasures, for example, from childhood, writing, or mathematics. In that case, each line is a victory. It is a good example of the power of individualized attention in a group setting

Fig. 8.6. This patient, earlier in his life was an independent man and a tough lawyer and businessman, but memory loss and serious behavioral problems that began 5 years ago caused difficulties in the family, which eventually found it impossible to manage him at home. At the Harmony House respite center he formerly had emotional outbursts and would not listen to the staff. Now Mr. Subramanian, the Care Manager, who worked for more than 20 years with leprosy patients, has gained his trust and the trust of others

Fig. 8.7. Emotional balance and harmony are rapidly enhanced thanks to contact with animals. Pet therapy recreates an ecological environment that makes patients happy. The pets contribute to a sense of a natural world, reducing the space that is occupied by the illness and the medical organization. The photograph of an encounter between Marion, the director of the pet therapy program for Silverado Senior Living's hospice program in Houston, Texas, and a hospice patient shows the positive impact that loving contacts in general and contacts through pet therapy in particular can have. In this photo, the patient's face lights up and her hands open. Sweetness and warmth pervade the session. This approach restores interpersonal links and helps create new ones, as well as enhancing the autonomous discourse of the patient. The choice and the decision of the patient to enter into the relationship are often immediate, no matter what the stage of the disease

Fig. 8.8. Lightness and good moments are among the best objectives to strive for in caring for patients in an Alzheimer's unit. But how can we wait for life to give enough of them when one is at an advanced age and affected by Alzheimer's disease? Good humor and complicity, with perhaps a little regression, can have a positive effect on mood, and can stimulate patients intellectually through exchanges between them. The general ambience of a unit is crucial because the patients sense tensions very profoundly; they also feel the serenity or enthusiasm of teams. In a group home in Nagoya, a party created extraordinary moments of joy and laughter, seen vividly in the photo

Fig. 8.9. The memory problems of those with Alzheimer's disease are primarily about the present, and they make the future difficult to imagine. It is thus their very identity that is affected. Older memories and autobiographies, however, are relatively well conserved. Reminiscence therapy is based on the evocation of these memories with the help of various supports such as photographs and music. The sharing of these souvenirs in a group helps to promote social exchanges and through this communication the quality of life of patients and family aides is improved. The face of this patient, participating in a memory clinic at a hospital in Nice, France, reveals the pride that she feels at showing the photograph of her grandson to other members of the group, talking about his birth

Conclusion

Patients with Alzheimer's disease live with a triple confinement. First, there is the confinement of their illness, a neurological disease which progressively deprives them of their competencies, of their means of action, of their liberty, of their decision-making power. Then it inevitably deprives them of their intellectual, physical, social and individual autonomy. They also live with the confinement created by imperfect and incomplete scientific concepts in the medical field and in the social domain. These concepts currently describe and define the illness. The patients are like prisoners of the ideas of the illness that are projected. It is seen as mysterious; it touches fundamental dimensions of identity, of memory and of thought; and it focuses on fundamental existential fears in many societies concerning forgetting and death.

Finally, people with Alzheimer's disease suffer from being submissive as they experience confinement in the institutions that welcome them. This isolation reinforces all the others and it is there that the responsibility of each structure rests. Opening these care units to real life, to the family, to intergenerational exchange, to the outside, to cultural and artistic life, to the world of work, to the non-medical non-hospital world, is an ethical necessity. This non-medical, non-pharmaceutical and extra-institutional approach succeeds simply, sometimes spectacularly, at the cost of strong human engagement, to at least partially restore dignity, autonomy, and well being, while an only academic approach most often engenders affective disinterest and an aggravation of symptoms.

In India there is still gross ignorance about the condition. Only some are taken for medical help and few get an early diagnosis and adequate care. Most families suffer in silence although things are slowly changing thanks to ARDSI's 15 years of awareness programs. Work is needed everywhere, not just in India, if we are to create environments beneficial to people with dementia. Around the world the stigma of the disease must be diminished, the fatalistic attitudes of too many doctors and other health professionals has to change considerably, and patients and family members need to learn the philosophy and practices that can increase self-management.

Cathy Greenblat's photographs testify to and teach us about the profound humanity of looks, gestures, attitudes. With an astonishing acuity she offers evidence of concrete daily situations of patients and of the permanent seeking by caregivers for better ways to help, in India, in Japan, in the West, beyond differences in medical, human, and environmental resources and beyond cultural differences. In the extreme situations that the illness leads to – loss of motor skills, loss of walking ability, loss of language, major anxiety, refusal of contact, refusal of care or of eating, refusal of living – the concept of autonomy or of self-management must be redefined at each step. It is also to be defined for each patient, each individual. It is the way to respect his ultimate liberty.

End-of-life Care for Patients with Alzheimer's Disease

Jenny T. van der Steen, Luc Deliens

Specific Challenges and Opportunities in End-of-Life Care for Patients with Alzheimer's Disease

In industrialized countries, many people are dying with dementia and a steep rise is expected over the coming decades. In the Netherlands, for example, at present one out of nine decedents has dementia (van der Meulen and Keij-Deerenberg 2003). Dementia patients, including those with Alzheimer's disease, should receive the best possible end-of-life care. Patients dying with dementia as a group resemble patients dying from other diseases such as cancer in that pain and shortness of breath are possibly the most common burdensome symptoms in the dying phase (McCarthy et al. 1997; van der Steen et al. 2007a).

However, there are a number of important issues that distinguish end of life with dementia from the last days of life with cancer. First, patients with cancer may remain lucid until the very end while dementia patients have frequently suffered from long-lasting cognitive impairment. This implies that, whereas cancer patients can often still make decisions for themselves, in the case of many dementia patients, proxies have to make decisions on care and treatment on their behalf. This is because living wills, if available, frequently do not capture exactly the specific circumstances of the situation. Second, dementia follows a frailty pattern of decline, which shows an overall slow but variable decline in function (Lunney et al. 2003). Cancer patients, by contrast, remain functional for longer, but there is a steep decline in the last phase. This is a key issue when it comes to prognostication. Because death is frequently from an acute intercurrent disease such as pneumonia, prognostic scores are not very helpful in predicting it with reasonable accuracy for more than a small minority of dementia patients (van der Steen et al. 2007b). The default is frequently curative treatment. Because of uncertainty in patient wishes and prognosis, it may be more difficult to get off the curative path in dementia patients compared with cancer patients (Mitchell et al. 2004). Dementia is thus not always viewed as a terminal disease. Third, dementia patients have often been institutionalized for a long time before they reach the terminal phase (Mitchell et al. 2005). Therefore, there is ample opportunity for professional caregivers to develop a relationship with patient and family and a good, shared understanding of the patient's condition, his/her life, personality and previous wishes. This can result in a solid basis for making complex and value-laden end-of-life and palliative care decisions.

In this contribution, we will first define palliative care and outline its recent advances and what is known about dying with dementia; we will then draw on this to outline an approach to palliative care in dementia before we come to self-management issues including how patients and proxies can contribute to optimal care.

What is Palliative Care?

According to the World Health Organization (WHO 2002), palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO 2002; Sepúlveda et al. 2002; see the following box for the remaining more detailed part of the definition).

Palliative Care (WHO 2002)

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;

- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

In addition to attending to physical needs, palliative care explicitly includes addressing of psychosocial and spiritual needs. This holistic care is frequently multidisciplinary. It is ideally initiated at the time of the diagnosis of any serious or life-threatening illness, independently of prognosis, and is delivered in concert with curative or life-prolonging therapies provided these are beneficial to the patient (Morrison and Meier 2003).

It is the individual patient and not the disease which is central to palliative care. Patient- (or person-)centered care is »care that incorporates respect for patients' values and preferences, provides information in clear and understandable terms, promotes autonomy in decision-making and attends to the need for physical comfort and emotional support« (Hewitt and Simone 1999). In other words, it parallels palliative care which has traditionally looked at the whole life and personality of the patient (i.e., »holistic«). It is said to affirm continuing »personhood« (Small 2007). This is further in line with self-management of care which assumes active participation of the patient or of proxies who consider the patient's (previous) wishes.

The core precepts of geriatrics and palliative care are identical: care is patient-centered, comprehensive and holistic; patients and families together are the unit of care, high priority is given to enhancing functional independence and quality of life, regular and formal assessment is employed to ensure the timely identification and treatment of problems, and an interdisciplinary team approach is required to address the spectrum of needs of patients and their families (Morrison and Meier 2003). The role of both specialties transcends the settings: care is delivered wherever the patient happens to be (home, hospital, nursing home, elderly home, etc.), at whatever stage of illness and for whatever diagnoses.

Palliative Care in Dementia

There is consensus among experts that palliative care applies to patients with dementia as it does to patients with incurable illness with more predictable trajectories to death (Davies and Higginson 2004). Deaths associated with dementia are frequently caused by impairments related to dementia and not necessarily by the neurodegenerative disease itself. Alzheimer's disease and other dementias are life-threatening diseases for which there is currently no cure and dementia limits life expectation. Survival of patients with Alzheimer's disease is shorter for men and for those with higher age at onset (Larson et al. 2004) and median survival is reported as between approximately 5 and 9 years (Larson et al. 2004; Williams et al. 2006).

Until recently, little attention has been given to development of palliative care for dementia patients and the provision of palliative care to this patient group is perceived as very challenging for all involved. However, palliative care is rapidly becoming the standard of care in advanced stages of Alzheimer's disease (Wolf-Klein et al. 2007). In dementia patients, it is particularly relevant that palliative care should be provided alongside potentially curative treatment (Davies and Higginson 2004; Lynn 2001). This is because people and families face many problems over many years and need help at any time and not just at an easily definable point immediately before death. Palliative care therefore applies to earlier stages of dementia rather than being limited to end-stage dementia (Hughes et al. 2005).

Palliative care includes early identification of problems. For dementia patients, anticipating problems that can be expected in the terminal phase, such as eating difficulties and pneumonia, is particularly relevant (Arcand and Caron 2005). Anticipating problems is the basis of advance care planning, which we will discuss in more detail further on. In practice, palliative care for dementia patients employs nursing comfort measures such as oral and body hygiene, positioning, wound care, warmth, and medications; foods and fluids are typically provided orally (Volicer et al. 2002).

Comfort care and hospice care are terms frequently used when referring to palliative care in dementia patients. Comfort care avoids therapies which cause discomfort and directs efforts to relieving suffering and to optimizing quality of life and quality of dying; it thus fits into the palliative care philosophy. Comfort care can be more narrowly conceived as care in which life-prolonging treatments are contraindicated. Hospice care, traditionally limited to homecare or care provided within a hospice, was applied to dementia by Professor Volicer in the 1980s (Volicer et al. 1986). Hospice care has been developed further in the US as a system of reimbursed care by a multidisciplinary team for patients with a life expectancy of 6 months or less and dementia patients are increasingly enrolled in these programs (Miller et al. 2004; Munn et al. 2006). Today, the term hospice care is frequently used as synonymous with comfort care.

What is Known About Dying With Dementia and How Advanced Is Palliative Care in Dementia Patients?

Both over-treatment with ineffective, curative and burdensome treatments and under-treatment of pain and symptoms have been described in a number of studies (Birch and Draper 2008; van der Steen et al. 2007a) and are summarized in this paragraph, as are recent developments in, and evidence of the effectiveness of, some treatments. Additionally, a number of local, mostly qualitative, studies have described problems in communication between professional caregivers and the families of institutionalized patients. Other problem domains appearing in the literature are difficulty in prognostication and support of the family, including bereavement issues, which are all addressed in later paragraphs.

Over-Treatment

Today, many people with dementia are over-treated. For example, about half (40% or more) of dementia patients received antibiotics shortly before death in studies in the US (D'Agata and Mitchell 2008; Sloane et al. 2003), Switzerland (Pautex et al. 2007), and Italy (Di Giulio et al. 2008) and tube feeding is prevalent in 1 to 4 out of 10 patients in the US (Ahronheim et al. 1996; Gessert et al. 2006; Mitchell et al. 2004; Munn et al. 2006; Sloane et al. 2003) and in up to 7 out of 10 patients dying with dementia in Israel (Aminoff and Adunsky 2006). In dementia patients, there is no evidence that tube-feeding increases survival or prevents aspiration (Gillick 2000). For nursing-home residents with pneumonia, whether they have dementia or not, hospitalization probably does not decrease mortality risk (Boockvar et al. 2005; Kruse et al. 2004; Loeb et al. 2006). Moreover, cognitive impairment was a risk factor for delirium in elderly patients hospitalized for hip fracture (Kalisvaart et al. 2006) and higher age, difficulty turning in bed, nursing-home residence, incontinence and other conditions that frequently apply to dementia patients were associated with increased risk of development of pressure ulcers in hospital (Baumgarten et al. 2006). Nevertheless, hospitalization of patients with dementia and pneumonia is regular practice in the US (van der Steen et al. 2004) and also in countries other than the Netherlands (van der Steen et al. 2007a). These studies speak to a default treatment of curative care. But: »Why suffer more now than in earlier times when technology was less advanced?« (Arcand and Caron 2005). Thus, lack of recognition that curative care has become futile has been identified as a major obstacle to effective palliative care (Travis et al. 2002).

Under-Treatment

Today, most people with dementia still die without having had access to palliative care. Under-treatment of pain and burdensome symptoms is a major and probably even more widespread problem. One US study found that advanced dementia patients hospitalized for hip fractures received one-third the amount of opioid analgesia as did cognitively intact subjects, 40% of whom reported severe pain postoperatively (Morrison and Siu 2000a,b). Evidence with regard to Alzheimer's patients suffering more or less from pain is conflicting. Dementia probably affects different aspects of pain differently, increasing the threshold, and failure to interpret sensations as pain while sensitivity to pain itself is preserved (Bjoro and Herr 2008; Kunz et al. 2008). Nevertheless, pain prevalence for dementia patients (including at the end of life) is estimated at between 28% and 83% (Bjoro and Herr 2008; van der Steen et al. 2007a; Zwakhalen et al. 2008).

Shortness of breath is also frequent (between 12% and 82%) in patients dying with dementia (van der Steen et al. 2007a). Treatment to relieve shortness of breath and other symptoms in patients dying with pneumonia was sparse both in the Netherlands and in the US in the late 90s (van der Steen et al. 2004).

Less is known on the frequency and treatment of psychological or behavioral problems at the end of life. Agitation, anxiety and resistiveness to care may be as prevalent in the last phases as pain and shortness of breath (Koopmans et al. 2008; van der Steen et al. 2009). Finally, reports on spiritual care for dementia patients are virtually absent.

Recent Developments in Palliative Treatment

Despite continuing concerns about balancing treatments, the most recent reports on palliative care in dementia patients are encouraging. In the US, nursing-home residents, including dementia patients, are increasingly enrolled in hospice programs (Miller et al. 2008). Recent studies show that families of nursing-home residents with dementia in hospices are more satisfied with care (Shega et al. 2008) although it is unclear whether this should in fact be attributed to death having been expected (Munn et al. 2006). Evaluations of hospice care are as favorable for dementia patients as for patients with other diagnoses (Mitchell et al. 2007).

Further, attention is increasingly being paid to adequate recognition and assessment of pain in dementia patients, with many new (observational) tools having appeared in recent years (Zwakhalen et al. 2006). Treatments to relieve symptoms in patients with pneumonia and dementia have increased tremendously – some have more than doubled – in the Netherlands over the past decade (manuscript under review). Another example is hospitalized dementia patients in Switzerland, cared for by a dedicated team and treated equally well as the cognitively intact hospitalized elderly (Pautex et al. 2007).

