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Autonomy Despite Multimorbidity in Old Age

Berlin Consortium AMA

Autonomy Despite Multimorbidity in Old Age

Summary

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DZA Deutsches Zentrum für Altersfragen
ROBERT KOCH INSTITUT
Freie Universität Berlin
WZB Wissenschaftszentrum Berlin für Sozialforschung
ALICE SALOMON FACHHOCHSCHULE BERLIN University of Applied Sciences

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GENERAL INFORMATION ON THE CONSORTIUM

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Objectives

Application is made for an interdisciplinary, applied research consortium, whose results are to contribute to the promotion of the autonomy of older people with multiple diseases. All research projects of the planned consortium are based on the assumption that the attainment of advanced age will continue to be accompanied by physical, mental and social limitations even if future generations reach the phase of old age in better health. Because of the ageing of the baby-boomer generations, for an increasing number of older people the individual desire for a lifestyle which is as autonomous as possible will need to be reconciled with multiple chronic health impairments, disabilities and functional limitations. This is not only a major challenge for the individuals affected but also for their social networks and for society's efforts to achieve a viable, modern and patient-oriented health system.

Against this background, the Berlin research consortium "Autonomy Despite Multimorbidity in Old Age" (AMA) will be devoting its efforts to two main goals. On the one hand, the research consortium will advance methodologies suited to tap multimorbidity in old age. Instruments will be adapted and pathways explored to adequately assess multimorbidity and autonomy of old and very old persons belonging to different target groups. The aim is to analyse the complex links between multimorbidity and autonomy in old age. On the other hand, the consortium will examine those resources – personal, socio-economic, social and environmental as well as medical, care and institutional factors – that support and maintain autonomy in the face of multimorbidity. Particular attention will be directed to phenomena strongly associated with multimorbidity, such as pain, sleep disorders and falls, and the role the resources mentioned play in coping with them. Anticipated results include:

- Instruments and pathways for a standardised assessment of multimorbidity and autonomy in old age.
- Findings on personal resources and competences of older people in dealing with multiple health impairments.
- Findings regarding social, physical and sociospatial environmental factors which support autonomy despite multimorbidity in old age.
- Results which link personal, social, socioeconomic, sociospatial and medical and care resources and findings on the interaction of these resources for the maintenance of personally adequate autonomy.

- Empirically sound implications for the planning, application and evaluation of social, medical, care and pharmacological intervention to increase the autonomy of older people with multiple diseases.
- The development of sustainable structures to develop an interdisciplinary geriatric-gerontological centre in Berlin (IBeGZ).

Key Words

Multimorbidity, autonomy, resources, methodological development

Project Duration

36 months (Phase 1, *hereby applied for*): (a) Development of standards for the assessment of multimorbidity and autonomy in old age. (b) Analysis of the personal, socio-economic, social and environmental, medical, care and institutional resources influencing the maintaining of autonomy despite multiple illnesses in old age. Complex health problems such as pain, falls or sleep disorders are at the centre of these analyses.

36 months (Phase 2, *intended second phase of the consortium application*): (a) Projects that process the implementation and evaluation of the resources identified to influence the maintaining of autonomy despite multimorbidity. (b) Determination of representative population data on multimorbidity and autonomy on the basis of standards developed and substantiated estimation of the health promotion, prevention and provision requirements in those societies undergoing demographic change.

Summary

The Berlin consortium „Autonomy despite Multimorbidty in Old Age" (AMA) aims to make a contribution to improving the situation of older people with multiple diseases. This endeavour is prompted by the fact that old age is associated with a high prevalence of multimorbidity, which poses a threat to the autonomy of ageing and old people.

Firstly, the consortium has the objective of developing the methodological prerequisites for a standardised assessment process for multimorbidity and autonomy in old age. This includes the adaptation of survey instruments and also the testing of pathways to relatively inaccessible sub-groups in the population of the old and very old. The second objective of the proposed research consortium is to identify resources that sustain autonomy in old age in the face of multimorbidity. The underlying assumption here is that medical, pharmacological, social and health care interventions as well as social, environmental, institutional and above all personal and socio-economic resources play an important role in maintaining autonomy despite multimorbidity. The effect of each of these resources individually and in interaction with each other on the maintenance of autonomy and how they can be conserved and promoted is investigated and exemplified in respect to complex health problems impacting on autonomy in old age – pain, sleep disorders and falls.

