



Federal Ministry for
Family Affairs, Senior Citizens,
Women and Youth

Latest **Research** and Model Projects concerning **Dementia**

Projects
Dementia
Research

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Preface

Approximately 1.2 million Germans now suffer from a dementing illness. Elderly dementia patients are generally diagnosed with Alzheimer's, but in many cases too late for suitable treatment.

Therapies that slow the progress of the disorder and palliate its symptoms are few and far between. Dementia is a disorder that tends to be swept under the rug.

Most dementia patients are cared for at home by family members, who, we should bear in mind, also suffer the effects of the disorder. Overburdened family caregivers often fall ill themselves, and according to U.S. researchers are 60 percent more likely to die prematurely than persons that are not subject to this particular kind of stress.

These problems will undoubtedly become more severe as populations age. We are also facing a situation where healthcare and social security infrastructures are being taxed to their limits.

Despite the many advances in dementia research over the past decade, a scientific breakthrough does not appear to be in the offing. This means that we must provide appropriate care and support for dementia patients and their families.

Toward this end, in recent years the German government has been making efforts to improve the lot of dementia patients and their families. The results of a number of recent research and pilot projects – some of which are described in the present pamphlet – have provided an invaluable impetus for the realization of quality dementia care.

Among the other exemplary undertakings in this domain are the multifaceted dementia research projects that have been carried out under the pilot program "Future support structures for the elderly," which is funded by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (Bundesministerium für Familie, Senioren, Frauen und Jugend, BMFSFJ), as well as demonstration geriatric care facilities and model facilities for the disabled whose conceptual and practical approaches are exemplars for, and transferable to, many different regions of Germany.

New approaches to group living and long term care also show how the quality of life of the elderly and disabled, and particularly persons suffering from dementing illnesses, can be sustainably improved (see www.baumodelle-bmfsfj.de (available in German only)).

Ever since 1991, several German ministries (initially the Ministry of Health and Social Affairs, and subsequently the Ministry of Health and the Ministry of Health and Social Security) have been funding a model program that aims to improve long-term care facilities for dementia patients and provide relatives caring for dementia patients with support. Of the 450 projects that have been funded, at least one-third implement "dementia paradigms."

For persons with dementing illnesses, quality care is the key to quality of life. And one of the most important guarantors of such care is providing support for the development of professional caregiving skills. The Federal Geriatric Care Act (Altenpflegegesetz) of 2003 aims to promote training program quality for geriatric caregivers and strengthen the practical orientation of such programs through measures such as the guidelines that have been devised for training courses on long-term dementia care.

These guidelines are available under the Forschungsnetz/Forschungsberichte rubric (in German only) at www.bmfsfj.de.

The German government is strengthening its support for the development of clearer and more widely accepted long-term care standards, as well as empirical methods for the measurement of dementia patients' quality of life. Moreover, in the interest of providing family member caregivers of dementia patients with support, we must carefully assess the effectiveness of existing instruments, and ensure that information on sources of assistance is readily available. Toward this end, the Alzheimers support line, which is funded by the Federal Ministry for Family Affairs under a contract with the German Alzheimer's Association, was established in 2001 and receives up to 6500 calls annually (www.deutsche-alzheimer.de).

Tomorrow's world will also be a world in which dementia is a prevalent disorder. We should respect the human dignity of persons with dementia.

In the interest of counteracting anxieties about dementia patients and avoiding their marginalization, we need to provide the general public with information on dementia and involve the community at large in the debate on the subject.

The present pamphlet will hopefully further this aim.

Further information on the projects and research described here is available (in German only) from the Web sites indicated in the various texts.

Potential and limitations of independent living in private households (MUG III)

Project period: July 2002 to June 2005

The *Potential and limitations of independent living in private households* (MuG III) study provided detailed insight into the circumstances relating to long-term care in private households before and after the advent of long-term care insurance benefits. Hence the study has implications for all long-term care as well as for the restructuring of long-term care arrangements and the development of group living paradigms. The study's main finding was that elders also like living on their own, and that this goal is realizable if the right home environment can be provided.

Realized by Infratest Sozialforschung München under the auspices of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (Bundesministerium für Familie, Senioren, Frauen und Jugend, BMFSFJ), the study was based on a representative survey of 3622 persons in need of long-term care. The other members of the research consortium were Zentralinstitut für seelische Gesundheit (ZI), Heinemann & Partnerinnen (c/o IGF Berlin), ISG Institut für Sozialforschung und Gesellschaftspolitik, and JSB GmbH.

The study provided results regarding the conditions that are needed for the maintenance, insofar as possible, of an independent lifestyle in private households for people (mainly elders) that are dependent on assistance. The study was realized beginning in 2003 by a TNS Infratest München research consortium as a clinical study that investigated the following: the potential and treatment options of elders; informal assistance and professional services; and the quality and controllability of caregiving structures. The study's empirically sound findings will make an important contribution to the debate on the future of home ambulant care.

The results of the study were satisfactory on the whole:

- Persons that have difficulty taking care of themselves, irrespective of the severity of their disorder, could be provided with care in their own homes over a long period, providing that the necessary conditions were in place.
- An average of more than *eight years* of long-term care is provided to persons living at home that have difficulty taking care of themselves. 92 percent of the probands receive assistance from either their families or their social environment.
- It is also completely feasible to provide dementia patients with home care, even in the advanced stages of the disease.
- The home environment and its immediate environs are crucial when it comes to providing quality care for persons that have difficulty taking care of themselves.
- In view of the increasing length of people's working lives, the furtherance of more efficient interfaces between family care activities and professional care services will take on growing importance in the coming years.

The ZI MUG III study, *Potential for and limitations of elders with dementing illness that live at home*, was the first German population study that provided current home care data for dementia patients on the basis of a nationwide sample.

Project director:

Dr. Martina Schäufele

Arbeitsgruppe Psychogeriatric, Zentralinstitut für Seelische Gesundheit

J 5

68157 Mannheim

Tel.:0621-1703-6352

e-mail: schaeufe@zi-mannheim.de

Issues investigated; objectives

The main goal of the investigation was to obtain a global picture of the living situation of dementia patients and their caregivers. Toward this end, data was collected on the home settings of, and care being provided to, dementia patients, as well as the circumstances of and mental strain on the relatives caring for these patients. Our aim was to determine (in conjunction with the results of the other project partners' work) which specific measures (e.g. skills training, optimized information structures) could potentially promote efficient and cost-saving home care for elders with psychic disturbances.

Methods and procedure

The research questions were addressed by means of an in-depth prevalence study whose one-year data gathering phase was initiated following conclusion of a nationwide representative survey conducted by Infratest. The study inclusion criteria were as follows: detection of memory and concentration problems during the screening for the representative survey; over 60 years of age; restrictions on daily activities such as shopping and personal hygiene. The study was realized by means of an interview with each proband that was conducted during a visit to the proband's home by a trained interviewer. The proband's family and friends were also surveyed, irrespective of whether or not they were acting as caregivers for the proband.

Results

A total of 306 care-dependent persons were investigated. 68.6 percent of the probands were females and the mean age was 80.2. A diagnostic investigation realized by the study team detected symptoms of dementia in 151 of the probands, whereas dementia was ruled out in the remaining 155 probands. At baseline, dementia had been medically diagnosed in less than one third of the probands, and only 15 percent were taking antidementia drugs. The dementia probands' need for care and assistance increased substantially as their dementia became more severe, and this need was in all instances higher than the need experienced by non-dementia probands. For example, only 12 percent of the severe dementia patients and 30 percent of the moderate dementia patients could be left alone for several hours at a stretch, versus 84 percent for care-dependent non-dementia probands. Accordingly, approximately 75 percent of the dementia probands availed themselves of services covered by statutory long-term care insurance, and use of these services increased markedly as the probands' dementia became more severe. 100 percent of the dementia probands availed themselves of these services at some point over the course of the study.