Effectiveness of Treatments and Other Interventions

What we do not know is whether increased treatment to relieve symptoms, or the withholding of burdensome treatments, results in reduced suffering at the end of life and in increased quality of life or of dying. That is, there is hardly any evidence of the effective treatment of burdensome symptoms in dementia patients (Sampson et al. 2005) as there is hardly any evidence of the effectiveness of specialized palliative care in general (Zimmerman et al. 2008). There is some evidence, however, for use of routine observational pain scales to improve pain treatment and reduce observed pain (Fuchs-Lacelle et al. 2008). Another study, however, found no effect of acetaminophen in reducing discomfort (not specific to the end of life; Buffum et al. 2004).

Observational studies with adjustment for confounding factors suggest treatment effects. For example, parenteral antibiotics did not decrease mortality risk in most patients with pneumonia apart from a small group of very high-risk patients (van der Steen et al. 2007c). Antibiotics were associated with slightly increased comfort in patients dying from pneumonia or intake problems, but further study of a possible role for antibiotics in palliating symptoms is needed before adopting their use (van der Steen et al. 2009b). In a retrospective interview study in the US, spiritual care at the end of life for long-term care residents (78% with cognitive problems) was associated with better evaluation of overall care (Daaleman et al. 2008)

Recommendations by palliative care teams, designed to increase palliative care based on communication strategies, were not effective in a hospital setting (Ahronheim et al. 2000), but communicating eligibility for hospice to physicians in US nursing home settings did result in increased use of hospices (Casarett et al. 2005). There is evidence that the effectiveness of planning for the withholding of curative care is effective which is outlined in the next paragraph.

Self-Management at the End of Life With Dementia: Advance Care-Planning

Principles of Advance Care-Planning

Advance care planning has been called »an outgrowth of patient-centered medical care that promotes shared decision-making such that medical care will meet the patient's needs and expectations« (Teno 2003). It is aimed at communication about treatment goals and at the formulation of contingency plans to meet those goals. It is therefore not limited to drawing up a living will but is more a process that starts early and needs continuous communication and reassessment when new phases are entered.

Dementia Patients' Involvement in Decision-Making

Choice and autonomy are important mainstays of patient-centered and palliative care, as stated in the previous paragraphs, and these are promoted by advance care-planning. Dementia patients cannot always participate in decisions about care. However, only a minority of dementia patients reaches the end stage with total impairment of functioning (e.g., being confined to bed, incontinent, and needing help with all activities of daily living) (Koopmans et al. 2007). Patients with mild to moderate dementia can still understand healthcare values and these may remain stable over 9 months (Karel et al. 2007). Further, even if patients are not competent to make major decisions, some patients with moderate dementia may still be able to reflect on their quality of life with the help of specific tools (e.g., Brod et al. 1999). Many patients can still be involved in small, daily decision-making. Menne and Whitlatch (2007) found that dementia patients with mild cognitive impairment (mean MMSE score 22, SD 5) who report more decision-making involvement are younger, female, have more education, have a non-spousal caregiver, have fewer months since their diagnosis, exhibit fewer problems with activities of daily living and fewer depressive symptoms, and place more importance on autonomy and self-identity.

Advance Care-Planning in Dementia

When the patient is still competent in the early stages of dementia, he or she can designate a proxy who will take decisions on their behalf in the event of lack of competence (proxy designation) or draw up a living will, ideally guided by a familiar professional caregiver (Volicer et al. 2002). Those who write living wills may want them to have binding force and not to be easily overridden by proxies, as demonstrated in a German study (Jox et al. 2008). Refusal of treatment should generally be respected, but legal systems in different countries vary in the degree that treatment can be requested. Living wills as a legal document may be a strong tool against the default of overly aggressive curative care in the US, Southern Europe, and Israel as described in the previous paragraph; they may also act as directives in countries where this default is less strong; e.g., in Canada and some Northern European countries.

Ideally, a patient has a written living will outlining goals of treatment and preferred treatment in a variety of clinical scenarios including those frequently encountered at the end of life. However, living wills are frequently too vague to apply directly to any specific condition, though they are helpful in expressing a general philosophy of end-of-life care (Gillick 2004; Perkins 2007). Patients should be well informed about the benefits and burdens of treatment alternatives to exercise autonomy via living wills; guidance in prioritizing care goals is needed (Gillick 2004; Teno 2003).

In later stages, decision-making capacity is inevitably lost (Morris et al. 1994). Advance directives and proxy decision-making can extend autonomy up to this phase (Volicer et al. 2002). Proxies can be involved in developing advance directives for possible future health problems. i.e., »proxy-planning« or »advance policy-making.« Because living wills or advance directives are frequently not specific enough to capture every possible clinical scenario, interpretation and action according to what those involved think is in the patient's best interest, or what most people may want in the particular situation (Gillick 2004) takes over. Several studies found that preferences for end-of-life care were moderately stable, and that in general, however, with aging or decline in health, interest in life-sustaining treatment decreases (Ditto et al. 2003; Wittink et al. 2008).

Advance Care-Planning in Dementia: Is It Helpful?

There is some evidence on the effectiveness of advance care-planning systems although we do not yet know in which settings which elements most effectively promote patient comfort and care in accordance with their wishes. A trial in Canada in nursing-home residents with and without dementia showed that advance directives resulted in fewer hospitalizations although satisfaction with care was unaffected (Molloy et al. 2007). For dementia patients, most evidence is restricted to specific orders leading to the requested withholding of treatment and with factors associated with such orders. For example, dementia patients in the US with do-not-hospitalize orders are less likely to be hospitalized (Lamberg et al. 2005).

Anticipating Problems in Dementia

Advance care-planning supposes consideration of possible future clinical scenarios. A number of problems are common in advanced dementia, and are worth anticipating because they are pertinent to decisions on whether or not to adopt aggressive treatments (Arcand and Caron 2005). One-third to two-thirds of dementia patients has pneumonia upon death (van der Steen et al. 2006); intake problems develop frequently with more severe dementia (Koopmans et al. 2007). Pertinent decisions include those on antibiotic treatment (none, oral or parenteral), tube feeding, intravenous fluids, and hospitalization. Parenteral fluids may provoke the need for restraints to prevent pulling out of an intravenous line or the need for hospitalization. Further, in many countries, cardiopulmonary resuscitation (CPR) is provided unless an order not to do so, a do-not-resuscitate (DNR) applies. CPR is generally considered futile in patients with severe dementia because the chance of success is extremely limited and, if patients survive, there is a high risk of remaining in a coma (Arcand and Caron 2005).

Standardized forms, to be completed by professional caregivers when discussing care may help by providing direction for discussions and by documenting preferences (see Volicer et al. 2002, for an example). Filling in the chart, regular updates and revisions whenever a proxy is uncomfortable are an element of adequate procedures.

Specific information available for families of patients with severe dementia which may also be helpful to others in considering care goals when drawing up a living will includes a decision aid on tube-feeding in dementia and a booklet which systematically goes through the relevant aspects of decision making (Mitchell et al. 2001) which is, unfortunately, only rarely provided by physicians (Graham et al. 2007). Further, a more comprehensive booklet for families addressing a variety of possible problems is currently available in English, French, Italian and Dutch (Arcand and Caron 2005), which may also help nurses in discussing end-of-life issues with families.

Also noteworthy in the planning ahead of dementia is a method of »peer education« developed in the UK whereby peers (other elderly people) discuss treatment and care options at the end of life between themselves (Seymour et al. 2006). Finally, there are some very accessible books which address end-of-life issues, including treatment decisions and advice for families on how to discuss sensitive end of life issues (Morris 2004ab).

Self-Management at the End of Life With Dementia: Family Caregiver Issues

Communication and Decision-Making with Family Caregivers

The recognition that prognosis is poor is important for adequate communication, realistic requests for treatment and planning for death (Emanuel and Emanuel 1998) and this applies to both professional and family caregivers if patients cannot be involved themselves. Proxy-planning should not be used as a substitute for ongoing discussions between proxies and members of the healthcare team (Volicer et al. 2002). Moreover, emotional preparation for future crises has been posited as more important than the fulfillment of directives by critics of advance directives (Perkins 2007). A central role for a physician or other professional caregiver responsible for coordination of patient care and guide families seems crucial (Miller et al. 2004; Shield et al. 2005; van der Steen et al. 2007).

Shared decision-making models involve decision makers (proxies and patients) as partners. Many publications show that physicians engage very little in shared decision-making, but to some degree they can learn to do so after educational interventions (Hanson 2008). New models may help physicians to guide families facing complex decisions by systematically outlining steps, beginning by determining at which point the patient or proxy is with the aim of providing guidance in creating a plan of care (Goldstein et al. 2008). Such models may also be helpful in addressing end-of-life care for dementia patients. The right timing in bringing up sensitive issues is an important element of communication with caregivers. Discussing competing global cross-disease outcomes can help clarify what is most important to elderly people faced with complex healthcare decisions (Fried et al. 2008). Enhanced information is important and may reduce decisional conflict, as found in older adults in a US study (Allen et al. 2008).

Grief and Bereavement

Palliative care includes attention to family needs up to the death of a patient with dementia. Being prepared for death and what to expect at the end of life is important for families; one study found that 23% felt they were not prepared and this group had more depression, anxiety and complicated grief symptoms (Herbert et al. 2006). Further, complicated grief was predicted by caregiver depression and burden pre-death in those who lived with the dementia patient (Schulz et al. 2006). Grief may be less pronounced for families of patients who resided in institutions or who died after many years of dementia, as pre-grief may have started much earlier (Kiely et al. 2008).

Conclusion

Because of the limited evidence of the effectiveness of palliative treatment in patients with dementia, it is not surprising that few guidelines or evidence-based quality indicators exist. Those which are available are based largely on expert consensus (e.g., Hadjistavropoulos et al. 2007; Holmes et al. 2008; Lloyd-Williams and Payne 2002; Lorentz et al. 2007; van der Steen et al. 2000). However, palliative care for dementia patients is advancing; many bottlenecks have been identified and the most recent research indicates that these are increasingly being addressed. New prospective observational studies (Mitchell et al. 2006; van der Steen et al. 2007a) and intervention studies will help set priorities to improve care, whether in medical treatment, nursing, psychosocial or spiritual fields.

In this chapter we have identified important issues with regard to self-management and dementia. Advance care-planning and the anticipation of problems are important in extending a patient's autonomy when he or she is no longer able to decide on treatment and care. Continuous communication by professional caregivers with proxies on the patient's preferences, condition, and best interest is needed to prepare for the end of life. It is hoped that the growing population with advanced dementia will benefit from timely advances in palliative care.

Acknowledgements

We thank Professor Ladislav Volicer, MD, PhD for his comments on an earlier version of the manuscript.

References

Ahronheim JC, Morrison RS, Baskin SA, Morris J, Meier DE (1996) Treatment of the dying in the acute care hospital. Advanced dementia and metastatic cancer. Arch Intern Med 156: 2094–2100

Ahronheim JC, Morrison RS, Morris J, Baskin S, Meier DE (2000) Palliative care in advanced dementia: a randomized controlled trial and descriptive analysis. J Palliat Med 3: 265–273

Allen RS, Allen JY, Hilgeman MM, Decoster J (2008) End-of-life decision-making, decisional conflict, and enhanced information: Race Effects. J Am Geriatr Soc 56: 1904–1909

Aminoff BZ, Adunsky A (2006) Their last 6 months: suffering and survival of end-stage dementia patients. Age Ageing 35: 597–601

Arcand M, Caron C (2005) Comfort care at the end of life for persons with Alzheimer's disease or other degenerative diseases of the brain. Centre de Sante et de Services Sociaux – Institut Uiversitair de Geriatrie de Sherbrooke, Canada, Sherbrooke (also available in French, Italian, and Dutch)

Baumgarten M, Margolis DJ, Localio AR, Kagan SH, Lowe RA, Kinosian B, Holmes JH, Abbuhl SB, Kavesh W, Ruffin A (2006) Pressure ulcers among elderly patients early in the hospital stay. J Gerontol A Biol Sci Med Sci 61: 749–754

Birch D, Draper J (2008) A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia. J Clin Nurs 17: 1144–1163

Bjoro K, Herr K (2008) Assessment of pain in the nonverbal or cognitively impaired older adult. Clin Geriatr Med 24: 237–262

Boockvar KS, Gruber-Baldini AL, Burton L, Zimmerman S, May C, Magaziner J (2005) Outcomes of infection in nursing home residents with and without early hospital transfer. J Am Geriatr Soc 53: 590–596

Brod M, Stewart AL, Sands L, Walton P (1999) Conceptualization and measurement of quality of life in dementia: the dementia quality of life instrument (DQoL). Gerontologist 39: 25–35

Buffum MD, Sands L, Miaskowski C, Brod M, Washburn A (2004) A clinical trial of the effectiveness of regularly scheduled versus as-needed administration of acetaminophen in the management of discomfort in older adults with dementia. J Am Geriatr Soc 52: 1093–1097

Casarett D, Karlawish J, Morales K, Crowley R, Mirsch T, Asch DA (2005) Improving the use of hospice services in nursing homes: a randomized controlled trial. JAMA 294: 211–217

Daaleman TP, Usher BM, Williams SW, Rawlings J, Hanson LC (2008) An exploratory study of spiritual care at the end of life. Ann Fam Med 6: 406–411

D'Agata E, Mitchell SL (2008) Patterns of antimicrobial use among nursing home residents with advanced dementia. Arch Intern Med 168: 357–362

Davies E, Higginson IJ (2004) Better palliative care for older people. World Health Organization (WHO), Geneva

Di Giulio P, Toscani F, Villani D, Brunelli C, Gentile S, Spadin P (2008) Dying with advanced dementia in long-term care geriatric institutions: a retrospective study. J Palliat Med 11: 1023–1028

Ditto PH, Smucker WD, Danks JH, Jacobson JA, Houts RM, Fagerlin A, Coppola KM, Gready RM (2003) Stability of older adults' preferences for life-sustaining medical treatment. Health Psychol 22: 605–615

Emanuel EJ, Emanuel LL (1998) The promise of a good death. Lancet 351 (Suppl 2): SII21-29

Fried TR, McGraw S, Agostini JV, Tinetti ME (2008) Views of older persons with multiple morbidities on competing outcomes and clinical decision-making. J Am Geriatr Soc 56: 1839–1844

Fuchs-Lacelle S, Hadjistavropoulos T, Lix L (2008) Pain assessment as intervention: a study of older adults with severe dementia. Clin J Pain 24: 697–707

Gessert CE, Haller IV, Kane RL, Degenholtz H (2006) Rural-urban differences in medical care for nursing home residents with severe dementia at the end of life. J Am Geriatr Soc 54: 1199–1205

Gillick MR (2000) Rethinking the role of tube feeding in patients with advanced dementia. N Engl J Med 342: 206–210

Gillick MR (2004) Advance care planning. N Engl J Med 350: 7–8

Goldstein NE, Back AL, Morrison RS (2008) Titrating guidance: a model to guide physicians in assisting patients and family members who are facing complex decisions. Arch Intern Med 168: 1733–1739

Graham ID, Logan J, Bennett CL, Presseau J, O'Connor AM, Mitchell SL, Tetroe JM, Cranney A, Hebert P, Aaron SD (2007) Physicians' intentions and use of three patient decision aids. BMC Med Inform Decis Mak 7: 20

Hadjistavropoulos T, Herr K, Turk DC, et al. (2007) An interdisciplinary expert consensus statement on assessment of pain in older persons. Clin J Pain 23 (1 Suppl): S1–43

Hanson JL (2008) Shared decision making: have we missed the obvious? Arch Intern Med 168: 1368–1370

Hebert RS, Dang Q, Schulz R (2006) Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: findings from the REACH study. J Palliat Med 9: 683–693

Hewitt M, Simone JV (1999) Ensuring quality cancer care. National Academies Press, Washington DC