The consortium's structural aim is the sustainable development of an interdisciplinary geriatric-gerontological centre in Berlin. This aim is to be furthered by the establishment of supra-institutional research groups and clinical practice, the development of data bases and the linking of the research consortium with an ongoing interdisciplinary graduate school on the topic of multimorbidity in old age.

Participating Partners

Title of Subproject	Institutes	Function in the Consortium	Contribution
AMA-INTEGRATION Coordination, methodological consultation, and scientific integration of the consortium	Charité – Institute for Medical Sociology	Coordination, management methodological consultation, integration	Organisation of internal structure and networking, methodological consultation, external relations of consortium, scientific integration, and feedback of results for practical application
OMAHA Operationalizing multimorbidity and autonomy for health services research in aging populations	Robert Koch-Institut Charité – Institute for Biostatistics and Clinical Epidemiology	Instrument development, analysis of pathways to elderly population	Conceptualization of the construct of multimorbidity and validation of a measure of quality of life which focuses on autonomy
MIGRANT-DEM Dementia and multimorbidity in non-native-German speaking migrant populations in urban areas	Charité – Clinic for Psychiatry and Psychotherapy	Instrumental development, analysis of approaches to migrant dementia sufferers	Development of screening instruments to determine dementia related changes in older migrants
PREFER Personal Resources of Elderly People with Multiple Illnesses: Fortification of Effective Health Behaviour	German Centre of Gerontology (DZA) Freie Universität Berlin- Institute for Health Psychology	Analysis of Personal Resources	Investigate personal resources affecting the progression of multimorbidity and functional limitations that jeopardize autonomy and quality of life
NEIGHBOURHOOD Maintaining autonomy after a fall in socially disadvantaged neighbourhoods	Social Science Research Center Berlin (WZB) Institute for Gerontological Research	Analysis of the interaction between individual and ecological resources	Identification of the socio-environmental and individual resources and structures influencing the autonomy of socially disadvantaged and multiply morbid older women and men
INSOMNIA Interrelation of sleep disorders and multimorbidity in nursing institutions for the aged	Alice-Salomon University of Applied Sciences Berlin	Analysis of care and medical resources in nursing facilities	Better understanding of the function of sleep as a health resource as well as a health risk
PAIN Pain and autonomy in nursing homes	Charité – Institute for Medical Sociology Charité – Institute for Clinical Pharmacology and Toxicology	Analysis of social, personal, institutional resources, development of access modes to the population in nursing homes	Identification of factors influencing pain and their relevance for autonomy, survey methods for pain and autonomy in the population in nursing homes

OBJECTIVES, INNOVATION AND RELEVANCE

Objectives and Overall Concept of the Consortium

A satisfactory state of health and the ability to cope with everyday tasks are the necessary prerequisites for leading a self-determined and autonomous life in old age. There is increasing empirical evidence for the fact that the average health of succeeding cohorts has improved over past decades (Fries 2003). The growing prevalence of chronic illness and multimorbidity will nevertheless continue in the future to be a feature of old and very old age. One of the major questions is therefore how the autonomy of ageing and older people in the form of self-determined functioning and self-reliance can be upheld in the face of multiple illnesses.

Multimorbidity and Autonomy in Old Age

Multimorbidty is the occurrence and persistence of several diseases simultaneously, whose significance for the restoration of health cannot be placed in a hierarchy. The probability of occurrence and the complexity of multiple illness increases with age and affects socially disadvantaged older people to a greater extent (Kuhlmey 2007). However, it is not currently possible to reliably estimate the prevalence of multimorbidty in the old age population due to lack of data in the field. This is partially explained by the fact that on the one hand, groups of people who are not easily accessible yet particularly vulnerable (i.e. very old, institutionalised, cognitively impaired people or those with a migration background) participate only marginally in representative population studies or are systematically excluded, at least in German research. On the other hand, there are methodological difficulties involved in the definition and assessment of multimorbidity and autonomy.

Against this background, it can only be cautiously assumed that one in three persons in Germany over 70 suffers from five or more moderately severe diseases and nearly one in four from diseases which are being treated concurrently (Steinhagen-Thiessen & Borchelt 1996). Multiple illnesses in turn constitute an increased risk for the onset of reduced capabilities and functioning. Consequently, multiple illnesses frequently lead to dependence and the need for care. Of a cohort of 73.000 older people insured with company health insurance funds (BKK), it could be demonstrated that 13.8% of those identified as chronically ill were in need of nursing care as defined by section XI of the German Social Security Code (SGB) (Winter, Kuhlmey, Maaz 2006). An increase in the number of prevalent diseases leads to a reduction in health-related quality of life (RKI 2003). This is often the result of phenomena associated with multimorbidity such as pain, sleep disorders and the after-effects of falls. Pain of various origin and localisation is, for instance, one of the three most common health complaints among older people (Gunzelmann et al. 2002) and sleep disorders in old age are frequently symptoms of and risk factors for further major diseases (Lautenbacher et al. 2006).