Relatives provided virtually all of the probands' care and assistance. The primary caregiver for over 70 percent of the probands was a female, usually a daughter or wife. 43.3 percent of these caregivers received support from professional services, as well as caregivers that the probands paid for out of their own pocket. According to a standardized assessment questionnaire, nearly 80 percent of the dementia probands benefited at baseline from stable home care arrangements, i.e. the proband was being provided with sufficient assistance, the primary caregiver was not overburdened; and there were no plans to move the proband to a home over the next 12 months, nor was such a move considered likely. The survey results showed that the extent to which home care arrangements remained stable was mainly determined by the extent to which the primary caregiver regarded herself as being overburdened by her caregiving duties. In other words, the more overburdened a caregiver felt, the more destabilized the care arrangements became. The most important contributor to mental strain on caregivers was the presence of affective, so-called non-cognitive symptoms such as apathy, depression, sleep disturbance, agitation, and aggressive behavior. The more severe these symptoms became, the more

overburdened the primary caregiver felt. The feeling of being overburdened was also affected by circumstances relating to the care setting and caregiver. For example, the primary caregiver felt that she had less of a burden if she was receiving substantial support from friends and neighbors, had a positive attitude toward her caregiving duties, and/or had previously provided care for a relative. Caregiving was far less of an emotional strain on male caregivers, who had substantially fewer depressive symptoms than their female counterparts.

Conclusions

The study findings are altogether striking:

- Like other people, dementia patients would prefer to spend their twilight years in their familiar home environment, and doing so is perfectly feasible, providing that care is provided under appropriate conditions.

The study results adumbrate the criteria such conditions must meet:

- The issue of the compatibility of caregiving and a career is deserving of particular attention, since in over 70 percent of cases the primary caregiver was a female, usually the proband's wife, daughter, or daughter in law. As dementia caregivers increasingly join the workforce, it will be necessary to adjust the conditions under which they provide care, as well as the terms and conditions of their salaried employment.
- Greater use should be made of the available diagnostic and therapeutic resources for dementia patients with a view to providing higher quality prophylaxis and care. This is particularly important when it comes to non-cognitive symptoms, many of which can be palliated non-medically (through specialized, needs oriented interventions, positive activities, and wellness optimization) and medically (via antidementia and psychotropic drugs). Such measures would also help to improve the quality of life of the patient and their caregivers.
- Caregivers should be afforded the opportunity to augment the patient's care by sending them to a day clinic if necessary.
- Statutory long-term care insurance benefits are a key element when it comes to planning and implementing individualized arrangements for this type of care.
- Optimized skills training for counselors, practitioners and caregivers in the realm of diagnostics, as well as non-medical and medical interventions for dementia patients could constitute an important first step toward providing home dementia caregivers with efficient support.

Unresolved and additional issues

Although non-medical interventions that provide adequate care and efficiently palliate non-cognitive dementia symptoms have been successfully developed and piloted, such methods are lacking for dementia home care. However, encouraging findings from the U.S. and Australia suggest that providing family-member caregivers with specific counseling and training in the realm of communication, as well as dealing with dementia, can reduce non-cognitive symptoms, improve the patient's physical health, and enable the patient to remain in his home environment for a longer time. Unfortunately hardly any such programs are available in Germany. There is a great need for research in this area.

Further reading

Schäufele, M., Köhler, L., Teufel, S., Weyerer, S. (2006). Demenzielle Erkrankungen bei älteren Menschen in Privathaushalten: Potenziale und Grenzen. In: U. Schneekloth & H.-W. Wahl (ed.). Selbständigkeit und Hilfebedarf bei älteren Menschen in Privathaushalten. Pflegearrangements, Demenz, Versorgungsangebote. Stuttgart: Kohlhammer, in press.

Köhler, L., Weyerer, S., Schäufele, M. (2006). Geschlechtsunterschiede in der häuslichen Pflege: Ergebnisse einer bundesweiten populationsbezogenen Studie. In: T. Klie, A. Buhl, A. Hedtke-Becker & H. Wallrafen-Dreisow (ed.). Generationen in Familie und Gesellschaft in einem zusammenwachsenden Europa. Frankfurt: Mabuse, in press.

Further information on the results of MUG III is available (in German only) in a condensed and complete version at www.bmfsfj.de (click "Forschungsnetz").

Dementia Competence Network

Dementia is steadily becoming a social challenge as life expectancy increases. To address this growing problem, the Dementia Competence Network was established, and has been receiving support by the Federal Ministry of Education and Research (BMBF) since 2002. This nationwide network includes 14 leading university centers in the field of dementia research. Other participants are hospitals, medical specialists and family doctors in private practice, industrial companies and self-help organizations such as the Deutsche Alzheimer Gesellschaft e.V. Network administration and coordination is task of Zentralinstitut für Seelische Gesundheit, Mannheim.

Participants of the Network:

FU Berlin (Frau Prof. Heuser)	Uni Bonn (Prof. Maier)
Uni Düsseldorf (Prof. Gaebel)	Uni Erlangen (Prof. Kornhuber)
Uni Frankfurt (PD Dr. Frölich)	Uni Freiburg (PD Dr. Schmidke)
Uni Göttingen (Prof. Rütger)	Uni Hamburg (Prof. van den Bussche)
Uni Heidelberg (Prof. Schröder)	Uni Homburg/Saar (Prof. Falkai)
Uni Leipzig (Prof. Angermeyer)	LMU München (PD Dr. Hampel)
TU München (Prof. Kurz).	

Goals and projects

The Dementia Competence Network aims to develop advanced national guidelines for the diagnosis and treatment of dementing diseases, thereby ensuring maximum quality in public health care. Another goal is to intensify and foster the exchange of knowledge between scientists and practitioners. Additionally special training is to be offered in particular to improve the early diagnosis and treatment of dementing diseases by general practitioners. Thus the research priorities of the Competence Network – early recognition and diagnosis; therapy; epidemiology and genetics – mainly focus on the development and optimization of methods for early diagnosis and treatment of dementia. The collection of epidemiological data and the identification of risk factors are expected to produce new insights into the origin and course of dementing diseases. Furthermore there are plans for establishing a central gene database for dementing diseases.

Contact

Network speaker: Prof. Dr. Wolfgang Maier, Bonn
Coordinating Center
Dr. Oliver Peters
Koordination "Kompetenznetz Demenzen"
Zentralinstitut für Seelische Gesundheit
J 5
D-68159 Mannheim
Phone: +49 (0)30/ 8445 8312
Fax: +49 (0)30 / 8445 8350
E-mail: demenz@zi-mannheim.de

Public Relations and Press Office

Ulrike Jansen
Presse- und Öffentlichkeitsarbeit "Kompetenznetz Demenzen"
Zentralinstitut für Seelische Gesundheit
D-68159 Mannheim
Phone: +49 (0)621 - 84 588 94
Fax: +49 (0)621 - 84 588 96
E-Mail: jansen@zi-mannheim.de

IT Office

Dipl.-Math. Birgitt Wiese
Institut für Biometrie
Medizinische Hochschule Hannover
Phone: +49 (0)511 532 - 44 14
Fax.: +49 (0)511 532 - 42 95
E-mail: wiese.birgitt@mh-hannover.de

Evaluation of special inpatient dementia care in Hamburg

Project period: December 2001 to December 2003

Drs. Siegfried Weyerer and Martina Schäufele
Zentralinstitut für Seelische Gesundheit, J5, D-68159 Mannheim
weyerer@zi-mannheim.de

Project focus and goals

Recent studies show that approximately two out of every three German nursing home residents suffer from some form of moderate or severe dementia, a disorder characterized by cognitive impairment, other psychiatric symptoms, and behavioral problems that impact the quality of life of the dementia patient, fellow nursing home residents and the nursing home staff.