Holmes HM, Sachs GA, Shega JW, Hougham GW, Cox Hayley D, Dale W (2008) Integrating palliative medicine into the care of persons with advanced dementia: identifying appropriate medication use. J Am Geriatr Soc 56: 1306–1311

Hughes JC, Robinson L, Volicer L (2005) Specialist palliative care in dementia. BMJ 330: 57–58

Jox RJ, Krebs M, Bickhardt J, Hessdörfer K, Roller S, Borasio GD (2008) How strictly should advance decisions be followed? The patients' opinion. Palliat Med 22: 675–676

Kalisvaart KJ, Vreeswijk R, de Jonghe JF, van der Ploeg T, van Gool WA, Eikelenboom P (2006) Risk factors and prediction of postoperative delirium in elderly hip-surgery patients: implementation and validation of a medical risk factor model. J Am Geriatr Soc 54: 817–822

Karel MJ, Moye J, Bank A, Azar AR (2007) Three methods of assessing values for advance care planning: comparing persons with and without dementia. J Aging Health 19: 123–151

Kiely DK, Prigerson H, Mitchell SL (2008) Health care proxy grief symptoms before the death of nursing home residents with advanced dementia. Am J Geriatr Psychiatry 16: 664–673

Koopmans RT, van der Molen M, Raats M, Ettema TP (2009) Neuropsychiatric symptoms and quality of life in patients in the final phase of dementia. Int J Geriatr Psychiatry 24: 25–32

Koopmans RT, van der Sterren KJ, van der Steen JT (2007) The »natural« endpoint of dementia: death from cachexia or dehydration following palliative care? Int J Geriatr Psychiatry 22: 350–355

Kruse RL, Mehr DR, Boles KE, Lave JR, Binder EF, Madsen R, D'Agostino RB (2004) Does hospitalization impact survival after lower respiratory infection in nursing home residents? Med Care 42: 860–870

Kunz M, Mylius V, Scharmann S, Schepelman K, Lautenbacher S (2009) Influence of dementia on multiple components of pain. Eur J Pain 13: 317–325

Lamberg JL, Person CJ, Kiely DK, Mitchell SL (2005) Decisions to hospitalize nursing home residents dying with advanced dementia. J Am Geriatr Soc 53: 1396–1401

Larson EB, Shadlen MF, Wang L, McCormick WC, Bowen JD, Teri L, Kukull WA (2004) Survival after initial diagnosis of Alzheimer disease. Ann Intern Med 140: 501–509

Lloyd-Williams M, Payne S (2002) Can multidisciplinary guidelines improve the palliation of symptoms in the terminal phase of dementia? Int J Palliat Nurs 8: 370–375

Loeb M, Carusone SC, Goeree R, Walter SD, Brazil K, Krueger P, Simor A, Moss L, Marrie T (2006) Effect of a clinical pathway to reduce hospitalizations in nursing home residents with pneumonia: a randomized controlled trial. JAMA 295: 2503–2510

Lorenz KA, Rosenfeld K, Wenger N (2007) Quality indicators for palliative and end-of-life care in vulnerable elders. J Am Geriatr Soc 55 (Suppl 2): S318–S326

Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM (2003) Patterns of functional decline at the end of life. JAMA 289: 2387–2392

Lynn J (2001) Perspectives on care at the close of life. Serving patients who may die soon and their families: the role of hospice and other services. JAMA 285: 925–932

McCarthy M, Addington-Hall J, Altmann D (1997) The experience of dying with dementia: a retrospective study. Int J Geriatr Psychiatry 12: 404–409

Menne HL, Whitlatch CJ (2007) Decision-making involvement of individuals with dementia. Gerontologist 47: 810–819

Miller SC, Kiely DK, Teno JM, Connor SR, Mitchell SL (2008) Hospice care for patients with dementia: does volume make a difference? J Pain Symptom Manage 35: 283–291

Miller SC, Teno JM, Mor V (2004) Hospice and palliative care in nursing homes. Clin Geriatr Med 20: 717–734

Mitchell SL, Kiely DK, Hamel MB (2004) Dying with advanced dementia in the nursing home. Arch Intern Med 164: 321–326

Mitchell SL, Kiely DK, Jones RN, Prigerson H, Volicer L, Teno JM (2006) Advanced dementia research in the nursing home: the CASCADE study. Alzheimer Dis Assoc Disord 20: 166–175

Mitchell SL, Kiely DK, Miller SC, Connor SR, Spence C, Teno JM (2007) Hospice care for patients with dementia. J Pain Symptom Manage 34: 7–16

Mitchell SL, Teno JM, Miller SC, Mor V (2005) A national study of the location of death for older persons with dementia. J Am Geriatr Soc 53: 299–305. Erratum in: J Am Geriatr Soc 53: 741

Mitchell SL, Tetroe J, O'Connor AM. A decision aid for long-term tube feeding in cognitively impaired older persons. J Am Geriatr Soc 49: 313–316

Molloy DW, Guyatt GH, Russo R et al (2000) Systematic implementation of an advance directive program in nursing homes: a randomized controlled trial. JAMA 283: 1437–1444

Morris JN, Fries BE, Mehr DR, Hawes C, Phillips C, Mor V, Lipsitz LA (1994) MDS Cognitive Performance Scale. J Gerontol 49: M174–182

Morris V (2004a) How to care for aging parents, 2nd edn. Workman Publishing, New York

Morris V (2004b) Talking about death. Algonquin Books of Chapel Hill, Chapel Hill, NC

Morrison RS, Meier DE (2003) Geriatric Palliative Care. Oxford University Press, New York

Morrison RS, Siu AL (2000a) Survival in end-stage dementia following acute illness. JAMA 284: 47–52

Morrison RS, Siu AL (2000b) A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture. J Pain Symptom Manage 19: 240–248

Munn JC, Hanson LC, Zimmerman S, Sloane PD, Mitchell CM (2006) Is hospice associated with improved end-of-life care in nursing homes and assisted living facilities? J Am Geriatr Soc 54: 490–495

Pautex S, Herrmann FR, Le Lous P, Ghedira M, Zulian GB, Michon A, Gold G (2007) Symptom relief in the last week of life: is dementia always a limiting factor? J Am Geriatr Soc 55: 1316–1317

Perkins HS (2007) Controlling death: the false promise of advance directives. Ann Intern Med 147: 51–57

Sampson EL, Ritchie CW, Lai R, Raven PW, Blanchard MR (2005) A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. Int Psychogeriatr 17: 31–40

Schulz R, Boerner K, Shear K, Zhang S, Gitlin LN (2006) Predictors of complicated grief among dementia caregivers: a prospective study of bereavement. Am J Geriatr Psychiatry 14: 650–658

Sepúlveda C, Marlin A, Yoshida T, Ullrich A (2002) Palliative Care: the World Health Organization's global perspective. J Pain Symptom Manage 24: 91–96

Seymour J, Sanders C, Clarke A, Welton M, Gott M (2006) Planning for choice in end-of-life care – educational guide. Help the Aged We Will, London

Shega JW, Hougham GW, Stocking CB, Cox-Hayley D, Sachs GA (2008) Patients dying with dementia: experience at the end of life and impact of hospice care. J Pain Symptom Manage 35: 499–507

Shield RR, Wetle T, Teno J, Miller SC, Welch L (2005) Physicians »missing in action«: family perspectives on physician and staffing problems in end-of-life care in the nursing home. J Am Geriatr Soc 53: 1651–1657

Sloane PD, Zimmerman S, Hanson L, Mitchell CM, Riedel-Leo C, Custis-Buie V (2003) End-of-life care in assisted living and related residential care settings: comparison with nursing homes. J Am Geriatr Soc 51: 1587–1594

Small N (2007) Living well until you die: quality of care and quality of life in palliative and dementia care. Ann N Y Acad Sci 1114: 194–203

Teno JM (2003) Advance care planning for frail, older persons. In: Morrison RS, Meier DE, Capello C (eds) Geriatric palliative care. Oxford University Press, New York, pp 307–313

Travis SS, Bernard M, Dixon S, McAuley WJ, Loving G, McClanahan L (2002) Obstacles to palliation and end-of-life care in a long-term care facility. Gerontologist 42: 342–349

van der Meulen A, Keij-Deerenberg I (2003) Sterfte aan dementie. Statistisch kwartaalblad over de demografie van Nederland (Statistics Netherlands; CBS) 51 (2) 24–28 http://www.cbs.nl/NR/rdonlyres/57D8293E-8EA9-4B53-B8C1-04DDEDFE1C00/0/2003k2b15p024art.pdf (in Dutch)

van der Steen JT, Gijsberts MJHE, Muller MT, Deliens L, Volicer L (2009a) Evaluations of end of life with dementia by families in Dutch and US nursing homes. Int Psychogeriatr (2009;21:321–329)

van der Steen JT, Kruse RL, Ooms ME, Ribbe MW, van der Wal G, Heintz LL, Mehr DR (2004) Treatment of nursing home residents with dementia and lower respiratory tract infection in the United States and The Netherlands: an ocean apart. J Am Geriatr Soc 52: 691–699

van der Steen JT, Mehr DR, Kruse RL, Ribbe MW, van der Wal G (2007c) Treatment strategy and risk of functional decline and mortality after nursing-home acquired lower respiratory tract infection: two prospective studies in residents with dementia. Int J Geriatr Psychiatry 22: 1013–1019

van der Steen JT, Mehr DR, Kruse RL, Sherman AK, Madsen RW, D'Agostino RB, Ooms ME, van der Wal G, Ribbe MW (2006) Predictors of mortality for lower respiratory infections in nursing home residents with dementia were validated transnationally. J Clin Epidemiol 59: 970–979

van der Steen JT, Mitchell SL, Frijters DH, Kruse RL, Ribbe MW (2007b) Prediction of 6-month mortality in nursing home residents with advanced dementia: validity of a risk score. J Am Med Dir Assoc 8: 464–468

van der Steen JT, Muller MT, Ooms ME, van der Wal G, Ribbe MW (2000) Decisions to treat or not to treat pneumonia in demented psychogeriatric nursing home patients: development of a guideline. J Med Ethics 26: 114–120

van der Steen JT, Pasman HRW, Ribbe MW, van der Wal G, Onwuteaka-Philipsen BD (2009b) Discomfort in dementia patients dying from pneumonia and its relief by antibiotics. Scand J Infect Dis (2009;41:143–151)

van der Steen JT, Ribbe MW (2007a) Dying with dementia: what do we know about it? Tijdschr Gerontol Geriatr 38: 288–297 (in Dutch)

Volicer L, Cantor MD, Derse AR, Edwards DM, Prudhomme AM, Gregory DC, Reagan JE, Tulsky JA, Fox E; National Ethics Committee Of The Veterans Health Administration (2002) Advance care planning by proxy for residents of long-term care facilities who lack decision-making capacity. J Am Geriatr Soc 50: 761–767

Volicer L, Rheaume Y, Brown J, Fabiszewski K, Brady R (1986) Hospice approach to the treatment of patients with advanced dementia of the Alzheimer type. JAMA 256: 2210–2213

Williams MM, Xiong C, Morris JC, Galvin JE (2006) Survival and mortality differences between dementia with Lewy bodies vs. Alzheimer disease. Neurology 67: 1935–1941

Wittink MN, Morales KH, Meoni LA, Ford DE, Wang NY, Klag MJ, Gallo JJ (2008) Stability of preferences for end-of-life treatment after 3 years of follow-up: the Johns Hopkins Precursors Study. Arch Intern Med 168: 2125–2130

Wolf-Klein G, Pekmezaris R, Chin L, Weiner J (2007) Conceptualizing Alzheimer's disease as a terminal medical illness. Am J Hosp Palliat Care 24: 77–82

World Health Organization (2002) National cancer control programmes: policies and managerial guidelines. 2nd ed. Geneva: World Health Organization. http://www.who.int/cancer/palliative/definition/en/

Zimmermann C, Riechelmann R, Krzyzanowska M, Rodin G, Tannock I (2008) Effectiveness of specialized palliative care: a systematic review. JAMA 299: 1698–1709

Zwakhalen SM, Hamers JP, Abu-Saad HH, Berger MP (2006) Pain in elderly people with severe dementia: a systematic review of behavioural pain assessment tools. BMC Geriatr 6: 3

Zwakhalen SM, Koopmans RT, Geels PJ, Berger MP, Hamers JP (2009) The prevalence of pain in nursing home residents with dementia measured using an observational pain scale. Eur J Pain 13: 89–93

Self-Management of Caregivers

Yung-Jen Yang, Marja Saarenheimo, Ulla Eloniemi-Sulkava, Kaisu Pitkälä

10.1 Self-Management Approaches of Caregivers in Dementia-Caring

Yung-Jen Yang

Roles of Caregivers and the Needs of the Patients with Dementia

Under every circumstance, the caregiver is an indispensable part in dementia caring. Only if there are sound caregivers, could they create suitable environment and provide good quality of life for the patients with dementia. Caregivers also play important roles in dementia caring throughout the whole disease course, and the roles may include child/spouse, friend, secretary, life assistant, nurse, attorney at law, and even parent. What makes the condition worse is that the roles may be interchangeable at times or even get mixed up at some moment. Just as the multiple roles for a given caregiver in facing the patient with dementia, the relationships and the caring strategies as well as approaches may differ in accordance with the roles (de Geest 2003). Most of the time, caregivers are the only persons facing the patients with dementia and the supportive resources are not always at hand. Good awareness of the roles at a given moment and then mature self-management approaches lead to successful dementia caring (Cohen-Mansfield 2006).

Roughly speaking, according to their background and the modes of care, caregivers can be divided into home caregivers and professional caregivers. From the long-term care perspectives, both the home caregivers and the professional carers are complemented and are equally important to the patients with dementia. For example, at the mild stage of dementia, as the patients with dementia reside at home, the home caregivers take over most of the caring activities, and then professional caregivers take over when the disease progressed into advanced stage (Mahoney 2003). No matter from where the caregiver comes, the ultimate goals and missions of a willing caregiver are thought to base on altruism by supporting the patients with dementia and providing high quality of care as possible.

From the need-contentment theory we learned, that all behaviors are propagated by the needs, and caring behaviors are no exception. In the management of dementia, the needs of both the patients with dementia and their caregivers are the key determinants to the caring behaviors. The needs of patients with dementia may change as the cognitive function and competency deteriorates, so will the roles and the approaches to care of caregivers change to meet the needs of the patients. For example, at the initial stage of dementia, the patients with dementia retain relatively good cognitive function. Because they could still perform most activities of daily living, the need for supporting basic living is low but they usually demand to preserve their autonomy in most life activities and decision-making. Thus the roles most caregivers serving for are facilitators to appropriate decision-making as consultant or assistants. However, as the cognitive deficits become more prominent, the caregivers could no longer carry out the roles they used to, and they usually have to be more dominant and involved in the life of the patients with dementia. In this rationale, the needs of the caregivers are also determined by their roles and, originally, the needs of the patient with dementia. There are many studies discussing the competition and the dynamics of the needs from both sides, but no definite conclusion of practice is available so far (Koffman et al. 1997; van der Roest et al. 2007). The final outward caring behaviors of the caregivers are mainly driven by the consequences of the dynamically balanced needs from both sides (Kovach et al. 2005; Davies 2006).