In gerontological research, autonomy and subjective wellbeing are discussed as complementary, interdependent constructs (Tesch-Römer & Wurm 2006). Both constructs are the conceptual basis for highly relevant outcome variables in basic and intervention research and are regarded by medical and nursing care practitioners as central therapeutic goals. In the context of the research consortium applied for, autonomy of ageing and older people is a decisive objective (“primary efficacy endpoint”), subjective wellbeing is a further central goal (“key secondary endpoint”) the assumption being made that wellbeing in itself influences the perception of life as autonomous. The autonomy of an individual increases in proportion to his or her ability to transform desires and aspirations into reality. The prerequisites for a person’s autonomy are individual factors such as knowledge, competences, abilities and material resources, as well as ecological, socio-economic and societal opportunity structures such as the housing environment, social networks, institutional constellations and community infrastructures. Autonomy can be regarded as the goal or product of every confrontation between the individual and the environment throughout the life course. Multimorbidity challenges the maintaining of auton-

omy. Health impairments in old age impact negatively on those abilities which are required for the attainment of life goals, the maintenance of activity patterns and the carrying out of every day routines.

Maintenance of Autonomy despite Multimorbidty in Old Age

The research consortium applied for will pursue two interlinking scientific objectives. On the one hand, it is intended to improve the theoretical, methodological prerequisites for the assessment of morbidity, autonomy and quality of life. On the other hand, a central goal of the research consortium is the empirical examination of factors influencing the maintenance of autonomy despite multimorbidity in old age. Personal resources, social and environmental resources as well as health and social care resources are highly relevant as factors maintaining autonomy despite multimorbidity in old age. Moreover, the interaction of these factors will be analysed, with a particular emphasis on socially disadvantaged elders. The research and the transfer of research outcomes into the everyday life of older people is intended to make a contribution to the maintenance, support and strengthening of autonomy despite multimorbidity. In this process, special emphasis will be given to the personal circumstances of the women and men involved, their gender-specific resources, life styles and backgrounds, with differentiation made according to age. The scientific objective of the research consortium is illustrated in figure 1 below.

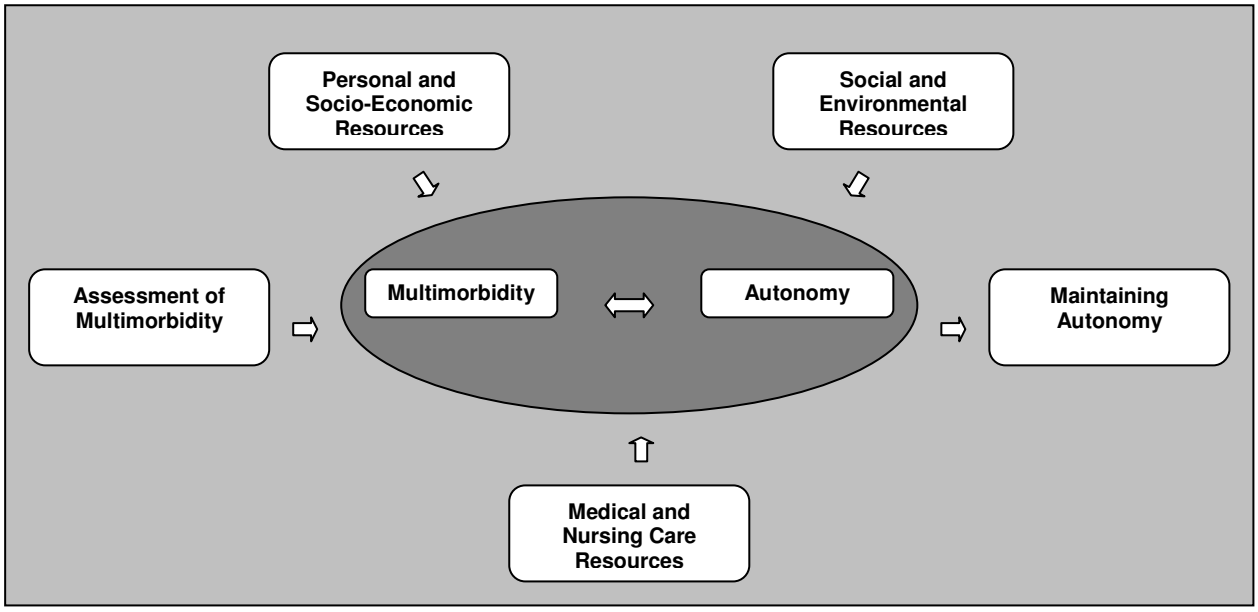

Figure 1: Scientific objectives of the research consortium “AMA”