In the interest of meeting these challenges, the special dementia care program at the University of Hamburg hospital has developed novel management methods for behavioral disturbances associated with dementia. Special inpatient dementia care can be realized on the basis of either a segregated or partially segregated model.

- The segregated model involves specialized, segregated round the clock care for dementia patients living in a special care nursing home unit.
- In the partially segregated arrangement, dementia patients share a residential unit with non-dementia residents but spend part of the day in a special group for dementia patients.

The acceptance criteria for special dementia units in Hamburg are as follows:

- *Diagnosis of irreversible dementia*, which means that the patient scores less than 18 points on the mini-mental status examination (MMSE);
- *A minimum of care level 2*, pursuant to a declaration from the insurer;
- *Severe behavioral problems*: a minimum of one severe or three mild disruptive behaviors according to the modified Cohen Mansfield Agitation Inventory;
- *Mobility*: the patient must be mobile enough to participate in group activities and general group social life.

The study addresses the following questions:

- How do care quality and quality of life differ for Hamburg's segregated dementia patients versus their partially segregated counterparts?
- In which respects is special dementia care in Hamburg nursing homes more beneficial than classic integrated dementia care provided by the city of Mannheim?
- How do nursing staff workload/mental strain differ in Hamburg's special care units and Mannheim's classic integrated units?

Methods and procedure

We adopted a longitudinal comparison-group study design for evaluation of special dementia care in Hamburg's nursing homes. Data was gathered at baseline and after six months. The control and comparison conditions corresponded to the classic integrated care that is widely practiced in Germany, whereby dementia and non-dementia patients receive care in the same residential unit without any specialized human resources, physical infrastructure or services. The comparison group of dementia patients receiving classic integrated care was recruited from nursing homes in Mannheim. The following two residential groups were studied longitudinally in both the classic and special care settings:

- New admissions within the framework of natural attrition
- The cross-section or baseline-date population of residents that were living at the nursing home on a specific reference date and who had thus spent a specific amount of time in the facility.

After carefully weighing the pros and cons of various data gathering methods (self evaluation by the dementia patients; observation of patient behavior; evaluation by relatives or nursing staff) we decided to have the nursing home's professional nursing staff gather the study data since they are the primary interaction partners for nursing home residents and, as previous studies have shown, can provide reliable assessments of care quality and quality

of life indicators. This type of standardized and efficient investigation method provides empirical data on all nursing home residents, including those with severe physical, cognitive and sensory problems.

The working conditions of and mental strain on nursing home staff were investigated through administration of a single cross-section survey that was based on a questionnaire developed by a group of psychogeriatric experts. We also employed the Center for Epidemiological Studies Depression Scale, which is widely used internationally.

Results

Numbers of patients in Hamburg's specialized dementia facilities:

At baseline (March 2002) there were 31 specialized dementia facilities in Hamburg with space for 744 patients, 62 percent of which were receiving segregated care and 38 percent of which were receiving partially segregated care. A total of 28 facilities with 594 residents participated in the study, i.e. more than 80 percent of all facilities in Hamburg were investigated.

Characteristics of the comparison group consisting of nursing home dementia patients receiving classic integrated care:

The comparison group was formed by selecting a random sample of patients from 11 Mannheim nursing homes who receive care in accordance with the classic integrated model. Toward this end, we conducted a screening of all 1009 persons residing in these facilities on the baseline date. It was found that 644 probands (63.8 percent) had moderate or severe dementia. Of the 573 dementia patients aged 65 or older, 13.7 percent satisfied the "Hamburg criteria," which means that they exhibited behavior problems and were not bedridden.

Results of the comparison of segregated and partially segregated dementia management in Hamburg:

The following advantages and disadvantages of segregated and partially segregated care were observed in Hamburg: Partially segregated residents were more active in absolute terms and over time and received more frequent visits from friends and relatives. However, segregated patients were asked for biographical information significantly more often than integrated patients. A higher proportion of segregated patients were under psychiatric care, and these patients were also given psychotropic drugs (antidementia and antidepressant preparations) significantly more frequently, but received fewer neuroleptics.

Results of the comparison of special dementia care in Hamburg and classic integrated dementia care in Mannheim:

This comparison revealed that according to a number of indicators, the quality of life of dementia patients in Hamburg's special care nursing home units was substantially higher. This was manifested by more frequent expressions of positive feelings, greater participation in more skill-building activities, greater involvement in the resident's care on the part of friends and relatives, more social interaction with nurses, fewer confinement measures, and higher quality psychiatric care. However, contrary to our expectations, behavioral problems amongst the patients under classic care tapered off more rapidly

Results of the comparison of the working conditions and workload/work related stress of nursing staff in Hamburg and Mannheim:

Staff from 21 of Hamburg's 31 special care dementia units completed the written staff questionnaire. Of the 482 questionnaires distributed, 237 (49.1 percent) were returned and could be evaluated. Of these, 183 were completed by staff in special care (segregated and partially segregated) dementia units and 54 by staff at integrated units. The staff at all 11 of Mannheim's classic integrated facilities participated in the survey. Of the 502 questionnaires distributed to staff members there, 247 (49.2 percent) were returned and could be evaluated.

It was revealed that for all criteria with the exception of "social climate," the staff in Hamburg's specialized dementia units gave their working conditions significantly higher rankings. The staff at Hamburg's specialized dementia units also have a lower workload, less work stress, and fewer depressive symptoms.

Conclusions; implementation options

Our evaluation of Hamburg's special dementia care units was Germany's first extensive and controlled longitudinal study of the impact of special care on dementia patients and their caregivers in nursing homes. In interpreting the results presented here, it should be borne in mind that Hamburg's special care dementia units were only investigated as an undifferentiated whole. It would therefore be useful to conduct a follow-up study with a view to testing specific hypotheses and measuring the efficacy of the various constituents of special nursing home care for elders with dementing illness, and the extent to which individual and transferable features of special care such as specialized personnel training and lower nurse-patient ratios would also be beneficial in classic integrated settings.

Further reading

Weyerer S, Schäufele M, Hendlmeier I, Kofahl C, Sattel H (2006) Demenzkranke Menschen in Pflegeeinrichtungen. Besondere und traditionelle Versorgung im Vergleich. Kohlhammer: Stuttgart

An executive summary of the study is available (in German only) at www.bmfsfj.de (click "Forschungsnetz")

Nursing home care quality development

Project period: November 2002 to April 2006

Bundeskonferenz zur Qualitätssicherung im Gesundheits- und Pflegewesen e.V.
(BUKO-QS), Güntherstr. 51, 22087 Hamburg (www.buko-qs.de)
Project office: Fritz-Wildung-Str. 22, 14199 Berlin

Objectives

In Germany and elsewhere in Europe, pilot projects are one of the most useful quality assurance, quality development and quality management tools in the healthcare and social policy spheres. The applicable best practice statutory regulations lay down requirements for such projects that all stakeholders are required to fulfill. The present pilot project set out to develop standardized quality assurance methods for chronic care by translating three empirically grounded quality levels (guidelines) into the central elements of inpatient nursing home care. Work was realized on the following issues and processes in collaboration with various partner research organizations:

- Mobility and confinement measures for dementia inpatients
- Oral administration of solid and liquid nourishment to nursing home residents
- Quality of life and social integration issues in the lives of persons that have difficulty taking care of themselves.