Needs of Caregivers: Propagations and Limits

The motivation of altruistic behavior like dementia caring of caregivers is modulated from both sides: the propagations and limits. As mentioned in the above paragraph, the behavior is driven by needs that caregivers perceived. However, the needs to take care of the patients are influenced by multi-level factors. First, from the individual level, there are some psychological components, including the self-contentment and fulfillment in helping the disadvantageous others out of the nature in our humanity. Second, concerning the family, it is commonly regarded as a commitment or a plight to take care of a spouse or an elder in the inborn relationships in a family. In many cultures, there have been expectations that remind every member in the family to take care of other family member who is in his or her disadvantageous status or illness. Finally, in society level, it is a common social norm to respect and help the elderly people, letting alone when they are ill. In some societies, the social norms even become public opinions and pressure on the individuals to take care of the family members without any cause and with all dedications.

On the contrary, there are also hurdles for caregivers in caring for the patients with dementia (Aneshensel 1993). On individual level, changing values such as newer ageism and negative attitude toward dementia are frequently observed. The family decreases the support as the family structure changed after the society became industrialized and modernized. For example, there are more and more core families in south-east Asia such as China, Korea, Singapore and Taiwan, where the supportive resources from other family members are reduced. In society level, the increased social-welfare coverage, such as the widespread long-term care facilities, may also deprive the caregivers of their motivation and subjective necessity to care for the demented patients in the community (Dening 1998). In summary, in promoting self-management of dementia-caring, the needs of the caregivers have to be taken seriously to enhance the motivation.

General Principles

For both patients with dementia and their caregivers, the benefits of self-management in dementia-caring include promoting healthier lifestyle, improving health status, lowering the demands on healthcare system and cost, and increasing self-confidence. Those benefits have been well discussed in other chapters in this book. Whatever self-management will be applied for dementia care, the ultimate goals are to slow the rate of deterioration and extend the time for final institutionalization for as long as possible. Either home family caregiver or professional caregivers, before starting the approaches, they all have to understand the illness condition of the patients they will take care. Then they have to manage and adjust their roles appropriately, identify and evaluate the needs of the patients and themselves. Finally, the caregivers have to integrate the available resources and then execute the caring.

But now the questions raise, what and how will self-management be carried out in real life? According to Markwick et al. (2002), self-management consists of several key components:

- Being aware of his/her condition.
- Being able to follow a treatment and care plan agreed with the health professionals.
- Actively sharing in decision-making with health professionals.
- Monitor and manage signs and symptoms of his/her condition.
- Managing the impact of the condition on his/her physical, emotional and social life.
- Adopting lifestyles that promote health.

▪ Figure 10.1 shows the core frame of self-management. From Markwick's concepts, we could realize that insight, awareness, and understanding of the condition are the first steps in self-management. However, not all caregivers have the capability to understand their situation, and nor do they fully know what and how they could deal with the difficulties. No matter the caregivers understand the condition, the health professionals are responsible to initiate and instill the concept of self-management in dementia care for the caregivers.

The Initiation of Self-Management for Dementia Caring

As mentioned above, the health professionals have the obligations to initiate self-management for the caregivers themselves. In our opinions, once the patients are diagnosed as dementia, it is the appropriate point for the treatment team to initiate and facilitate the self-management in dementia caring (Carpentier 2005; Zarit 2008). At the beginning of initiating for self-management, the treatment team

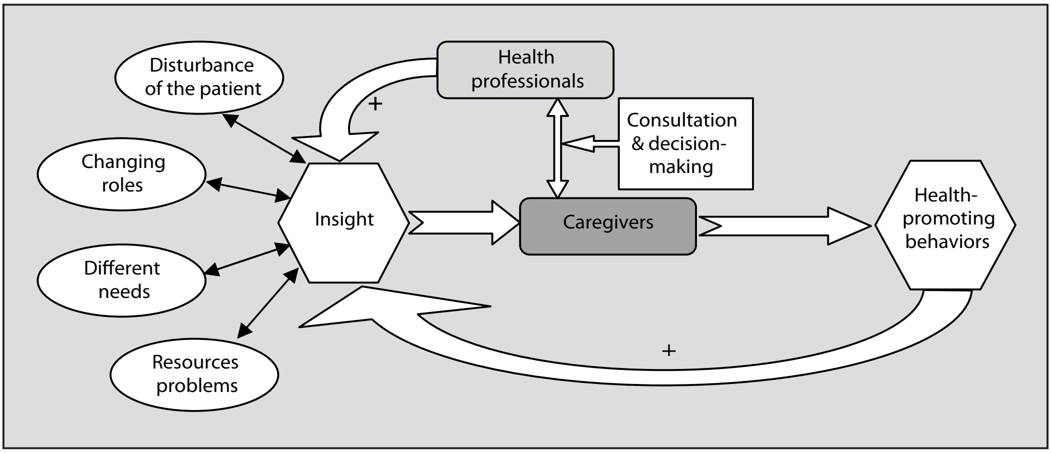


Fig. 10.1. Scheme of self-management for caregivers

should do the following recommendations in the ensuing contacts:

- Explain the types of dementia the patients are diagnosed, and make it as thorough as possible, including the treatment philosophy, available medications, disease course and stages, outcomes and prognosis.
- Assess the cognitive function and competence for the life activities, especially focusing on the influence of upcoming cognitive decline concerning the legal rights and relevant ethical issues.
- Explore the needs of the patients with dementia and of their caregivers, respectively, and respect their attitude about the future.
- Evaluate and introduce the available caring resources and the models of long-term care.
- Educate the self-management skills.
- Integrate the above information and facilitate the consensus in facing the illness.

Self-Management Approaches Across the Stages of Dementia

To achieve a successful self-management of dementia care, literatures show that education is an extremely important contributing factor (Hepburn 2001; Mundt 2001). The aims of education are to empower the caregivers with the capability to cope with any task in dementia-caring through stepwise thinking processes. With mastering the processes, the caregivers are enabled to solve the difficulties in their caring process spontaneously and efficiently. The education should be provided, reminded, discussed and integrated whenever possible in clinical practice. The proposed self-management skills to be instructed are the following:

- Awareness of the symptoms and possible tasks in each stage of dementia.
- Identifying and eliciting the problems in dementia-caring.
- Capability to weigh the influence in the caring activities.
- Familiarizing the available resources and then utilizing them appropriately and efficiently.
- Re-inspecting the effects of the skills used for management.
- Recording and sharing with others as means for positive feedback and self-gratification.

Self-management of dementia-caring for caregivers could be applied according to the stages of the demented patients because there are different clinical manifestations and needs in each stage of dementia. The clinical features of each stage are well disclosed in ► chapter 4 in this book and will not be reiterated again here. The authors conceptualize a specific model to approach the tasks at each stage. We suggest two necessary aspects to manage dementia in addition to the conventional bio-psycho-social 3-axial model, and these axes are biological, psychological, social, legal, and spiritual (Stolley 1999). Within each stage, some health-promoting activities are proposed and recommended. The authors believe that this model of approaches is clinically practical and could provide broader coverage of the needs of the patients.

Approaches at the Mild stage of Dementia

Most cognitive functions as well as the activities of daily living are preserved at the mild stage of dementia. However, the patients with dementia may be aware of the deteriorations in cognitive performance and the difficulties in decision-making. As a result, the patients are especially susceptive to experienced emotional distress and demoralization from the emerging problems and from the uncertain future. At this stage, the main goals of management are respecting the dignity of the patients, preventing demoralization, enhancing the awareness and insight about the illness, and establishing trustful relationships with the caregivers and the therapists. The following recommendations are useful to the caregivers:

- Biological: Make efforts to enhance the activities for health promotion and prevent disease progression, including maintaining existent healthy behaviors, close monitoring the health status, and taking prescribed medication appropriately to the instructions.
- Psychological: The priorities at this stage for the caregivers are to protect the dignity and self-esteem of the patients, to reassure, accept and instill hope for the upcoming deteriorations, to facilitate capability for problem-solving and decision-making, to form strong alliance and develop trust between them, and to promote self-gratification from the positive events in caring and daily living.
- Social: It is the starting and crucial point for the caregivers to establish the resources for caring in the community at this stage. The caregivers should seek contact with the formal supportive networks, such as the local Alzheimer's Associations, social welfare authorities, and other supportive groups. The caregivers also ought to tie up available informal supportive resources in the community, such as the neighbors, volunteer service groups, and some community charity service teams.
- Legal: Throughout the disease course of dementia, it is the most appropriate chance to achieve the legally related issues while respecting and involving the true intentions and decisions of the patients'. Upon being diagnosed of dementia, the caregivers should discuss with the patients about possible legal issues in the future, such as the succession of heritage, the assignment of deputies or proxies, and even living wills.
- Spiritual: Although more commonly applied in end-life care, the concept of pastoral care and hospice may be illustrated at the beginning of management and provided as alternatives for the patients and their caregivers to select. Due to its unique nature, religion could be the key and solution to some unanswerable questions. For instance, in some anxious patients and caregivers with prominent uncertainty or fear of facing dementia, the aids from the clergy may sometimes provide the dramatically synergic effects to the routine treatments. Some empirical experiences imply that the involvement of religious activities in addition to the conventional caring contributes to better quality of life for the demented patients and the caregivers who are devout for their religions (Tompkins 2008). At mild stage of dementia, enhancement of spiritual care aims to pave the ways for future hospice or pastoral care in the end-life (Everett 1999).

Approaches at the Moderate Stage of Dementia

The cognitive deterioration is more obvious and become influential to every domain of daily life activities. At this stage, behavioral and psychological symptoms of dementia (BPSD) deserve most active and aggressive intervention for its exhausting effect for caregiver burden. The risks for dangerous behaviors as a result of inappropriate judgment and cognitive deficits are highest for the patients, and the temporary goals for treatment mainly remain on the prevention of possible harms to the patients and amelioration of the caregiver burden.

- Biological: The prescriptions of medication, especially the psychotropic agents, increase significantly if BPSD intensifies, and, hence, the risk for unfavorable medical complications increases. As the competence to manage the medication by themselves is decreased, increased supervision and better packaging of the medication for the demented patients are necessary.
- Psychological: Due to BPSD, the psychiatric symptoms become florid, and can cause heavier burden to the caregiver in addition to the routine caring activities. The caregivers should learn the common knowledge of BPSD, and try to apply non-pharmacological skills to the troublesome behaviors or psychiatric symptoms.
- Social: At times, because BPSD could not be relieved by the caregivers alone, the caregivers should be trained to take good advantages of the supportive resources in the community. Other modes of care could be considered, including day hospitals, day care, group home, respite care and even admission to psychiatric acute ward. The caregivers should also be encouraged to join in the supportive group or some experience-sharing meetings to learn alternative caring skills and receive mutual encouragement to reduced loneliness and burnout.
- Legal: Some BPSD behaviors do cause legal problems, such as shoplifting, excessive spending of money, violence, assaults or crimes due to delusions, impaired judgment and inappropriate cognition. For caregivers in such situations, adjudication of disfranchisement or other measures to compromise the basic human rights may be considered.
- Spiritual: In some extreme cases, as shown in the literatures, attendance to religious activities such as chanting hymns or praying may reduce physically aimless aggression of the patient with BPSD. Spiritual care and religious activities should be continued if the patients was used to routine religious activities beforehand. For caregivers, attendance to the religious activities may also be beneficial because the activities or ceremonies may provide philosophical explanations for their suffering on the cognitive perspective.

Approaches at the Advanced Stage of Dementia

As the disease progressed into advanced stage, most meaningful cognitive functions, disturbing BPSD and the capability to manage the activities of the daily life are diminished. The patients may be fragile, bedridden, or even live on life-supportive equipments. The main goals of caring may only be reducing possible medical complications and sustaining life. Most caring activities are transferred to, or only possible with increased support from professional caregivers.

- Biological: Closely observe the vital signs and make all efforts to prevent infection, pressure sores, contracture of the limbs, and other medical complications.
- Psychological: Even in the advanced stage of dementia, some non-pharmacological interventions are proved to be effective in reducing aggression of severely demented patients. It is ideal for the caregivers to continue non-pharmacological interventions into the advanced stage of dementia.
- Social: The costs of end-life care are expensive, and the caregivers should re-assess and integrate the available resources for long-term caring.
- Legal: At this stage, the patients are no longer able to express their needs or make any effective decisions. If not done at previous appropriate stages, conflicts or lawsuits over the assets are quite common. If possible, the related obliges should make consensus through appropriate legal procedures to let the issue done fairly. Although there have been advocates for euthanasia for advanced dementia, there is still no definitive conclusion or recommendation in terms of this issue.
- Spiritual: The importance of spiritual care is especially highlighted at the advanced stage of dementia. For caregivers at this stage, it is

a common question »what is the meaning of life near the end of life«. Although the answers are multi-perspective, the spiritual approaches may open the window for everyone. The concepts of hospice, palliative care and pastoral care have been discussed in medical literature and are convinced to maintain or even improve the overall quality of life for everybody. Spiritual care may reduce the demoralization, regain the motivation for continuous care, and instill hope for the future in end-life care of dementia (O'Gorman 2002).

Preventive Approaches for Psychiatric Illness of Caregivers

Numerous evidences have indicated that caregivers of demented patients could be influenced by their surrounding conditions on their life via psychological distresses (Victoroff 1998; Beeson 2000; Edwards 2002; Martin 2006). In this way, they bear higher risk for psychiatric illness throughout the disease course, (O'Rourke 2007) and sometimes even persisted after the patients' death (Tweedy 2007). Among these mental illnesses, depressive disorders are most prevalent and influential (Brodaty 1998). In the self-management model of caregivers themselves, the caregivers should be instructed and empowered with the capability to identify the depressive symptoms and the ways to cope with them.

The caregivers should be familiar with the early signs and symptoms of depression:

- Depressive mood, including subjectively »feeling blue« or »feeling down«.
- Loss of interests for pleasure or motivation for favorite activities.
- Changes of body weight or appetite.
- Sleep disturbances.
- Increased irritability, hot tempers, or easy tearfulness.
- Negative thinking, feelings of guilt, hopelessness, worthlessness and helplessness.
- Death wishes, suicidal ideations or even suicidal attempts.
- Increased physical discomforts, either subjectively or objectively.

Whenever the caregivers experienced the above symptoms or signs, they should be encouraged for seeking supports from supportive group, local mental health agents, or direct psychiatric consultation.

Conclusion

In the war of combating dementia, both patients with dementia and their caregivers are all warriors facing challenges without limits. Self-management of dementia-caring is their basic but most effective weapon and becomes the best protective body armors at the same time. Only when the concepts of self-management of dementia care are widely applied and incorporated into the caring strategies for every dementia caregiver, can the patients with dementia receive good quality of care and life.

References

Aneshensel CS, Pearlin LI, Schuler RH (1993) Stress, role captivity, and the cessation of caregiving. J Health Soc Behav 34: 54–70

Beeson R, Horton-Deutsch S, Farran C, Neundorfer M (2000) Loneliness and depression in caregivers of persons with Alzheimer's disease or related disorders. Issues Ment Health Nurs 21: 779–806

Brodaty H, Luscombe G (1998) Psychological morbidity in caregivers is associated with depression in patients with dementia. Alzheimer Dis Assoc Disord 12: 62–70

Carpentier N, Ducharme F (2005) Support network transformations in the first stages of the caregiver's career. Q Health Res 15: 289–311

Cohen CA, Colantonio A et al. (2002) Positive aspects of caregiving: rounding out the caregiver experience. Int J Geriatr Psychiatry 17: 184–188

Cohen-Mansfield J, Parpura-Gill A, Golander H (2006) Salience of self-identity roles in persons with dementia: differences in perceptions among elderly persons, family members and caregivers. Soc Sci Med 62: 745–757

Davies S, Nolan M (2006) ‚Making it better': self-perceived roles of family caregivers of older people living in care homes: a qualitative study. Int J Nurs Studies 43: 281–291

de Geest G (2003) The relation between the perceived role of family and the behavior of the person with dementia. Am J Alzheimer's Dis Other Dementias 18: 181–187

Dening T, Lawton C (1998) The role of carers in evaluating mental health services for older people. Int J Geriatr Psychiatry 13: 863–870

Edwards AB, Zarit SH, Stephens MA, Townsend A (2002) Employed family caregivers of cognitively impaired elderly:

an examination of role strain and depressive symptoms. Aging & Mental Health 6: 55–61

Everett D (1999) Forget me not: the spiritual care of people with Alzheimer's Disease. J Health Care Chaplaincy 8: 77–88

Hepburn KW, Tornatore J, Center B, Ostwald SW (2001) Dementia family caregiver training: affecting beliefs about caregiving and caregiver outcomes. J Am Geriatr Soc 49: 450–457

Koffman J, Taylor S (1997) The needs of caregivers. Elderly Care 9: 16–19

Kovach CR, Noonan PE, Schlidt AM, Wells T (2005) A model of consequences of need-driven, dementia-compromised behavior. J Nurs Scholarship 37: 134–140

Mahoney DF (2003) Vigilance. Evolution and definition for caregivers of family members with Alzheimer's disease. J Gerontol Nurs 29: 24–30

Markwick M, Reece M, Battersby MW (2002) Chronic disease self-management education in indigenous settings. Sharing Health Care Initiatives – Early Wins Workshop, Hobart, Commonwealth Department of Health & Ageing

Markwick M, Reece M, Battersby MW (2002) Chronic disease self-management in indigenous communities. Early Wins Conference, Tasmania

Markwick M, Reece M, Battersby MW (2002) The development and implementation of a generic assessment tool in chronic disease self-management. Health Outcomes 2002: Current Challenges and Future Frontiers, Canberra

Martin Y, Gilbert P, McEwan K, Irons C (2006) The relation of entrapment, shame and guilt to depression, in carers of people with dementia. Aging & Mental Health 10: 101–106

Mundt JC, Kaplan DA, Greist JH (2001) Meeting the need for public education about dementia. Alzheimer Dis Assoc Disord 15: 26–30

O'Gorman ML (2002) Spiritual care at the end of life. Crit Care Nurs Clin N Am 14: 171–176

O'Rourke N, Cappeliez P, Neufeld E (2007) Recurrent depressive symptomatology and physical health: a 10-year study of informal caregivers of persons with dementia. Can J Psychiatry 52: 434–441

Stolley JM, Koenig H, Buckwalter KC (1999) Pastoral care for the person with dementia. J Health Care Chaplaincy 8: 7–23

Tompkins C, Sorrell JM (2008) Older adults with Alzheimer's disease in a faith community. J of Psychosoc Nurs Mental Health Services 46: 22–25

Tweedy MP, Guarnaccia CA (2007) Change in depression of spousal caregivers of dementia patients following patient's death. Omega-J Death Dying 56: 217–228

van der Roest HG, Meiland FJ, Maroccini R et al. (2007) Subjective needs of people with dementia: a review of the literature. Int Psychogeriatr 19: 559–592

Victoroff J, Mack WJ, Nielson KA (1998) Psychiatric complications of dementia: impact on caregivers. Dement Geriatr Cogn Disord 9: 50–55

Zarit S, Femia E (2008) Behavioral and psychosocial interventions for family caregivers. Am J Nurs 108 (Suppl): 47–53

10.2 Enhancing Empowerment and Self-Management in Elderly Families with Dementia

Marja Saarenheimo, Ulla Eloniemi-Sulkava, Kaisu Pitkälä

Introduction

In the case of Alzheimer's disease the concept of self-management introduces new challenge to social and health services: patients and their caregivers are seen as collaborative partners with professionals (Bodenheimer et al. 2002). Within this approach, the role of healthcare professionals remains to support Alzheimer families to live the best possible quality of life with this chronic condition. Patients and their caregivers are seen as experts of their own life, and they are expected to take an active agency regarding their health and illness. Supporting self-management differs from traditional knowledge-based patient education (Coleman and Newton 2005). With Alzheimer families it includes dimensions such as helping patients and their caregivers to identify their problems, developing their own problem-solving skills, and improving their self-efficacy to master their every-day life.

In medical literature self-management is often discussed with concepts such as patient's empowerment, self-efficacy and mastery, coping with illness, and motivation (Gonzales et al. 1990; Bodenheimer et al. 2002; Lorig and Holman 2003). In the case of Alzheimer's disease and other memory disorders, self-management and its related concepts are frequently as much of a concern of the family caregiver and other close family members as of the patient him/herself. The demands for information, advice and emotional support are often shared by the family members but in some cases the needs of the family caregiver may be contradictory to that of the patient. Whatever the case, the needs for information are deeply intertwined. Thus, they pose a distinct and demanding challenge to the professionals working with these families.

The main aim of this chapter is to analyse the complicated issues related to self-management in elderly spousal caregivers. We conducted an extensive study on family care of demented persons in Finland including qualitative analyses of observation and interviews as well as a randomized, controlled intervention trial. The study was conducted in 2003–2006 by the Central Union for the Welfare of the Aged. We will reflect the findings of our studies related to self-management and, as well, provide some examples of successful support of self-management.

Concepts Related to Self-Management and How They Affect Care-giving Families

Empowerment and Its Relationship to Self-Management in the Elderly

The World Health Organizations Health Promotion Glossary (1998; see also Rappaport 1984) defines empowerment as a social, cultural and psychological process through which individuals and groups will be able to express their needs and gain control over decisions and actions that influence their health. Taking empowerment as a starting point to health promotion has been justified with ideological (Rappaport 1984) as well as economical (Levin-Zamir et al. 1991) and practical arguments (Bodenheimer et al. 2002).

In his article »*The Philosophical Foundations of Empowerment*« P.G. Clark (1989) presented four interpretations of empowerment regarding older persons and their healthcare:

1. Empowerment as effective deliberation and moral reflection
2. Empowerment as personal process (identifying personal resources)
3. Empowerment as political action and social process
4. Empowerment as balance and interdependence

It has been argued that understanding empowerment solely as a personal process or as a cluster of personal strengths is too simplifying as empowerment should lead to collective action and collective efforts to influence and control important issues concerning large groups of people. The preconditions for individual's empowerment include societal and social resources that facilitate autonomy and free choice (McCall et al. 2001). Clark (1989) argued that it is a kind of mockery to even speak about empowerment in the presence of conditions that do not allow elderly people to exercise autonomy.

The concepts of empowerment and self-management are at least partly overlapping, since empowerment can be conceptualized as a prerequisite to self-management. As a personal process, empowerment has been defined as a »process of recognizing, promoting and enhancing people's ability to meet their own needs, solve their own problems and mobilize necessary resources in order to feel in control of their own lives« (Gibson 1991). Empowerment thus requires a continuous dialog between the individuals and the service providers. However, Clark (1989) argued that an oversimplified focus on personal autonomy ignores and even detracts elderly people's needs to be connected with others in a meaningful web of interdependence.

In the following parts, we will look at the role of self-management in the everyday lives of dementia families. First, we will very shortly present relevant literature concerning the strategies that family caregivers generally use in their efforts to master the care-giving situation. Secondly, we present findings from our own study where elderly care-giving couples were visited and interviewed in their homes in order to understand their everyday reasoning and activities from inside.

Coping with the Illness of the Spouse: How to Manage Everyday Care-giving

Caregivers' Strategies to Master Everyday Living. Based on a large body of coping literature originating in Lazarus's and Folkman's seminal work, successful coping is essentially mediated by the person's cognitive appraisal of the current situation and of her/his own capacity to respond to the potential challenges of the situation (Lazarus and Folkman 1984). Moreover, it is assumed that not being able to make sense of the situation typically prevents mastery and meaningful action (Antonovsky 1979). There can be several factors in the care-giving situation that produce or enhance feelings of powerlessness in the family caregiver of a demented person. The illness of the spouse may itself evoke confusion and fear in the care-giving partner. On the other hand, the complicated nature of the service system often makes it difficult for the caregiver to develop trust, confidence and optimism towards the future.

The literature on family care has pointed to the importance of resilience as a means of dealing successfully with the demands of care-giving. Resilience has been defined as an individual's ability to withstand and rebound from crisis and adversity (Walsh 1996). From the perspective of family care-giving, however, it is not only the individual's resilience but also the relational resilience of the family as a functional unit that is of importance. Cohesion, flexibility, open communication, problem solving, and affirming belief systems have been proposed as the core elements of family resilience (Walsh 1996).

Qualitative methodology has offered useful tools for looking at the coping strategies of family carers in a detailed manner. Steven Albert (1990) was one of those, who conducted thematic interviews with adult children caring for their disabled parents at home. According to Albert's study, one of the most common strategies in easing the family's care situation was setting limits in the obligation to render care. This was often done through establishing distinct routines for care-giving tasks and thus defining the rest of the day as »non-care-giving time«. Many interviewees even seemed to measure their mastery of the situation by the routines they had established. Although the routines mostly serve as an adaptive strategy, Albert argues that if transformed into ceremony or ritual, they have a tendency to take on a life of their own. Such rituals can be as disruptive as caring tasks themselves.

In our data, the caregivers often described their everyday life with the demented partner as monotonous or even boring. On the other hand, the sameness of the days and weeks produced safety. From this perspective, sticking to routines was a way to protect the continuity of the family life. Many interviewees had given up their own hobbies and social contacts. Looking after the routines and paying constant attention to the demented spouse was experienced as a full time job that took all the strength of the carer. Routines were thus adaptive for the family as a unit but not always for the caregiver as an individual.

Another adaptive strategy in Albert's study was redefining the parent–child roles. Especially if the parent had a memory disease, the adult children often described the current situation as a kind of role reversal in which the parents became »children of their own children«. Some carers addressed that they cared for their parent as a patient or as a stranger. In a similar way, the spousal caregivers of our study sometimes redefined their demented partners as their children or as strangers, for example, in order to alleviate their own feelings of loneliness or abandonment followed by the transformation of their spouse.

Positive Attitude to One's Own Life Situation. Since the 1980's, the literature on family care-giving has largely focused on the burden of care with its many negative consequences for the caregiver, such as chronic fatigue, depression, psychological stress (Neundorfer 1991; Brodaty et al. 1993; Schulz et al. 1995; Vernooij-Dassen et al. 1997; Meiland et al. 2001; Toseland et al. 2001), and a heightened vulnerability to physical illnesses (Vitaliano et al. 2003). However, during the last two decades the meaning and function of positive attributions of care-giving has been recognized (Cohen et al. 1994; Farran 1997; Kramer 1997). From the perspective of self-management, it is important to explore which aspects of care-giving are experienced as rewarding by the caregivers, what kind of resources the families have and what type of coping strategies the caregivers use (Lundh and Nolan 2003).

In our data, being able to find even minor positive aspects in the care situation was experienced by the caregivers as alleviating the burden and as a means to strengthen the caregivers' self-efficacy. For many interviewees, positive thinking was more or less conscious strategy:

> You just can't keep telling yourself how miserable you are or how hopeless this is. All the time I've been having this feeling (..) that everything is precisely as it should be. /// I've never let myself to consider that some day this will end …

For this female caregiver, the caring situation had been going on for several years, and she crystallized her positive attitude to an idea that »everything is precisely as it should be«. This type of acceptance was typical for the caregivers who seemed to have adapted well to their role as a caregiver. When the current life situation is defined as »precisely as it should be«, there is no room for bitterness which usually originates in the negative comparison between the real and ideal.

In addition to acceptance, other aspects of positive attitude included the use of humour and taking life one day at a time. The caregivers often consciously avoided planning for future or even thinking about the future because they wanted to avoid further disappointments. A female caregiver whose husband was doing quite well during the research project commented afterwards her participation in the caregiver support group:

> At that time I really didn't know what it would be like when the illness gets worse. When I was listening to the other [caregivers], it was very difficult for me to identify with them. I guess I didn't want to, because that would have made it impossible for me to maintain my courage and morale.

Insights and Solutions to Ease Care-giving. Family carers in this study used a variety of active problem solving strategies in order to ease care-giving. The insights and solutions were often »tricks« that made the communication with the demented person smoother or helped to get the everyday domestic chores done. Even though the meaning of such tricks is mostly pragmatic, they also have significant psychological meanings and consequences for the families.

Earlier in this chapter, we have analysed the meaning of routines in the adaptation of the family caregiver. Sometimes, however, it is precisely the breaking of the routines that makes it possible to continue caring at home. Many of these re-arrangements were very creative and were executed without professional help, but sometimes official services were also needed. The personal solutions and rearrangements seemed to play an important role in the self-management of the family in that they enhanced the cohesion of the couple and strengthened the experience of »us«. Describing personal solutions to the interviewer can be understood as a way to convey inside knowledge concerning the uniqueness of the family.

Enhancing the self-management of a patient or a family caregiver is often done by giving information and professional advice. Instructions coming from the professionals do not, however, necessarily correspond to the unique characteristic of a care-giving family. We have used the concept of »microculture« to refer to the different systems of thought and action followed by different families and units of the service system. When the microcultures of a family and service system collide, even a well-meaning advice can turn futile. Personal insight from the part of the family members is usually needed before even a most helpful advice can be successfully executed. Giving information and advice thus should be tailored according to the personal characteristics of a caregiver and the unique microculture of a family. For a highly dutiful caregiver, it is often frightening to break loose from the familiar and safe routines even if the new working methods are presented to her/him as a ready-made package. Effective problem-solving usually presupposes personal goals and individually tailored implementation. If successful, the process often results in a heightened self-confidence and empowerment.

Redefining Oneself as a Strategy to Master Care-giving. Specifically for the older spouses, identifying themselves as a family caregiver is not self-evident. Many caregivers in our project emphasized that rather than family caregiver, they experienced their role as a spouse with an unquestionable obligation and will to care for their partner. The term family caregiver was often associated with the official family carer's monthly allowance that the Finnish municipalities allocate to caregivers who prove eligible regarding among other things their functional capacity.

Our data show that setting the limits to care-giving duties and defining themselves as carers may prove to be most difficult to spousal caregivers. One of the female interviewees in our study defined the care work as a »joint hobby« between her and her husband. This family had experiment-ed with various care arrangements, and finally arrived at a model where the demented spouse spent one week per month in a short-term ward. For the wife, this was a period of empowerment and rest. Emotionally, this was an ideal arrangement for both partners, because a longer time of separation would have meant mutual longing and feelings of loneliness.

The above example manifests the meaning of autonomy and choice for the caregiver's self-management. »A joint hobby« is here a metaphor of voluntariness, belonging, and a positive attitude. In addition, this caregiver also used the metaphors of »job« and »employer« when describing the family's arrangements. When preparing for the short-term period in the hospital, she used to ask playfully her husband whether he as an employer would like to allow her for a short vacation. This was presented as a manifestation of the equality of the spouses. Defining oneself as an employed care worker was sometimes used by the caregivers also as a way to moderate the emotional burden of the family care-giving.

Motivation: the Moral Identity of a Caregiver

As stated earlier, elderly spousal caregivers typically suffer from various diseases and disablements, and the burden of care tends to expose them to psychological stress and also somatic illnesses. In spite of this, many of the elderly spouses feel inclined to carry on as caregivers because of their emotional and moral commitment to their spouse (Pot et al. 2001; Eloniemi-Sulkava et al. 2001; Saarenheimo et al. 2007).

From the perspective of empowerment and self-management, the question of coping with the burden of care-giving is a complicated one. One of the male participants in our study formulated his »survival strategy« as follows:

> Well, sometimes I'm coping well and sometimes not. Most of the time, I'm not coping at all. But that's not really the point, isn't it? It doesn't really matter how I'm doing, because this is my mission, the aim of my life. If I wasn't doing this, where would I be? What would I do with my life?