Methods and procedure

The relevant quality levels were defined on the basis of (a) a comprehensive and pluridisciplinary search of the evidence-based literature; and (b) an interdisciplinary procedure involving collaboration between research teams and pluridisciplinary experts' groups. These experts established objectives and standards on the basis of a standardized consensus procedure. The method employed mainly followed the 2001 recommendations of the European Council on the development of medical guidelines.

Implementation tools were developed by the German conference on quality assurance in the field of healthcare (Bundeskonferenz zur Qualitätssicherung im Gesundheits- und Pflegewesen) on the basis of a so called structural model consisting of the following levels: theme related core statements, the objectives derived therefrom, and a matrix setting forth the requirements to which internal and external stakeholders are subject. The structural model and attendant method, whose use was mandatory for all three teams of experts, also took into account the problems faced by persons in need of long-term care and/or their proxies, as well as the role of volunteerism in nursing care.

Results

The pilot project described bears testimony to the strong commitment amongst researchers and practitioners to the fields of quality development and long term nursing care. Interest in internal and external quality insurance methodologies has greatly increased amongst cost centers, facility owners, the quality assurance community and other stakeholders. Successful quality management must above all be transparent and impartial, and must legitimate and define quality standards that provide reliable guideposts.

Finding a quality assurance balance between patient orientation and paradigm viability

In pursuing quality level related goals and approaches, the specific requirements of elders in need of long-term care must also be taken into account. This also presents a paradigm conceptualization challenge in light of the increasing importance of ethical standards in the quality domain, particularly (though not solely) in settings where cognitive or severe degenerative disorders make elders dependent on others, or where it is necessary to accept individual decisions during an elder's final illness. In such situations, it is necessary to find a balance between patient orientation and paradigm viability, which means that caregiving paradigms must be

conceptualized and implemented in such a way that the practical needs of persons in need of long-term care, as well as the needs of their families and friends, are taken into consideration.

Issues relating to the scope of adequate care for persons with dementing illness played a predominant role in all three projects.

Aggregation of pluridisciplinary know-how

It was clear from the public hearing and the work realized by quality-level experts' groups that the development of quality nursing care now benefits from a strongly committed lobby comprising a broad spectrum of occupational groups. However, this lobby needs systematic support, including assistance in coordinating its efforts and synthesizing the relevant information. Diverse though the motives driving this increased interest in long-term care quality assurance may be, there appears to be a growing consensus amongst all stakeholders that the development of evidence based internal and external quality assurance methods is indispensable in this particular area of healthcare.

The present pilot project addressed these issues, and in so doing developed quality levels and piloted methods that meet the requirements described above in the following ways:

- The project elaborated empirically based quality objectives from the standpoint of persons that have difficulty taking care of themselves and devised guideposts for the implementation of these standards in everyday practice.
- The procedure used was pluridisciplinary and involved care recipients in the paradigm development process.
- The project defined the spheres of responsibility for the various disciplines and described the specific role played by volunteers, family and friends.
The project addressed the issue of the social integration and autonomy of care recipients and placed their needs at center stage.
- The project promoted transparency and in so doing defined the shared spheres of responsibility of internal and external stakeholders for qualitative long-term care.

Quality standards versus cost efficiency

The project experts specifically mentioned that the conflict between achieving specific quality standards and cost efficiency can in some cases be a problem owing to the interplay between the financial impact of quality standards and the cost of statutory entitlements to medical care. But the experts also unanimously agreed that this problem should not be allowed to jeopardize the quality standard development process, which in turn means that the attendant negotiation process should unfold in a different context. The experts even assert that quality care can have long term economic benefits, particularly in the context of an aging population.

Pluridisciplinary quality levels in the European context

The demonstration project also conducted a literature search with a view to (a) basing the project's standards development process on German and international experience with pluridisciplinary quality development; and (b) finding relevant application scenarios in the relevant disciplines. This search revealed that precious little methodical know-how exists in this domain. In addition, the literature search on quality levels showed that little hard data is available on the central issues in the field of long-term care.

The validity of the paradigm and thrust of the present pilot project is borne out by the direction the European quality debate on long term care has taken of late, as well as the tendency to integrate healthcare recipients into the process of developing quality assurance measures.

Practicability and acceptance

The need for public sector legitimization of healthcare costs and resources has greatly increased the importance of mandatory validation of quality assurance methods throughout Europe. The piloting of best practice quality levels and the evaluation of the attendant implementation process is decisive in evaluating quality level viability and practicability. The implementation process also plays a major role in (a) achieving durable acceptance and widespread implementation of the relevant quality levels; (b) allowing for recourse to the courts where

necessary; and (c) the application and recognition of quality levels by quality assurance entities. Although an implementation method for our model is currently under development, the quality levels can be used in their present form for internal quality management purposes.

For further information on the project, as well as the work of the German conference on quality assurance in the field of healthcare (Bundeskonzferenz zur Qualitätssicherung im Gesundheits- und Pflegewesen), visit www.buko-qs.de (available in German only).

Development of quality assurance, assessment and auditing tools for specialized dementia care (QSP)

Project period: 2002-2006

Deutsche Expertengruppe Dementenbetreuung e.V. (DED e.V.)
Rakower Weg 1
24354 Rieseby

Issues investigated; objectives

1. Baseline situation

The issue of quality management and assessment in geriatric care is more topical than ever before. Now that statutory across the board quality/quality assurance standards and metrics have been defined, quality assurance must be documented and is subject to assessment based scrutiny. Hence the need for efficient quality management and assurance systems is greater than ever before and is increasing for long-term care facilities as well. But the quality assurance systems currently available in Germany, which were developed for industrial or military applications (and are now being marketed in the healthcare sector), are unsuitable or only marginally suitable for specialized dementia care. Such systems, which have little or nothing to do with nursing care, are based on normative structures and systems. But in order for elders with dementing illness to be provided with suitably individualized care, it is often necessary to set aside the usual norms.

2. Background of the study

Experience with the unsuitability of existing quality management and assurance systems for the specific needs of specialized dementia care prompted the German dementia care association (Deutsche Expertengruppe Dementenbetreuung, DED) to initiate a proactive quality program in 2003. In meetings with officials of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (Bundesministerium für Familie, Senioren, Frauen und Jugend, BMFSFJ), it became clear that suitable quality management systems for specialized dementia care are lacking. The DED was awarded a contract to realize the following activities: (a) assess the suitability of German and foreign quality management systems for persons with dementing illness; (b) conduct a praxis oriented research project with a view to developing a quality management system that meets the specific needs of institutions that provide specialized dementia care for the elderly. The quality management efficacy of the newly developed quality management system was then tested by eight such institutions.

The project addressed the following issues:

- Which quality management system has the capacity to (a) determine whether specialized dementia care meets “best practice” standards; (b) promote the optimization and allow for the third party assessment of such standards?
- Which criteria reflect the current state of knowledge in the field of care for elders with dementing illness? Which of these criteria are amenable to “best practice” assessment in institutions that provide specialized dementia care?

Methods and procedure

We employed the German Integrated Quality Management system (IQM), which is based on the Canadian Council on Health Services Accreditation (CCHSA) Standards for Long Project period/Continuing Care Organizations. IQM is currently the only German quality management system that was developed by and for the continuing care sector and thus takes its specific needs into account.

The IQM system places the elder and their family at center stage. It eases caregiving personnel into a system involving the following: a self-assessment process; calling into question existing structures, processes and outcomes; identifying discrepancies between the services offered and the experience of receiving those services on the part of elders and their families; self determination of quality levels and quality development processes.

Thus rather than (pre)defining quality standards, the system specifies criteria that continuing care must meet in order for the quality of the services provided to be palpable for facility residents and their families.