The statement of this caregiver exemplifies the importance of the quest for moral adequacy in the psychological constitution of the caregivers in the oldest generation. When analysing the conversational data collected in the caregiver support groups of our intervention study, it became evident that coping for these caregivers was essentially based on their will to do the right thing and to act according to their moral identity. The definition of moral identity is traditionally based on cognitive theories. Lately, however, moral identity has been redefined as a self-regulatory mechanism that motivates people to make choices and pursue actions that are consistent with their moral self (Aquino & Reed 2002). Maintaining moral adequacy is assumed to be central in the constitution of identity, though the substance (content) of moral identity is socially and culturally constructed. The ideals, norms and values vary temporally, culturally and locally. Moreover, the different generations have different moral identities. The political history of Finland with the periods of war and reconstruction has had a strong impact on the moral identity of our oldest generation with the central features of unconditioned persistence and prioritizing hardship over well-being and pleasure. Giving up one's caring mission can, for these caregivers, be interpreted as abandonment, selfishness and insensitivity. Even a temporary leave seems to be out of question to some of the caregivers since it threatens their moral and emotional continuity.

Moral ideals and values are not necessarily tied to a single course of action (Aquino and Reed 2002). Rather, they can be adapted according to the context and perspective one adopts. A constant moral conflict, on the other hand, can be a substantial source of psychological distress. In the next extract, a somewhat younger female caregiver is speculating about her role as a caregiver.

> You all seem to be very noble-minded and unselfish as you are so committed to the caring of your spouses. I must say that I am rebellious. I have been put into this position completely unprepared and untrained. Am I really the only one responsible here? What about the society? I am a wife, not a carer. What happens if I refuse to take care of him? Who will do it? Can we still

> stay home? Of course I feel awful to say these things. And of course I will continue caring for him. But in my mind I sure am annoyed.

Here, the speaker questions the nowadays-common division of responsibilities between family and society where the spouse is expected to carry the main responsibility for the disabled partner. The speaker presents an »alternative interpretation for the marriage vow«. According to her interpretation, the vow is about being a wife or husband, not a carer. In this case, the anger and rebelliousness seem to stay at an imaginary level, but it is likely that the future generations will seriously question the self-sacrificing model of spousal care-giving.

To sum up, moral adequacy in terms of a deep responsibility and family commitment constitutes a typical caring resource for the older spousal caregivers in Finland. Recognising the moral aspects of care-giving may also help the professionals to understand why the elderly caregivers sometimes refuse support services that are based on a straightforward idea of the caregiver's needs for rest, recreation and relaxation. The discourses of self-actualisation and self-expression do not seem to be meaningful in the context of caring for the oldest caregivers.

How to Support Self-Management in Elderly Care-giving Families with Dementia

We conducted an intervention study supporting people with dementia and their spouse caregivers in 2004–2006. In this study we implemented the core elements enhacing self-management of care-giving families found in our previous qualitative study described above. A family care coordinator (FCC) and a geriatrician, carried out a support program in which they pursued (1) to support empowerment and mastery of couples, (2) to identify the needs for services in cooperation with families, (3) to support their autonomy, accepting also »poor« decisions of families, (4) to enhance problem solving in crises threatening community care, (5) to see the family as a whole: to support normal life, functioning and well-being, and (6) to provide psychosocial support and education. The FCC coordinated individually tailored, flexible services in collaboration with families. In addition to the work of family care coordinator and the geriatrician the intervention included also goal-oriented support groups for caregivers. One aim of these was to enhance empowerment and self-efficacy of caregivers via peer support.

Supporting Self-Management

We used a wide spectrum of services in the support program. They were developed in cooperation with the couples. Thus, empowerment and involvement of the families were important intervention elements (Connor et al. 2008). Well-established working principles guided the implementation of the support program (◘ Table 10.1). These principles were based on awareness of the frictions in the traditional service system hindering effective collaborative care and partnership between care-giving families and health professionals. These problems have been identified in many previous studies (Nankervis et al. 1997; Dello Buono et al. 1999; Toseland et al. 2002; Saarenheimo et al. 2007).

The FCC acted as an appointed professional responsible for delivering the versatile services and worked in collaboration with the couples, respecting their autonomy. The FCC co-operated with each couple to tailor services to suit their individual needs and wishes. A genuine dialog between the two parties was a starting point in setting the goals, assessing the needs and planning for the adequate services for each family.

Understanding the family as an autonomous, resourceful and self-managing agent had several important consequences to the support process. First, it presupposed a dialog relationship between the family and the professionals. Second, it created a continuous need to negotiate and re-negotiate the roles and responsibilities of different parties. Third, it necessitated an empowering orientation from the part of the professionals in order to avoid paternalization, and at the same time to communicate a willingness to come up with practical solutions acceptable by the service system in a given context. Optimism was encouraged in the families, and they were also urged to use their own resources and networks. The assessment of the care-giving

Table 10.1. Frictions in traditional service system and corresponding working principles of care-giving intervention for dementia care-giving families in the Central Union for the Welfare of the Aged

Frictions in traditional service system	Working principles of intervention supporting self-management
Authoritative service delivery: professionals as experts	Shared expertise: equality and collaboration between families and professionals
Treating clients as passive objects and allocating expertise to professionals	Respecting autonomy, enhancing empowerment, optimism and use of families' own resources
Neglecting the intertwined and interrelated nature of the needs of care-giving couples	Supporting the family as a whole
Rigid and fragmented service system often fails to respond adequately to acute problems and crisis of dementia families	Supporting families to identify their problems and responding flexibly and immediately when needed; coordination of services
Families and service system have different understandings of care-related issues and family life. Family care is often considered simply as an extension of the service system.	Promoting families' and professionals' awareness of their different 'microcultures'. Appreciating families' needs to maintain their own customary way of life.

situation was to be based on understanding the spouses as a family as well as separate individuals. This meant a redefinition of the concept of need as a dynamic and relational process. Much emphasis was put on flexible and immediate actions in acute problems and crises since it was obvious that the situations and needs of the families would change rapidly and continuously. There was a conscious attempt from the part of the professionals to recognise the specific »microcultural« features of each family and act according to these. The important function of professional help was to recognise and appreciate the families' needs to maintain their normal and routine way of everyday life in spite of the illness of one of the spouses.

During the process of the support program it became obvious that following working principles, as described above, were extremely important. The principles created the substantial core of the support program. In other words, the core of the program was not merely to deliver relevant services but to do it in a way that emphasized the genuine collaboration between the families and professionals.

The intervention resulted in postponing of long-term institutional care of persons with dementia. Furthermore, working in collaboration with families led to a reduction in the use of community services (Eloniemi-Sulkava et al., submitted). Families were very satisfied with the support program.

Conclusion

In our studies on dementia care-giving, we have explored the issues related to self-management and empowerment. Our results showed that these complicated concepts are in fact embedded in the every-day lives of care-giving families. In addition, we succeeded to prove that it is possible to involve these concepts in living practice of the service system. Empowering care-giving families and involving them into partnership do not contradict with effectiveness or economic efficiency of services.

References

Albert SM (1990) The dependent elderly, home health care, and strategies of household adaptation. In: Gubrium J, Shankar A (eds) The home care experience: Ethnography and policy. Sage Publications. Newbury Park, CA, pp 19–36

Antonovsky A (1985) Health, stress, and coping. Jossey Bass, San Francisco, CA

Bodenheimer T, Lorig K, Holman H, Grumbach K (2002) Patient self-management of chronic disease in primary care. JAMA 19: 2469–2475

Brodaty H, McGilchrist C, Harris L, Peters KE (1993) Time until institutionalization and death in patients with dementia. Arch Neurol 50: 643–650

Brodaty H, Gresham M (1989) Effect of a training programme to reduce stress in carers of patients with dementia. Br Med J 299: 1375–1379

Clark PG (1989) The philosophical foundations of empowerment. J Health Aging 3: 267–285

Cohen CA, Gold DP, Schulman KI, Zucchero CA (1994) Positive aspects in caregiving: an overlooked variable in research. Can J Aging 378–391

Coleman MT, Newton KS (2005) Supporting self-management in patients with chronic illness. Am Fam Physician 8: 1503–1510

Connor KI, McNeese-Smith DK, Vickrey BG, van Servellen GM, Chang BL, Lee ML, Vassar SD, Chodosh J (2008) Determining care management activities associated with mastery and relationship strain for dementia caregivers. J Am Geriatr Soc 56: 891–897

Dello Buono M, Busato R, Mazzetto M et al. (1999) Community care for patients with Alzheimer's disease and non-demented elderly people: use and satisfaction with services and unmet needs in family caregivers. Int J Geriatr Psychiatry 14: 915–924

Eloniemi-Sulkava U, Saarenheimo M, Laakkonen ML, Savikko N, Kautiainen H, Tilvis RS, Pitkälä KH (2009) Family care as collaboration: effectiveness of a multi-component support program for elderly couples with dementia. Randomized controlled intervention study (submitted)

Farran CJ (1997) Theoretical perspectives concerning positive aspects of caring for elderly persons with dementia: stress adaptation and existentialism. Gerontologist 37: 250–256

Gibson CH (1991) A concept analysis of empowerment. J Adv Nurs 16: 354–361

Gonzalez VM, Goeppinger J, Lorig K (1990) Four psychosocial theories and their application to patient education and clinical practice. Arthritis Care Res 3: 132–143

Heyn P, Abreu BC, Ottenbacher KJ (2004) The effects of exercise training on elderly persons with cognitive impairment and dementia: a meta-analysis. Arch Phys Med Rehabil 85: 1694–1704

Huusko TM, Karppi P, Avikainen V et al. (2000) Randomised, clinically controlled trial of intensive geriatric rehabilitation in patients with hip fracture: subgroup analysis of patients with dementia. BMJ 321: 1107–1111

Lazarus RS, Folkman S (1984) Stress, appraisal, and coping. Springer, New York

Kramer B (1997) Gain in the caregiving experience: Where are we? What next? Gerontologist 37: 218–232

Levin-Zamir D, Peterburg Y (2001) Health literacy in health systems: perspectives on patient self-management in Israel. Health Promotion Int 1: 87–94

Lorig KR, Holman H (2003) Self-management education: history, definition, outcomes, and mechanisms. Ann Behav Med 1: 1–7

McCall ME, Heumann LF, Boldy DP (2001) Empowerment: definitions, applications, problems, and prospects. In: Teoksessa: Heumann LF, McCall ME, Boldy DP (eds) Empowering frail elderly people. Opportunities and impediments in housing, health, and support service delivery. Praeger, Westport, Connecticut, pp 3–24

Meiland FJM, Danse JAC, Wendte JF, Klazinga NS, Gunning-Schepers LJ (2001) Caring for relatives with dementia – caregiver experiences of relatives of patients on the waiting list for admission to a psychogeriatric nursing home in the Netherlands. Scand J Public Health 29: 113–121

Mittelman MS, Ferris SH, Shulman E et al. (1996) A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial. JAMA 276: 1725–1731

Nankervis J, Schofield H, Herrman H et al. (1997) Home-based assessment for family carers: a preventative strategy to identify and meet service needs. Int J Geriatr Psychiatry 12: 193–201

Neundorfer NN (1991) Coping and health outcomes in spouse caregivers of persons with dementia. Nurs Res 40: 260–265

Pot AM, Deeg DJ, Knipscheer CP (2001) Institutionalization of demented elderly: the role of caregiver characteristics. Int J Geriatr Psychiatry 16: 273–280

Raivio M, Eloniemi-Sulkava U, Laakkonen ML et al. (2007) How do officially organized services meet the needs of elderly caregivers and their spouses with Alzheimer's disease? Am J Alzheimers Dis Other Demen 22: 360–368

Rappaport J, Swift C, Hess R (1984) Studies in empowerment. Steps toward understanding and action. Haworth Press, New York

Rappaport J (1987) Terms of empowerment/exemplars of prevention: Toward a theory for community psychology. Am J Community Psychol 15: 121–128

Saarenheimo M, Nikula S, Eskola P (2007) Exploring the borderlines of family caregiving in Finland. In: Paoletti I (ed) Family caregiving for older disabled people: relational and institutional issues. Nova Science Publishers, New York, pp 333–357

Schulz R, O'Brien AT, Bookwala J et al. (1995) Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. 1995; 35: 771–791

Stuck AE, Siu AL, Wieland GD et al. (1993) Comprehensive geriatric assessment: a meta-analysis of controlled trials. Lancet 342: 1032–1036

Teri L, Gibbons LE, McCurry SM et al. (2003) Exercise plus behavioral management in patients with Alzheimer disease: a randomized controlled trial. JAMA 290: 2015–2022

Toseland RW, Smith G, McCallion P (2001) Family caregivers of the frail elderly. In: Gitterman A (ed) Handbook of social work with vulnerable and resilient populations. Columbia University Press, New York

Walsh F (1996) The concept of family resilience: crisis and challenge. Fam Process 3: 261–281

Vernooij-Dassen M, Felling A, Persoon J (1997) Predictors of change and continuity in home care for dementia patients. Int J Geriatr Psychiatry 12: 671–677

Vitaliano PP, Zhang J, Scanlan JM (2003) Is caregiving hazardous to one's physical health? A Meta-analysis. Psychol Bull 129: 946–972

Financial Benefits of Self-Management

Julia Hintermann

Even today, many people in Switzerland are confronted by problems associated with Alzheimer's disease, be they patients, care-giving relations, people with cases in their family or among their close or more distant acquaintances, or members of support organisations. In addition to the 98,000 patients who currently suffer from Alzheimer's, more than 300,000 persons in Switzerland are directly concerned as care-giving family members or close friends. About 40,000 dementia patients are being looked after by trained staff in homes (Swiss Alzheimer's Association, status 2008). Indirectly, however, none of us is spared as we bear our share of the nursing cost through our health and social-insurance contributions. If the present forecasts should come true, the number of Alzheimer's cases will rise to 120,000–140,000 by 2030 (Monod-Zorzi 2007).[1] This is a challenge that must be tackled at many levels.

Home care of Alzheimer's patients by family members is continuously gaining in importance, not least because of cost considerations. In Switzerland, only those who are entitled to supplementary benefits are currently in a position to recompense their family members for their services (Latzel 2008). It is worth considering whether this approach could not be applied to Alzheimer's patients in order to promote family self-management. Supporting the self-organisation of patients and their relations by training is a method that is already being practiced in many places. From the economic point of view, self-management programmes are interesting: As 'empowered' partners of the medical professionals, patients assume responsibility for and control over most of those aspects of their life that are affected by their disease, thus relieving the burden on public-health institutions. In view of the high and still-growing cost of public health, these programmes constitute an alternative that merits closer inspection.

Present and Future Challenges

People in Switzerland reach an increasingly high age. With age, the susceptibility to diseases increases as well as the probability of having to call on the assistance of physicians or caregivers (Vuilleumier 2007; Goldman 2005). High age is an essential factor in the prognosticated increase of Alzheimer's cases.[2] Moreover, as the birth rate is going down, the elderly are confronted by fewer and fewer economically active young people (WHO Europe 2004). While the proportion of those aged 65+ amounts to 15% of the total population today, it will probably reach 25% by 2050 (Monod-Zorzi 2007). The first wave of baby boomers will reach retirement age by 2010, meaning that very many of those who are informal caregivers today will cease to be economically active and run an increasing risk of needing care themselves. Moreover, as many families have been fragmented by divorce, migration, or external pressures (WHO Europe 2004), there is no answer to the question of which of their members will feel responsible for caring for their older relations. It is clear even now that in the long run, care by family members will be superseded by other forms of care such as the personal assistance that is being provided to the handicapped today.