A checklist of requirements and questions for specialized dementia care was developed by the DED experts committee (with technical assistance from IQM expert Alfred T. Hoffmann) on the basis of the aforementioned

Canadian quality management system. Six “best practice” organizations that provide specialized care for elders with dementing illness tested the effect of IQM on quality development in their institution for a period of 30 months. Quality coordinators and workshop moderators received 23 days of training in preparation for work with six pluridisciplinary self-assessment teams. Over 150 staff members of the various organizations were involved in the IQM trial, which involved the following activities:

- The self-assessment teams defined quality requirements and questions for the following quality domains: care and assistance; and management in the realm of information, risk, human resources, everyday activities, and strategy. A strength-weakness analysis was then realized on the basis of a five-level evaluation scale for each of the 93 requirements and 412 questions with a view to assessing quality fulfillment and documenting any weaknesses that were detected.
- In the succeeding phase, 20 quality improvement projects were developed, tested and implemented by the staffs of the various institutions.
- The IQM quality assurance feedback tool devised by the DED’s experts committee allowed the various organizations to have a final assessment of the IQM trial realized by trained peers. A profile elaborated for each organization characterized the congruence between the following elements:
 - (a) self assessments and outside assessments;
 - (b) assessments by families and staff;
 - (c) the various functional domains in each institution.

The degree of congruence that was determined provided insight into the level of quality at the various institutions, and allowed for identification of strengths, successes and weaknesses. Each organization then proceeded to define its own quality development process.

Results to date

All project outcomes were exhaustively assessed in collaboration with the project participants. This assessment process revealed that IQM had an overwhelmingly positive impact on organizational and quality culture, as well as quality development.

The IQM system

- sets standards for quality development;
- results in a development spiral;
- promotes self-critical introspection;
- allows for the detection of problem areas;
- promotes transparent accountability;
- enhances the organization’s individuality;
- engenders staff loyalty and value orientation;
- promotes networking

Specialized dementia care requires specialized structures in order to achieve outstanding quality outcomes. And this in turn necessitates an appropriate attitude toward elderly people with dementing illness – and people in general. Quality is always a dynamic process that cannot be successfully realized without a high level of awareness and an intelligent implementation solution. IQM graphically demonstrates to all stakeholders the importance of developing an appropriate attitude toward persons with dementia, and in so doing encourages staff members to create and maintain an organizational culture that fosters such an attitude. The self-assessment process promoted by the IQM system clearly reveals to all stakeholders the interaction between staff attitude, awareness, and professional expertise on one hand, and user/consumer satisfaction on the other.

There is no place in the IQM system for the kind of territorial stance (“This is my bailiwick and no one else’s business”) and secrecy (“I keep my cards close to my chest”) that are so widespread nowadays. The IQM system takes the exact opposite tack in that structures, processes and outcomes become so transparent that all stakeholders can orient themselves to these elements and act accordingly.

The final assessment of the IQM by the project organizations was as follows: “The IQM system, including its feedback mechanism, allows for detailed quality mapping to a far greater extent than any other quality management system, thus promoting quality development in the specialized dementia care sector.”

Conclusions; implementation options

The range of care services currently available in Germany for elders with dementing illness is bewilderingly extensive, with virtually every continuing care organization offering specialized dementia services. It is for this reason that the German professional dementia care association (Deutsche Expertengruppe Dementenbetreuung) is making efforts to institute a system whereby all long-term care organizations that specialize in care for elders with dementing illness are required to assess internally, and continually improve the quality of, their services on the basis of the Integrated Quality Management system (IQM). Currently under consideration are implementation of an accreditation procedure, as well as realization of a broader-based follow-up “field study” involving 30-40 continuing care organizations that specialize in care for elders with dementing illness.

For further information (in German only) visit www.demenz-ded.de

Networked volunteers and residential groups for elders with dementing illness: the Freiburg approach

Support for a network for residential groups of elders with dementing illness, staffed by volunteers and family members who carry out all caregiving and logistical tasks

Funding aim: promote volunteerism and network formation; funded by the Federal support for the elderly program of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (Bundesministerium für Familie, Senioren, Frauen und Jugend, BMFSFJ).

Project period: May 2004-June 2006

The project was realized under the aegis of Kontaktstelle für praxisorientierte Forschung e. V. at Evang. Fachhochschule Freiburg. Dr. Thomas Klie, chairman of the university's gerontology and continuing care department, served as science and professional consultancy coordinator for the project.

Kontaktstelle für praxisorientierte Forschung e.V. an der Evang. Fachhochschule
Bugginger Strasse 38
79114 Freiburg

Tel.: 0761-47812-638

Fax: 0761-47812-699

klie@efh-freiburg.de

Project focus and goals

In view of the challenge posed by demographic aging in Germany and the attendant growing need for long-term dementia care, residential groups provide a viable alternative to family or nursing home care. Taking the welfare mix and collaboration/networks (coproduction) paradigms as a starting point, the present study investigated the conditions that promote successful participation by family members and volunteers in residential groups for elders with dementing illness. The study focused on the following factors:

- Participants' motivational and sociocultural background
- The role of collaboration/networks (coproduction) consisting of volunteers and professionals in long-term care and household management
- Implementation of a viable stabilizing network for residential groups
- The impact of social security regulations and the attendant conditions on residential groups
- Quality assurance

Methods and procedure

Initially, a literature search and analytical evaluation of empirical studies were realized with a view to gathering data on lay volunteer involvement in residential units and residential groups. In a second phase, qualitative, guideline supported interviews were conducted with 17 experts and volunteers from nine residential groups and the results were evaluated analytically. A comparison of the activity protocols (volunteers and family members) and work schedules of professional caregivers will provide further insight into the workflows and division of labor. The initial results of the study were presented in February 2006 at a two-day workshop that was attended by the respondents, as well as representatives of local governments, the Baden-Württemberg Ministry of Social Affairs, and the lead health insurer associations.

Interim results

Respondents become involved in a dementia residential group for a number of reasons, which are also subject to change as time goes on, or depending on whether the group is just being established or is up and running. The following reasons were identified:

- The respondent has a relative with dementia
- The opportunity to perform meaningful tasks such as long-term care
- Like-mindedness
- The pursuit of ideals or idealistic goals
- To acquire skills/knowledge and/or for personal development

- Work related reasons or the opportunity to participate in an innovative/progressive undertaking
- Financial reasons

Family members and volunteers translate the actual task – namely caring for elders with dementing illness – into a personal task image that is based on the opportunity to shape a new undertaking. This redefinition encompasses person related primary tasks (e.g. cooking with and for group members, the realization of basic and specialist care tasks, conversing with the residents and taking walks with them) as well as auxiliary organizational tasks such as financing, legal matters, management, supervision, moderation and meeting with family members. The opportunity for self-determination is a key commitment motivator for family members and volunteers (professional caregivers say much the same thing). This degree of task orientation is essentially a form of intrinsic motivation. Hence, the commitment to work in dementia residential groups is attributable to the following factors from an empirical and paradigmatic standpoint: (a) the opportunity to perform meaningful tasks; (b) the opportunity to determine the nature of these tasks and then carry them out; and (c) the opportunity to carry out tasks from beginning to end. This completeness is reflected by the fact that volunteer and family member tasks pertain to more than just a single dimension of a specific activity and that these individuals feel that (a) their “whole self” is involved (residents group 2, 2) and (b) “everyone does everything” when it comes to the logistics of their residents group (this statement was made in all interviews).

The four elements of the welfare mix model – market, public sector, family, and the third sector with its proprietary functional logistics – converge in residential groups in a minute space, where they are integrated, in some cases in one and the same person. Any envisaged and predefined fixed role allocation, or limiting a volunteer’s sphere of responsibility to their own relative, or limiting the sphere of responsibility of a professional caregiver to specific residents, contravenes the basic tenets of the welfare mix model, as well as the reality of the residential groups that we investigated. The various elements of this model interact in the microcosm of the residential group in accordance with the context, and at the same time are dependent upon the conditions and resources that accrue to the other elements. This requires the volunteers and family members to discuss and agree upon the scope of the various tasks, and in so doing evolve a shared *modus operandi*.

The data on the sociocultural background of the volunteers, quality assurance, and the *raison d’être* of a network have not yet been evaluated. This will be realized at a later time on the basis of respondent feedback (communication based validation).

Conclusions; implementation options

The case management process should concern itself with the integration of volunteers’ perceptions of themselves, their roles and their tasks. In addition, current laws that are a hindrance to the realization of volunteers and residential groups should be changed.

Further reading

The study report will be completed by October 31, 2006.

For further information (in German only) on the project as a whole, visit www.freiburger-modell.de.

Reduced used of physical restraints for dementia patients residing in nursing homes

Demonstration project (ReduFix) aimed at reducing the use of belt restraints and confinement measures for dementia patients residing in nursing homes

Project period: May 2004 to June 2006

The project was realized under the aegis of Kontaktstelle für praxisorientierte Forschung e. V. at Evang. Fachhochschule Freiburg. Dr. Thomas Klie, chairman of the university's gerontology and continuing care department, served as science and consultancy coordinator for the project.

Kontaktstelle für praxisorientierte Forschung e.V. an der Evang. Fachhochschule,
Bugginger Strasse 38
79114 Freiburg

Tel.: 0761-47812-638

Fax: 0761-47812-699

klie@efh-freiburg.de

Robert Bosch Krankenhaus

Klinik für Geriatrische Rehabilitation

Dr. Clemens Becker, Director

assisted by Petra Koczy, Ulrich Rissmann, and Denis Beische

Auerbachstrasse 110

70376 Stuttgart

Tel: 0711-8101-3101

Fax: 0711-8101-3199

clemens.becker@rbk.de

Assistance was also provided by Dr. Doris Bredthauer, Fachhochschule Frankfurt, Forschungskolleg Geriatrie Robert Bosch Stiftung

Project focus and goals

Restraining measures count as one of the most controversial interventions for agitation, proneness to falls, and behavioral disorders in dementia patients, and undoubtedly constitute the most severe violation of the human rights of nursing home residents with dementia. 5-10 percent of nursing home residents are currently restrained using belts. According to a study of nursing homes in Munich, more than 90 percent of restraining measures are realized on the grounds that the patient is prone to falls (Klie/Pfundstein 2004).

The ReduFix demonstration project was realized with a view to reducing the use of physical restraints by employing dedicated interventions without putting residents at risk. The project was realized in nursing homes and senior citizens homes in the German states of Bavaria, Baden-Wurttemberg, and Saxony. The goal was to reduce, within the term of the project, restraint times and the number of persons that were restrained, without incurring any increase either in fall related injuries or the administration of psychopharmaceuticals.

Methods and procedure

The project was realized using a controlled waiting list control design model whereby the participating organizations were divided into two groups via random distribution. The group of organizations that realized interventions began participating in the program immediately, whereas the waiting group entered the program three months later after receiving training. The primary end points were identified on the basis of continuous documentation of the restraints that were realized for each resident during the project period. Basic data on residents that were restrained and on the participating institution was gathered on cutoff dates at baseline and at the conclusion of the interventions, which comprised the following elements:

- a training program in which alternatives to restraints were demonstrated and discussed from a paradigm, legal, and psychosocial standpoint
- information on the relevant laws
- providing psychological and gerontopsychiatric expertise regarding the handling of psychopharmaceuticals and behavioral problems, as well as the use of new technologies such as movement sensors and (soft) attenuating hip protectors.

Results

A total of 45 nursing homes in the German states of Baden-Württemberg, Bavaria and Saxony (and one pilot facility) participated in this demonstration project. 514 residents were found to be restrained, and owing to the application of various exclusion criteria, data was evaluated for 364 of these individuals. A comparison of the intervention and waiting group data revealed the following statistically significant results:

- Restraints were removed from 20.8 percent of the residents in the intervention group and 11.3 percent of the residents in the waiting group.
- Restraint times were reduced by 20 percent for 23.81 percent of the intervention group residents and for 14.29 percent of the waiting group residents.
- Although the number of falls in the intervention group was significantly higher than in the waiting group, there was no increase in the number of injuries, no substantial rise in the administration of psychopharmaceuticals, and behavioral abnormalities were somewhat less prevalent. The results of the adjunct qualitative research suggest that the aforementioned effects could be heightened if communication and cooperation between nurses, physicians, families and the courts were improved.

Thus, for 20 percent of the residents studied, either restraints were removed entirely or restraint time was reduced without any negative consequences for the residents.

Conclusions; implementation options

The ReduFix demonstration project showed that restraints can be reduced or avoided through the use of dedicated interventions. These findings represent a first step, although the question arises as to whether the model employed here is applicable elsewhere.

One of the main success factors in the present study was its training program, whose purpose was to provide mentors (and through them, nurses) with a greater sense of professional and legal security in dealing with restraints, and point out alternatives to their use. An upcoming project in the German state of Baden-Württemberg (which will be funded by Landesstiftung Baden-Württemberg) will develop regional mentor training courses and offer in-house training. The project will also conduct an experimental program aimed at determining how volunteers can be integrated into the process of reducing the use of restraints..

A training manual is in preparation (see below).

Further reading

The final report, as well as the presentations given at the final symposium on July 11, 2006 can be downloaded (in German only) from www.efh-freiburg.de/agp/redufix.htm

A training manual will be published by Vincentz Network of Hannover in late 2006 or early 2007.

The following articles on the project have been published in the professional literature:

- Koczy P. Alternativen zu bewegungseinschränkenden Massnahmen gesucht. *Zeitschrift Altenheim* 10/2004. 29.
- Koczy P., Klie T., Kron M., Bredthauer D., Rissmann U., Branitzki S., Guerra V., Klein A., Pfundstein T., Nikolaus T., Sander S., Becker C. Effektivität einer multifaktoriellen Intervention zur Reduktion von körpernaher Fixierung bei demenzerkrankten Heimbewohnern. *Zeitschrift für Gerontologie und Geriatrie* 38/2005. 33-39.
- Branitzki S., Koczy P. ReduFix - Eine Studie zur Reduktion von körpernaher Fixierung: Heimbewohner vor Schaden bewahren. *Pflegezeitschrift* 5/2005. 310-313.
- Rissmann U., Guerra V. Schadensbegrenzung. *Zeitschrift Altenpflege* 8/2006. 26-28.

Experts' recommendations on strategies for dealing with challenging behaviors in dementia patients in nursing homes

Project period: June 2004 to May 2006

Dr. Sabine Bartolomeyczik
Universität Witten-Herdecke, Institut für Pflegewissenschaft
Stockumer Str. 12
68453 Witten
sbartholo@uni-wh.de

KDA Forschungs- und Beratungsgesellschaft für Altenhilfe mbH
An der Pauluskirche 3
50677 Cologne

Issues researched, goals and procedures

Working with dementia patients often poses major problems for nursing home staff, particularly when these patients are aggressive, prone to extremes of compulsive movement, have major orientation problems, inflict injury on themselves and others, and/or exhibit so called behavioral "abnormalities."

With a view to addressing these issues, the German Ministry of Health awarded a contract to the University of Witten-Herdecke and KDA Beratungs- und Forschungsgesellschaft (a subsidiary of Kuratorium Deutsche Altershilfe) to elaborate recommendations for dealing with challenging behaviors in nursing home dementia patients.