In Switzerland, the total direct expenditure on healthcare amounts to EUR 29 bn (around CHF 47 bn, status 2003). The sum expended on brain disorders including dementia ranges around EUR 5.3 bn (c. CHF 8,5 bn, Jäger 2008). Estimates indicate that about 2 out of 7.3 million Swiss citizens – well above one quarter of the population – are currently suffering from one or more brain disorders. The cost of Switzerland's 36,000 institutionalised dementia patients amounts to CHF 2.4 bn (Hallauer 2006). As a patient's state of health deteriorates, non-medical costs increase in proportion (Hill 2002; Fillit 2005).[3] Claiming two thirds of the annual cost of demen-

---

[1] A general forecast for the industrialised nations predicts that the number of Alzheimer's patients will increase by 30–50%. In the USA, it is expected that dementia costs will go up by 83% in the period from 2000 to 2020 and by another 60% between 2020 and 2040 (Monod-Zorzi 2007).

[2] The number of those aged 80 and over will presumably increase from 340,000 today to 625,000 in 2030 (Weaver 2008).

[3] By way of reference, I should like to quote a US study which found that total direct cost increases from approximately $ 9239 per patient per year at baseline, when all patients are at the early stage of the disease, to $ 19,925 by year 4. Any additional comorbid condition will increase the total direct cost by 14.3% (Zhu 2006). See also Hill (2006).

tia, professional long-term care absorbs the lion's share of the funds (Bonin-Guillaume 2004).[4] Institutionalised care (CHF 73,300 per person and year) is 22.4% more expensive than home care (CHF 59,900 per person and year) (Volz 2000). Similarly, a US longitudinal study of Alzheimer's patients concluded that the total direct cost is 20.8% lower for patients living at home compared with those living in an institutional setting (Zhu 2006). Consequently, it is expected that avoiding hospitalisation will yield the greatest cost savings.

If the number of Alzheimer's patients should indeed increase as predicted, the number of spaces available for long-term patients in old-age and nursing homes might prove a bottleneck.[5] To provide sufficient long-term care spaces for the expected number of Alzheimer's and other patients in need of care, existing capacities will have to be greatly expanded and new homes built. At the moment, most of the cost of building and maintaining (state) buildings is furnished by public funds (federal, canton, and local governments) or, in other words, by tax revenues. These expenditures do not appear on the public-health bill which shows only operating costs. Even today, well above one third of the total of 1500 homes is privately owned (Federal Statistical Office 2008). One feasible option might be to collaborate with private providers on stopping the gaps that are now expected and, more importantly, relieving family caregivers by institutionalising patients for brief periods as a temporary solution.

In view of these developments, speedy action is urgently needed. The point is not to save on current costs but to invest in the proper places so as to avoid future cost increases.

Family Caregivers – the World's Largest Care Service

Informal caregivers (family members, friends, acquaintances, neighbours) normally provide much or even most of the care needed by dementia patients[6]. In Switzerland, most dementia patients (62%) live at home, with 18% living alone and 44% with their relations (Köppel 2006). It is apparent at first glance that the cost to society of caring for patients under their own roof is much lower because they can use their own living accommodation and their private social networks. While caring for patients in hospitals or nursing homes does relieve the burden on their relations, this is not what either the patients or their relations want in most cases. Home-care expenditures, which can only be estimated, amount to the equivalent of about 5.5 hours per day or 2068 hours per year (Volz 2000). Whether we value this time entirely at the general rate of CHF 19.80 per hour or part of it at the average gross pay of CHF 35.30 which relations might earn if they were not caring for a family member (opportunity cost), their unpaid work is worth a considerable amount. Whenever we discuss the investments needed to improve the situation of family members we should, therefore, remember that their work is a gift not only to the patients but to society as a whole.

The fact that care-giving relations receive no compensation so far does not imply that no cost is involved. Caring for a seriously ill patient for a long time affects the caregiver's health, well-being, and financial security (WHO Europe 2004). The known side effects on family caregivers in regular employment include lost working hours, reduced performance on the job, time constraints, and susceptibility to illness (DGB 2006)[7]. These

---

[4] On the development of the cost of long-term care in Switzerland cf. Weaver (2008).

[5] In Switzerland, the average number of long-term care spaces available to every 1000 inhabitants aged 65+ is 70.3 in nursing homes but no higher than 2.5 in old-age homes (Federal Statistical Office 2008).

[6] The ratio of formal to informal care is estimated at 1:1 in the US, 1:2 in Norway, and 1:4 in the UK (Monod-Zorzi 2007, status c. 2000).

[7] In the Swiss survey conducted by Volz, 15% of the key caregivers interviewed said that they were gainfully employed. Because of their duties as caregivers, they lost between 4 and 42 hours of work per week (Volz 2000). In Germany, employees who look after their relations consider it most important that their employers should give them leave of absence to fulfil their care-giving duties (Barkholdt 2004). Their employers, in turn, are confronted by the cost of finding stand-ins for absentees and recruiting replacement staff in case of resignation. The total estimated cost to employers in the U.S. for full-time employees with intense care-giving responsibilities is $ 17.1 bn (MetLife 2006).

expenditures show up elsewhere: in corporate accounts, they appear as per-capita productivity or working-time losses, the unemployment and/or social insurances have to step in when employees resign, and when they fall ill, they appear on the health bill of the national economy. To offset the physical, emotional, and financial strain as well as the demands on their time which increase as the illness progresses, relations need support to enable and motivate them to go on fulfilling their duties. It is they who are able to contribute a great deal towards reducing the cost of treating Alzheimer's patients. Consequently, we must seek ways to relieve them so that they do not fall ill themselves.[8]

Family Member Self-Management

As the disease progresses, the relations of Alzheimer's patients assume more and more tasks, deputising for the patient (principal) as agents and making decisions that conform to his wishes.[9] Moreover, they are experts at optimising home care and determining when help from outside should be called in. The classic dyad of patient and healthcare professional thus expands to form a triad. Time constraints may be eased by placing the patient in a home for a limited period or obtaining help to assist in household management and home care. To secure their autonomy and empowerment within the public-health system, either the patients themselves or the relations of those in an advanced stage of the disease should be allowed to decide on their own about the suitability of assistants and the use of the budget to which the patient is entitled. It appears apposite to investigate whether two models that are currently being used in Europe to strengthen the autonomy of handicapped persons can be adapted to the situation of family caregivers.

Under the *employer model*, handicapped persons purchase the services they require on the free market. Acting as employers, they recruit their assistants according to their own criteria, employing them in conformance with applicable legal regulations, taking charge of their training, management, and supervision, and handling most of the administrative work. No longer dependent on the services offered by existing socio-medical institutions such as Spitex, the handicapped themselves decide what kind of service exactly meets their needs and who is best at providing it. Under this arrangement, they are able to go on staying at home, even employing their own relations. Thus, the employer model strengthens the autonomy of the patients and provides a degree of financial security for their families that is based not on subsidies but on services rendered. At the same time, it relieves the burden on the public-health system, for freedom of choice implies that the administrative work that used to be handled by government authorities must now be done by the handicapped employer. Also known under the name of *personal assistance*, the employer model is even now being used successfully in a number of countries, including Sweden, the Netherlands, Belgium, France, Portugal, Greece, Spain, Italy, Austria, Germany, and the UK. Personal assistance is financed in different ways (through income tax relief or employment subsidies), but assistance payments are normally organised by the social insurance system.

The *personal budget* model expands the patients' autonomy to include sovereign control of the financial support payments to which they are entitled. In most cases, it provides for the conversion of previous benefits in kind into a specific cash benefit which, covering the needs of a physically handicapped person in a given period, is fixed jointly by the handicapped and their funding agencies. Paid in advance, such cash benefits enable recipients to allocate their financial resources autonomously. At the end of such a period, recipients have to account for their use of funds. Funding agencies benefit because their administrative activities are now confined to reviewing the final accounts. In the Netherlands, for example, handicapped persons may choose between receiving a personal budget to organise their own assistance

---

[8] The (still unfinished) »work & care« study by the Swiss National Fund investigates the conditions under which gainful employment and care for relations can be reconciled (Bischofberger 2008). See also Welti (2006).

[9] The principal-agent theory is used in economics to explain, for example, the position of the administrative board representing the shareholders (principal) relative to the management (agent).

or receiving assistance from an organisation like Spitex (Leuenberger 2005). To deal with the administrative functions associated with personal budgets, people with a mental handicap need support which, in Germany for example, is provided mostly by legal guardians and family members and partly by social institutions (Metzler 2007).[10]

The relations of Alzheimer's patients would have to assume the same rights and obligations defined for handicapped persons in the employer and personal-budget models. Periodic accountability provides a certain amount of control ensuring that relations manage the patients' budgets in accordance with their wishes. As in all principal–agent relationships, however, a certain risk remains which may be reduced by contractual regulations. Whether or not to use the saving potentials offered by care self-organisation and budget self-administration is a political decision. While public-health costs may be expected to decrease to a certain extent, the major savings will probably turn up in the administration expenses of the authorities concerned which appear in another budget account.

However, those offers of support that have been made so far aim less at easing the burden of everyday care and more at providing training designed to promote the freedom of action and the decision-making competence of both patients and their relations in the narrower context of the disease.

Efficiency of Programmes to Support Patient Autonomy

The economic efficiency of various programmes to promote patient autonomy has been investigated in a number of studies. Essentially, efficiency is judged by the decline in the number of consultations and stays in hospital. Judging the efficiency of the programmes is not an easy task (Richardson 2005). Demonstrable significant benefits include improvements in the psychological distress and the knowledge of caregivers (Brodaty 2003; Thompson 2007). Cost-cutting effects differ in strength. This may be because some programmes are not tailored to the needs of their target groups (Thompson 2007), because quality requirements (e.g. intelligibility of instructions, integration into daily management, Nagelkerk 2006) have not yet been standardised (Redman 2007a), or because interaction quality was not considered. Not only the content of a training course but also the manner of interaction may crucially influence the self-management capabilities of the people concerned.

Involving patients and relations, inter-disciplinary cooperation among health professionals, remunerating doctors for patient education, and instituting training for healthcare professionals have emerged as key factors for the success of training programmes. ◘ Table 11.1 presents a survey of the programmes which may be employed in the course of the disease:

Targeted disease-specific training under a *disease management* system will cause a perceptible reduction in the number of hospitalisations and consultations in patients with different types of the disease (Bourbeau 2006; Wheeler 2003; Gozzoli 2001). The additional costs of training will turn into savings given an adequate number of course participants or an extended period of regular training (break even). Further factors of success include inter-disciplinary cooperation and patient involvement (Tschopp 2002).

The strong suit of the *case-management* approach is that it coordinates segmented services and fine-tunes all measures to the clients' actual requirements (»tailoring«, Hofstetter 2007). These measures are intended to provide comprehensive support to the clients and save costs at the same time – a conflict of interest which may well backfire on the clients (Hofstetter 2008). According to a Swedish study, case management of patients with severe mental illness has led to a decrease in the use of psychiatric services (Björkman 2007). However, reviewing two older five-year follow-up investigations (Borland 1989, McRae 1990), Björkman and Hansson found that, while intensive care management did significantly reduce the number

---

[10] Experience with the pilot assistance budget programme for recipients of disability insurance in Switzerland shows that the quality of life of the handicapped persons improved and the cost to society declined when they left their nursing homes. At the same time, however, nursing costs increased because family members were recompensed for their hitherto unpaid work (Balthasar 2007).

Table 11.1. Programmes to enhance patient autonomy during the course of the disease (developed from Merz Pharma http://www.merz.de/presse/pressemappen_gesundheit/alzheimer/verlauf/)

Early stage	**Intermediate/moderate stage**	**Severe stage**
Cognitive deficits	Impaired independence Behaviour abnormalities	Need for intensive care
0 to 3 years	3 to nearly 6 years	nearly 6 to 9 years (or longer)
Disease management: Amalgamation of all measures (from prevention, diagnosis, and treatment to after-care) into a coherent process. Guidelines plus frequent self-treatment and training programmes.	**Case management:** Patient care coordination by determining care needs, developing a care plan, organising and monitoring care, and cultivating contacts with patients and their relations.	**Care management:** Rehabilitation designed to slow down the growing need for care.
Expert patient (lay-led) education programmes: e.g. sessions addressing symptom management, dealing with anger, fear and frustration, problem-solving, and action plans (UK expert patient programme). **Self-management education:** e.g. group-based workshops led by a pair of lay leaders with health problems of their own (Stanford Self-Management Program), teaching by case managers and skill-oriented patient workbooks, written action plans, and instruction in how to react when symptoms worsen.		

of hospital days, hospitalisations (McRay 1990) as well as the number of residential days in the community (Borland 1989) increased after the intervention terminated. This might indicate that the interest, commitment, and availability of specialists during the case management period were crucial for success and need to be sustained over prolonged periods to keep the investment from being nullified by the Hawthorne effect[11]. At the same time, the persons in contact with the patients need not be (expensive) specialists (Ford 2001), which make for lower payroll costs.

There are different opinions about the efficiency of (lay-led) *expert patient* programmes that are mainly used in the UK (Griffiths 2007; Kennedy 2007). The weakness of their economic impact may be traced back to the fact that effective self-care skills cannot be achieved by patient training alone. What we also need is a holistic view of the triad patient – informal caregiver – service organisation and wider time horizons for observation (Kennedy 2007).

Self-management programmes aim at enabling patients to deal with their chronic conditions more independently. Depending on circumstances, the process which patients have to undergo to become competent partners of healthcare professionals will be helped along most effectively if training programmes address the patients' questions and needs (Ockleford 2008; Redman 2007a). Moreover, professional caregivers and doctors need to be trained in how to provide efficient and sensitive support (Kennedy 2005; Rogers 2005).

After a successful pilot phase (2001–2004), the British National Health Service (NHS) is now implementing *self-management* programmes (Redman 2007b). Efficiency assessments differ: While the incidence of hospitalisation declined markedly (Gadoury 2005), the psychological effect on the patients, although positive, did not lead to any short-term reduction in the number of consultations (Buszewicz 2006). In Switzerland, no more than 24% of general physicians and pulmonologists in the canton of Zurich use patient education in their dealings with their asthma patients, although most appreciate the benefits (Steurer-Stey 2006). One explanation may be that doctors are not paid for the time they spend educating their patients. If this is true, the remuneration system would have to be adapted so as to improve the

---

[11] The Hawthorne effect implies that people change their behaviour when they are aware that they are being observed, and that any change at the workplace (negative changes included), will briefly increase employee productivity. However, the impact of the effect is not sustained.

conditions for high-quality chronic care (Redman 2007b; Lorig 2003).

In dementia cases, programmes to strengthen patient autonomy also serve to support care-giving relatives. A German study of relations caring for dementia patients in Germany, Austria, and Switzerland revealed that the 'Help for Helpers' training course launched by the German Alzheimer Society had no measurable impact on either the frequency of stays in homes or the timing of the final institutionalisation (Kurz 2005). A Swiss study (Wettstein 2005) came to a similar conclusion. It may be that the patients' relations were encouraged by their training to take their own needs seriously, so that a certain amount of economic efficiency was realised through improvements in their health and productivity. However, measuring this was not an object of the study. Kurz believes that the reason for its result lies in the fact that options to address the participants' individual problems and resources were limited. Moreover, the training programme did not provide for any practical relief for the patients' relations which, in the author's opinion, had been an essential factor of success in former related studies. Conversely, individualised interventions with spouses of Alzheimer's patients led to a significant reduction in the frequency of nursing home placements, a marked improvement in their personal well-being (Mittelman 2006), and an extra hour of discretionary time per day (Nichols 2008).