The proposals were developed in accordance with the recommended methodological procedure of the German healthcare quality assurance network (Deutsches Netzwerk für Qualitätssicherung in der Pflege, DNQP).

First an analytical literature search was realized under the supervision of an experts committee, primarily with a view to evaluating inpatient dementia caregiving interventions that are described and discussed in the literature. Recommendations were then elaborated on the basis of the findings from the literature search and the views of members of the experts group, and reasons were given for making these specific recommendations.

The results were then presented, discussed and approved at a conference.

The project results provide a quality management solution that is based on the experts committee's recommendations, which provide a framework for concrete action but are neither specific procedures nor individual and verifiable criteria. This framework can be fleshed out in a subsequent phase with a view to elaborating professional standards or for other purposes.

The experts committee's recommendations were as follows:

Recommendation 1: Empathic diagnoses

The experts committee recommended that an empathic model be applied to the diagnosis of challenging behaviors in dementia patients, whereby the patient's point of view and concerns should constitute the lynchpin of the caregiving process. Efforts to understand the dementia patients' behavior should take into account an optimally broad range of causal factors that are not directly related to the patient himself. Toward this end, the committee recommended that the need-driven compromised behavior (NDB) model or a similar instrument be employed. The committee also stated that the entire caregiving process should be discussed with the patient's family and friends, and that insofar as possible the patient's consent to the caregiving interventions should be obtained and/or the interventions should be discussed with the patient.

Recommendation 2: Challenging behaviors in caregiving settings should be documented and assessed objectively and methodically

The experts committee recommended that a specific assessment method be used to document challenging behaviors in cases of dementia. Such methods help to objectivise caregivers' key observations and thus make a major contribution to reaching empathic diagnoses that are also evidence based. The experts committee unanimously agreed that challenging behaviors should be documented in a largely structured manner since empathic diagnoses and the consequent interventions (or absence thereof) can only be based on standardized documentation and evidence based characterization of challenging behaviors.

Recommendation 3: Validation

The experts committee recommended that work and interaction with dementia patients that exhibit challenging behaviors should be fundamentally accepting and positive, i.e. caregivers should be empathic with the patient's situation, and should be accepting of the dementia and its impact on the patient's life. A validating attitude mainly focuses on the feelings and drivers of the behavior, and enables caregivers to deal with and respond to the dementia patient in an empathic and understanding manner, and to respect the patient's feelings. All caregiving organization staff should be familiar with methods that promote, as well as the importance of, dementia patient validation. Validating methods should be combined with other empathic methods and paradigms in accordance with the individual situation. The experts committee did not define a specific orientation for the validation process.

Recommendation 4: Affording the individual with dementia opportunities to reminisce

The experts committee recommended that reminiscing be realized as a discrete activity and that it be incorporated into caregiving related interaction with dementia patients that exhibit challenging behaviors. Recalling biographical events and past relationships strengthens the patients' identity and their sense of social integration. As dementia progresses, individuals in the patient's social environment should increasingly afford the patient opportunities to reminisce about pleasant experiences. This type of "reminiscence support" helps persons with dementia to maintain their social identities, their self-image and their ties to other people and the world.

Recommendation 5: Touching, basal stimulation and snoezelen

The experts committee recommended that the stimulation of one or more senses be integrated into caregiving activities and that such stimulation be realized in a judicious manner in dementia patients that exhibit challenging behaviors. In addition to the beneficial effect of this approach in ad hoc situations, it can also help to prevent challenging behaviors over the long term. However, such interventions should scrupulously avoid invasiveness. The committee also discussed touching as a vehicle for interaction, and the potential role of basal stimulation and snoezelen.

Recommendation 6: Promote physical activity

The experts committee noted that dementia patients that exhibit challenging behaviors should be afforded the opportunity to realize adequate daily exercise according to an individual regimen. Exercise is important for the health of all individuals, and studies suggest that physical activity has a beneficial effect on challenging behaviors. The experts committee stated that all daily activities should integrate elements that stimulate physical movement and promote the patient's awareness of his body, and that a series of sequenced movements should be realized daily for at least 30 minutes, the patient's capabilities permitting. This can be realized in a variety of ways, including through the use of passive exercises if necessary. If a patient's heightened urge to move is manifested by walking around, the patient should be afforded space in which to do this, preferably out of doors.

Recommendation 7: A caregiving attitude should be adopted toward acute psychiatric crises in dementia patients

The experts committee recommended that dementia patients that are prone to challenging behaviors and that have psychiatric crises induced by delusions, panic attacks, hallucinations or aggressive behavior should be valued and accepted. Caregivers should attempt to address the feelings underlying the behavior with a view to shifting the individual's focus away from their behavior, without casting the individual's perception of reality in a negative light. Caregivers should also avoid reinforcing the patient's delusions. De-escalation strategies should be employed in cases of aggressive behavior, and the committee found that Sauter's "in the event tensions rise or

risk is involved” principle is applicable to such settings. Restraining the patient should be the strategy of last resort and should be avoided whenever possible.

Further reading:

Halek, Margareta; Bartholomeyczik, Sabine (2006): Verstehen und Handeln.
Forschungsergebnisse zur Pflege von Menschen mit Demenz und herausforderndem Verhalten. Schlütersche,
Hannover

Extensive documentation regarding the committee’s recommendations, including reasons and background texts,
will be published in the fall of 2006 (in German only).

For further information (in German only) visit www.kda.de or www.bmg.bund.de.

Heidelberg method for the evaluation of dementia patients' quality of life (H.I.L.DE)

Project period: June 2003 to May 2006

Institut für Gerontologie der Universität Heidelberg
Bergheimer Str. 20
69115 Heidelberg
Tel.: 06221/548180
andreas.kruse@urz.uni-heidelberg.de

Sektion Gerontopsychiatrie des Universitätsklinikums Heidelberg
Vossstrasse 4
69115 Heidelberg
Tel.: 06221/564463

Project directors:

Dr. Andreas Kruse (Department of Gerontology)
Dr. Johannes Schröder (Department of Geriatric Psychiatry)

Subject experts:

Dr. Stefanie Becker (psychologist, gerontologist)
Roman Kaspar (psychologist)
Dr. Susanna Re (psychologist and gerontologist)
Uli Seidl, M.D.
Lena Völker (doctoral candidate)

Issues investigated; objectives

The HILDE project was based on the assumption that differentiated measurement of the residual resources of persons with dementing illness provides a pivotal starting point for shaping the strategic use of these resources. It is all too easy to underestimate the resources that are available to persons with dementia. Manifest cognitive disorders can lead physicians, nurses and relatives to conclude that the dementia patient is incapable of normal human interaction and lacks all grasp on reality. However, recent research has shown that even persons in the advanced stages of dementia are able to respond to situations in an emotionally differentiated manner. Inasmuch as such individuals can express themselves nonverbally at a minimum, viable interaction should be well within the reach of physicians, nurses and family members. Hence an instrument that measures dementia patients' quality of life such as that developed by the HILDE project takes on great significance in a caregiving context for the following reasons:

1. The HILDE method makes physicians, nurses and relatives more aware of the nuances of dementia patients' perception of and response to specific situations. This in turn allows for access to the individual experience and behavior of the dementia patient, and also helps nurses perceive the patient in the light of his potential competencies, rather than just his deficiencies.
2. The method helps raise nurses' awareness of the impact of their caregiving activities on the emotional states of dementia patients. Thus an instrument that measures patient quality of life can also motivate nurses to reflect on their own caregiving praxis.
3. Staff reflection on their caregiving praxis, the consequent increased focus on the dementia patients' current physical state, and iterative application of the instrument can potentially result in an improved quality of life for dementia patients.

Methods and procedure

A comprehensive psychiatric and psychological examination was performed on 365 nursing home residents in the city of Heidelberg. The results of these examinations were then used as a basis for differentiated assessments of the patients' cognitive status, psychopathological symptoms, everyday competencies, and affect.

The sample at a glance: Average age: 85.4 (range: 59-103). Average residency period in the home: 3.4 years (range: one month to 35.9 years). Mean MMSE value: 11.9 (standard deviation: 9.8). Mean GDS value: 4.7 (standard deviation: 1.8). Mean ADL score: 48.8 (out of 100; standard deviation 28.2). Proportion of residents with psychiatric problems (determined using NPI): 87 percent. The psychological findings yielded analogous results. Depression was the most prevalent symptom (52 percent), followed by apathy (41 percent), cognitive agitation (38 percent) and behavioral agitation (34 percent).

Two or more interviews with nurse caregivers were realized for each resident. In these interviews, the nurses provide the following information on each resident: emotional state in specific situations; favorite place to spend time inside and outside the facility; family and friends (using Antonucci's concentric circle method; the affective tenor of the relationship was also documented); conflicts in social relationships and possible conflict resolution strategies. Each resident's pain status, including pain localization and intensity, was also assessed using a specially developed pain diagnosis tool that is based on observed facial expressions, body language and vocal articulation.

Emotions in specific situations and settings were measured using the Facial Action Coding Systems (FACS; Ekman and Friesen, 1978) and Apparent Affect Rating Scale (AARS; Lawton et al., 1999). A comparison of the results obtained with the two methods showed that the AARS allows for accurate identification and classification of the various emotions with a far higher degree of probability. Subjective assessments of the patients' quality of life were based on the emotions manifested in specific situations, the ability to maintain a stable emotional state, and residents' own statements about their levels of satisfaction. Objective assessments of the patients' quality of life were based on the investigation team's assessments of (a) the quality of the residents' physical and infrastructure environment; and (b) the quality of the medical and nursing care provided.

Results

Four distinct competency groups were observed in the sample. Group 1: mild dementia (everyday competency intact, resident in an early stage of dementia). Group 2: moderate dementia (some everyday competencies intact, moderate cognitive and non-cognitive (emotional and behavioral) problems). Group 3: severe dementia accompanied by somatic symptoms (reduced everyday competency, severe cognitive problems, apathy). Group 4: severe dementia accompanied by psychopathological symptoms (reduced everyday competency, severe cognitive problems, high number of non-cognitive problems (mainly agitation and depression)).

The emotional state profiles corresponded to these four groups. Severe patients showed a far less favorable emotional balance, although the positive emotionality of the patients with behavioral problems was fully intact.

Of the categories into which the residents' activities fell – social activities, movement related activities, and support activities for persons with dementia – it was found that social activities elicited the most positive feelings amongst the patients. Here too substantial differences were observed amongst the four competency groups.

A favorite facility location – i.e. a setting that elicits positive feelings – was identified for 71 percent of the residents. However, it also emerged that a relatively high proportion of these favorite places could only be accessed with assistance.

42 percent of the residents experience pain (9 percent severe, 29 percent moderate, 4 percent mild).

59 percent of the residents are being managed satisfactorily via psychopharmacological therapy, 29 take an unsatisfactory drug or combination thereof, 13 percent are not dosed satisfactorily and 7 percent appear to be ripe for a switch to a different drug.

Conclusions; implementation options

The HILDE method allows for differentiated measurement of the following parameters: residents' options and activities (including the attendant emotional states); objective physical environment; subjectively perceived physical environment; subjectively perceived social environment, interpersonal conflicts and strategies for their resolution; current and long term emotional states; and pain statuses.

The optimization realized during the final phase of the HILDE I project primarily involved streamlining both the paradigm and praxis of the data gathering procedure, thus paving the way for an investigation of the practical usefulness of the method's current version (HILDE II). Queries received by the project team thus far from care facilities relate to HILDE's applicability to quality of life analysis methods for residential groups and private households.

Further reading

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For further HILDE related information (available in German only) visit www.gero.uni-heidelberg.de (click "Projekte").

An executive summary of the final project report is available (in German only) under "Forschungsnetz" at www.bmfsfj.de.

Longitudinal Study of Dementia Caregivers (LEANDER)

PD Dr. Susanne Zank & Dr. Claudia Schacke
Fachbereich Erziehungswissenschaften und Psychologie
Freie Universität Berlin
Habelschwerdter Allee 45
14195 Berlin

Project focus and goal

There is a high prevalence of dementia in old age and the disease often results in need of care. In the majority of cases, family caregivers provide the necessary care for these patients. The caregiving tasks are mentally and physically demanding. LEANDER wants to investigate these demands and their consequences for the caregivers in Germany. The study is based on theoretical assumptions derived from stress theory and aims at:

1. The development and methodological evaluation of a theory-guided complete measure of caregiving stress which should be sensitive towards change.
2. The identification of different profiles of caregiving with regard to specific characteristics of the caregiving situation (f.i., gender, kinship, duration of care, dementia status) in order to develop tailored interventions.
3. The description and prediction of different caregiving profiles over time.
4. The evaluation of different interventions.

Methods and procedure

In a first step, the Berlin Inventory of caregivers' burden of dementia patients (BIZA-D) was developed and psychometric properties were analyzed (Zank, Schacke & Leipold, 2006). The inventory consists of 20 subscales with 88 items. The following dimensions were considered: Objective caregiving tasks, Subjective burden due to dementia related behaviour problems, Subjective conflicts between personal needs and caregiving tasks, Job-caregiving conflicts and Family conflicts.

The study consisted of 5 measurement points at intervals of nine months, which means that the longitudinal time pattern lasted 36 months. The sample at time 1 consisted of 888 caregivers, complete data over five measurement points were obtained from 226 caregivers.

Results

LEANDER has a huge data set; here we can mention a few results, only (Zank & Schacke, 2006). The analyses of subgroups show that there are different types of caregivers with specific patterns of burden which have to be addressed by different interventions. For example, there is no difference between men and women in objective burden but a great difference in subjective burden. Caregiving spouses show higher burden than daughters and daughters in law. The burden due to objective tasks is high but the amount of subjective burden differs on specific scales. Generally very high is caregiver's burden due to the loss of the former relationship to the patient. This burden is especially high for spouses.

The objective need of care at time 1 is very important for the development of burden over time. A high amount of tasks at measurement point 1 results in a more positive development over time because some objective tasks disappear over time. The pattern is quite different for the development of subjective burden. In this case, the initial amount of burden is not very important.

LEANDER also evaluated different interventions (out-patient care facilities, day-care facilities, and therapeutic groups (Zank & Schacke, 2006).

Conclusions

The inventory proves to be reliable, valid and sensitive towards change. It is suitable for the description of different subgroups of caregivers as well as for evaluation studies. Depending on the objective of intervention studies, subscales can be used separately. In order to transfer results into praxis and encourage different services to evaluate their effects, consulting and training in using the instrument would be necessary. Therefore, two approaches would be desirable:

- The detection of clinical relevant parameters and a modification of the instrument for practical purposes.
- Training sessions for different kind of services in order to optimize evaluations in practice.

In addition to these practical suggestions, further basic research questions could be answered by additional data collection. Results from the U.S.A. suggest that severely burdened caregivers have a 60% higher mortality rate than caregivers with low amount of burden. It would be of fundamental political and ethical interest to control whether this effect can be found in Germany, too.

Further reading

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A summary of part one of this study is available (in German only) at <http://ipg.psychologie.fu-berlin.de>.

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