The needs of informal caregivers and the peculiarities of the three-way interaction between patients, service providers, and caregivers will have to be researched more closely so as to avoid misdirected investments (Docherty 2008). From the relations' point of view, it is important that the physical and psychological hardships of their work should be appreciated, that they should be heard, and that they should be able to share the responsibilities of care with reliable partners (Stoltz 2006). Once the success criteria identified in the foregoing have been integrated in the design of self-management programmes, they may be expected to show an effect. However, extended support is necessary for this effect to be sustainable. It is patently obvious that follow-up periods will have to be lengthened if economic effects are to be measured.

Conclusions

Taken seriously, the self-management of patients and their relations demands that all parties involved change their thinking from the ground up: patients will have to be trusted to solve most of their disease-related problems themselves, responsibly supported by their relations. Naturally enough, this includes organising their own care and disposing of the cash benefits to which they are entitled, as described under the employer and personal-budget models.

Training measures to strengthen the self-management capabilities of patients and informal caregivers (especially relations) may potentially lower the cost of the public-health system. Given an adequate number of participants, any investment in developing and implementing programmes is bound to pay off after a certain time. This presumes, however, that such programmes are specifically designed to meet the participants' needs and are not implemented in isolation. To relieve the burden on relations, the range of decentralised outpatient and inpatient care facilities close to the patients' place of residence will have to be enlarged (Monsch 2008).

To see how efficient it is to accord greater autonomy to patients and their relations, we should look not only at the cost of public health but also at those accounts of the national budget which may be expected to show positive side-effects. Given the foreseeable increase in the cost of public health, it is important to make the right decisions now. This includes answering the fundamental question of how the well-being and the experience of autonomy of the patients and their relations should be weighted vis-à-vis cost savings in the public-health system or, in other words, how to resolve the conflict between helping and economic efficiency. Virtually all the approaches discussed here call for occasionally considerable initial investments before producing any cost-cutting effects which, in any case, have not yet been demonstrated to stringent standards. Though it may not be the only alternative, the self-management approach permits tackling the future actively, besides offering the prospect of discovering hitherto unknown savings potentials along the way.

References

Balthasar A, Müller F (2007) Pilotversuch Assistenzbudget – Zwischensynthese. Beiträge zur sozialen Sicherheit des Bundesamts für Sozialversicherungen, Forschungsbericht Nr. 12/07. http://bsv.admin.ch/themen/iv/00023/00372/index/html?lang=de

Barkholdt C, Lasch V (2004) Vereinbarkeit von Pflege und Erwerbstätigkeit. Expertise für die Sachverständigenkommission für den 5. Altenbericht der Bundesregierung. http:www.bmfsfj.de/bmfsfj/generator/RedaktionBMFSFJ/Abteilung3/Pdf-Anlagen/barkholdt-vereinbarkeit-von-pflege-und-erwerbstaetigkeit

Bischofberger I, Höglinger M (2008) Herausforderungen für die Vereinbarkeit von Erwerbstätigkeit und Angehörigenpflege. Schweizer Arbeitgeber 20: 36–39

Björkman T, Hansson L (2007) Case Management for Individuals with a Severe Mental Illness: A 6-Year Follow-Up Study. Int J Soc Psychiatry 53: 11–22

Bonin-Guillaume S, Zekry D, Giacobini E, Gold G, Michel JP (2004) Conflits médico-économiques d'une société vieillissante: l'exemple de la maladie d'Alzheimer. Médecine et hygiène 62: 1445–1449

Borland A, McRay J, Lycan C (1989) Outcomes of five years continous intensive case management. Hosp Com Psychiatry 40: 369–376

Bourbeau J, Collet JP, Schwartzman K, Ducruet T, Nault D, Bradley C (2006) Economic benefits of self-management education in COPD. Chest 130: 1704–1711

Brodaty H, Green A, Koschera H and A (2003) Meta-analysis of psychosocial interventions for caregivers of people with dementia. JAGS 51: 657–664

Buszewicz M, Rait G, Griffin M, Nazareth I, Patel A, Atkinson A, Barlow J, Haines A (2006) Self management of arthritis in primary care: randomised controlled trial. BMJ 333: 879

Deutscher Gewerkschaftsbund (DGB) Bundesvorstand (2006) Vereinbarkeit von Beruf und Pflege. Positionen und Hintergründe Nr. 6, Bereich Gleichstellungs- und Frauenpolitik

Docherty A, Owens A, Asadi-Lari M, Petchey R, Williams J, Carter YH (2008) Knowledge and information needs of informal caregivers in palliative care: a qualitative systematic review. Palliative Medecine 22: 153–171

Federal Statistical Office (Bundesamt für Statistik, BFS) Aktuell (2008) Statistik der sozialmedizinischen Institutionen 2006 – Standardtabellen. Definitive Resultate. Neuchâtel. http://www.bfs.admin.ch/bfs/portal/de/index/news/publikationen.html?publicationID=3088

Fillit H (2005) Cost consequences and cost benefits of treating patients with moderate to severe Alzheimer disease. Neurology 65: S31–S33

Ford R, Barnes A, Davies R, Chalmers C, Hardy P, Muijen M (2001) Maintaining contact with people with severe mental illness: 5-years-follow-up of assertive outreach. Soc Psychiatry Psychiatr Epidemiol 36: 444–447

Gadoury M-A, Schwartzman K, Rouleau M, Maltais F, Julien M, Beaupré A, Renzi P, Bégin R, Nault D, Bourbeau J (2005) Self-management reduces both short- and long-term hospitalisation in COPD. Eur Respir J 26: 853–857

Goldman D, Shang B, Bhattacharya J, Garber AM, Hzrd M, Joyce GF, Lakdawalla DN, Panis C, Shekelle P (2005) Consequences of health trends and medical innovation for the future elderly. Health Affairs Web Exclusive 26 September 2005. http://content.healthaffairs.org/cgi/reprint/hltaff.w5.r5v1

Griffiths C, Foster G, Ramsay J, Eldridge S, Taylor S (2007) How effective are expert patient (lay led) education programmes for chronic disease? BMJ 334: 1254–1256

Gozzoli V, Palmer AJ, Brandt A, Spinas GA (2001) Economic and clinical impact of alternative disease management strategies for secondary prevention in type 2 diabetes in the Swiss setting. Swiss Med Wkly 131: 303–310

Hallauer JF (2006) Kosten-Nutzen-Aspekte der Demenztherapie. Präsentation am Symposium »Sollen wir die Vergessenden vergessen? Kosten-Nutzen-Aspekte der Alzheimertherapie.« 28. September 2006 im Kunsthaus Zürich. http://www.alzheimerforum.ch/images/stories/kostensymposium/4_hallauer.pdf

Hill JW, Futterman R, Duttagupta S, Mastey V, Lloyd JR, Fillit H (2002) Alzheimer's disease and related dementias increase costs of comorbidities in managed Medicare. Neurology 58: 62–70

Hill J, Fillit H, Thomas SK, Chang S (2006) Functional impairment, healthcare costs and the prevalence of institutionalisation in patients with Alzheimer's diseases and other dementias. Pharmacoeconomics 24: 265–280

Hofstetter Rogger Y (2007) Ressourcen- und sozialraumorientiertes Case Management. In: Haller H, Hinte W, Kummer B (eds) Jenseits von Tradition und Postmoderne. Sozialraumorientierung in der Schweiz, Österreich und Deutschland, pp 116–125

Hofstetter Rogger Y (2008) Widersprüche im Case Management. Case Management 2: 88–92

Jäger M, Sobocki P, Rössler W (2008) Cost of disorders of the brain in Switzerland. Swiss Med Wkly 138: 4–11

Kennedy A, Gask L, Rogers A (2005) Training professionals to engage with and promote self-management. Health Education Research 20: 567–578

Kennedy A, Rogers A, Bower P (2007) Support for self care for patients with chronic disease. BMJ 335: 968–970

Köppel R (2006) Das optimale Angebot für Demenzkranke. Schweizer Gemeinde 4: 12–13

Kurz A (2005) Multizentrische, randomisierte und kontrollierte Prüfung einer modular aufgebauten Schulungsreihe für pflegende Angehörige Demenzkranker. http://deutsche-alzheimer.de/fileadmin/alz/pdf7AENEAS-Schlussbericht_0307.pdf

Latzel G, Andermatt Brains C (2008) Personen mit einer Hilflosenentschädigung IV: Vergütung von Pflege und Betreuung durch die Ergänzungsleistungen. Beiträge zur Sozialen Sicherheit des Bundesamts für Sozialversicherungen, Forschungsbericht Nr. 6/08. http://www.bsv.admin.ch/praxis/forschung/publikationen/index.html?lang=de&bereich=1&jahr=2008.

Leuenberger S (2005) Persönliche Assistenz: Organisation und Finanzierung in europäischen Ländern. Managed Care 3: 30–32

Lorig K (2003) Self-management education. More than a nice extra. Medical Care 41: 699–701

McRay J, Higgins M, Lycan C, Sherman W (1990) What happens to patients after five years of intensive case management stops? Hosp Comm Psychiatry 41: 175–179

Merz Pharma: http://www.merz.de/presse/pressemappen_gesundheit/alzheimer/verlauf/

MetLife Mature Market Institute, National Alliance for Caregiving (2006): The MetLife Caregiving Cost Study: Productivity Losses to U.S Business. http://www.caregiving.org/data/Caregiver%20Cost%20Study.pdf

Metzler H, Meyer T, Rauscher C, Schäfers M, Wansing G (2007) Begleitung und Auswertung der Erprobung trägerübergreifender Persönlicher Budgets. Abschlussbericht. Wissenschaftliche Begleitforschung zur Umsetzung des Neunten Buches Sozialgesetzbuch (SGB IX) – Rehabilitation und Teilhabe behinderter Menschen. Förderkennzeichen: VKZ 040501. http://bmas.de/coremedia/generator/23072/property=pdf/f366:forschungsbericht.pdf

Mittelman M, Haley WE, Clay OJ, Roth DL (2006) Improving caregiver well-being delays nursing homes placement of patients with Alzheimer disease. Neurology 67: 1592–1599

Monod-Zorzi S, Seematter-Bagnoud L, Büla C, Pellegrini S, Jaccard Ruedin H (2007) Maladies chroniques et dépendance fonctionelle des personnes âgées. Données épidémiologiques et économiques de la littérature. Document der travail 25. L'Observatoire suisse de la santé, Neuchâtel

Monsch, AU, Hermelink M, Kressig RW, Fisch HP, Grob D, Hiltbrunner B, Martensson B, Rüegger-Frey B, von Gunten A, and Expertengruppe der Schweiz (2008) Konsensus zur Diagnostik und Betreuung von Demenzkranken in der Schweiz. Schweiz Med Forum 8: 144–149 (online)

Nagelkerk J, Reick K, Meengs L (2006) Perceived barriers and effective strategies to diabetes self-management. J Adv Nurs 54: 151–158

Nichols LO, Chang C, Lummus A, Burns R, Martindale-Adams J Graney, MJ, Coon DW, Czaja S (2008) The cost-effectiveness of a behaviour intervention with caregivers of patients with Alzheimer's disease. J Am Geriatr Soc 56: 413–420

Ockleford E, Shaw RL, Willars J, Dixon-Woods M (2008) Education and self-management for people newly diagnosed with type 2 diabetes: a qualitative study of patients' views. Chronic Illness 4: 28–37

Redman BK (2007a) Accountability for patient self-management of chronic conditions; ethical analysis and a proposal. Chronic Illness 3: 88–95

Redman BK (2007b) Responsibility for control; ethics of patient preparation for self-management of chronic disease. Bioethics 21: 243–250

Richardson G, Gravelle H, Weatherly H, Ritchie G (2005) Cost-effectiveness of interventions to support self-care: A systematic review. Int J Technol Assess Health Care 21: 423–432

Rogers A, Kennedy A, Nelson E, Robinson A (2005) Uncovering the limits of patient-centeredness: implementing a self-management trial for chronic illness. Qual Health Res 15: 224–239

Steurer-Stey C, Fletcher M, Vetter W, Steurer J (2006) Patient education in asthma: a survey of physicians' knowledge of the principles and implementation of self-management in practice. Swiss Med Wkly 136: 561–565

Stoltz P, Willman A, Uden G (2006) The meaning of support as narrated by family carers who care for a senior relative at home. Qual Health Res 16: 594–610

Swiss Alzheimer's Association (Schweizerische Alzheimervereinigung): http://alz.ch/d/data/data_384.pdf

Thompson CA, Spilsbury K, Hall J, Birks Y, Barnes C, Adamson J (2007) Systematic review of information and support interventions for caregivers of people with dementia. BMC Geriatr 7: 18

Tschopp JM, Frey JG, Pernet R, Burrus C, Jordan B, Morin A, Garrone S, Imhof K, Besse F, Marty S, Uldry C, Assal JP (2002) Bronchial asthma and self-management education: implementations of Guidelines by an interdisciplinary programme in a health network. Swiss Med Wkly 132: 92–97

Volz A, Monsch AU, Zahno, Wettstein A, Stähelin HB, Grünig R (2000) Was kostete die Schweiz die Alzheimer-Krankheit 1998? Eine präliminare Analyse. Praxis 89: 803–811

Vuilleumier M, Pellegrini S, Jeanrenaud C (2007) Déterminants et évolution des coûts du système de santé en Suisse. Revue de la littérature et projections à l'horizon 2030. Office fédéral de la statistique (OFS). Neuchâtel. http://www.bfs.admin.ch/bfs/portal/fr/index/news/publikationen.Document.101691.pdf

Weaver F, Jaccard Ruedin H, Pellegrini S, Jeanrenard C (2008) Les coûts des soins de longue durée d'ici à 2030 en Suisse. Document de travail 34. L'Observatoire suisse de la santé, Neuchâtel. http://bfs.admin.ch/bfs/portal/de/index/infothek/publ.Document.106018.pdf

Welti M (2006) Die Perspektive der Angehörigen. Präsentation am Symposium »Sollen wir die Vergessenden vergessen? Kosten-Nutzen-Aspekte der Alzheimertherapie.« 28. September 2006 im Kunsthaus Zürich. http://www.alzheimerforum.ch/images/stories/kostensymposium/7_welti.pdf

Wettstein A, König M, Schmid R, Perren S (2005) Belastung und Wohlbefinden bei Angehörigen von Menschen mit Demenz. Eine Interventionsstudie. Zürich

Wheeler JRC (2003) Can a disease self-management program reduce health care costs? The case of older women with heart disease. Med Care 41: 706–715

WHO Europe (2004) Better palliative care for older people. World Health Organization Regional Office for Europe. http://www.euro.who.int/document/E82933.pdf

Zhu CW, Scarmesas N, Torgan R, Albert M, Brandt J, Blacker D, Sano M, Stern Y (2006): Longitudinal study of effects of patient characteristics on direct costs in Alzheimer disease. Neurology 2006;67:998–1005.

Conclusion

Sabine Bährer-Kohler

This book gives a wide range of information concerning self-management and of self-management of dementia. It includes an overview about aging of the population with the consequence of increased risk for chronic disease, diabetes, cardiovascular conditions and especially dementia. It is unlikely, that a drug will be found in the near future, which can cure Alzheimer's disease. Therefore, other conceptions have to be supported with the overall aim to increase the quality of life of patients and their families or caregivers, including financial aspects.

The second half of the book describes possible approaches in self-management in chronic disease, possibility to inform the patient and his caregivers about the disease and to train new ways of coping with the condition. This conception is not yet sufficiently implemented in the therapy process of patients suffering from Alzheimer's disease.

This book, with contributions by many internationally recognized authors from different countries, could help to support the development of innovative evaluation tools, concepts, and programs to promote self-management of chronic diseases, and to introduce a topic as important as the self-management of chronic diseases – with a special emphasis on AD – into the daily life of the patients and their caregivers and in worldwide treatment.

Subject Index