(a) Assessment of Multimorbidity and Autonomy

Two of the projects are concerned with methodological issues. Attention is focussed primarily on questions of definition and operationalisation of multimorbidity, autonomy, and quality of life in the population groups with multiple illnesses. In addition, empirical pathways to sub-groups hitherto largely ignored in old age are examined (i.e. socially disadvantaged elderly women and men). One area of emphasis is the validation of an instrument for measuring quality of life. This instrument takes the autonomy of the respondent directly into account by means of individualised assessment (Ruta DA et al. 1994). The two most important outcome variables are tested for suitability to age and applicability in a health survey by instruments which assess multimorbidity and quality of life. In this way, the methodological prerequisites are set for ongoing health monitoring of the old age population (Project: OMAHA).

Dementia serves as an example for examining the extent to which instruments of screening, assessment and diagnosis are interculturally comparable and what adaptations are required in order to guarantee transcultural equivalence. Possibilities of accessing the population in residential care homes and adapting autonomy and multimorbidity survey instruments to these groups, who are also subject

to a high prevalence of dementia, will be included in the work of further projects (Project: MIGRANT-DEM).

(b) Analysis of Resources Relevant to Autonomy

Personal and socio-economic resources, socio-cultural and environmental conditions, medical and social care are factors influencing how and to what extent pathogenic changes in body structures and functions lead to reduced capabilities and thus to loss or retention of autonomy. Within the consortium "AMA", four projects are concerned with analysing resources which support old and very old persons with multiple illnesses to maintain autonomy in daily life.

Whether an older individual can maintain high autonomy and quality of life despite multimorbidity and to what extent he or she is affected by functional limitations or need of care depends not only on the number and severity of illnesses. Personal resources, in particular motivational and volitional factors, contribute considerably to the way an older person copes with his or her health status. The importance of personal resources for older people with multiple illnesses has not been sufficiently examined. Regarding personal resources, special attention should be paid to motivational and volitional factors such as individual views on ageing (e.g. Wurm, Tesch-Römer & Tomasik, in press), and self-efficacy and outcome expectancies (e.g. Schwarzer et al. in press). Thus one important goal of this research consortium is to investigate personal resources which influence the progression of multimorbidity and functional limitations and support the individual to maintain autonomy and quality of life in old age (Project: PREFER).

The social-spatial environment – urban and rural districts and neighbourhoods – constitutes the world in which most older men and women live, especially those who are socially disadvantaged and whose mobility is impaired. The material and socio-cultural resources on hand in this environment (physical, technical and social surroundings, infrastructures for everyday support and medical care) can act both as facilitators or as barriers and either reinforce or mitigate the effects of illness (Kümpers et al., 2006; Rosenbrock & Gerlinger, 2006). Thus neighbourhoods define the scope for autonomy and quality of life for those concerned. At the same time, the perceptions of older people themselves are influenced by gender and milieu specific ideas about their own possibilities and the legitimacy of their expectations of help as well as by the social, economic and cultural resources available to them (Heusinger & Klünder 2005, Heinemann-Knoch et al. 2006). The risks and potentials for the chances of maintaining autonomy and quality of life despite multimorbidity in socially disadvantaged homes are caught in the interplay between social environment and individual resources and are hitherto relatively unknown. Hence, the influence of neighbourhoods is being researched with particular emphasis on the avoidance of falls and on coping with the effects of falls (Project: NEIGHBOURHOOD).

Sleep disorders and pain belong to a series of complex health problems which interact closely with multimorbidity. The question of whether multimorbid individuals are disabled or functionally impaired, how many services they need and how high their risk of mortality actually is depends not only on the diseases themselves, but much more on the presence of "moderating" factors and symptoms such as pain or insomnia (Verbrugge et al. 1995; Freedman et al. 2000). Both health problems are subjective in nature. However, they do have consequences that could be objectively measured, such as the reduction of functional capabilities, loss of independence, the increase of intensity of somatic and psychiatric illnesses etc. Therefore, analysing sleep disorders and pain in the context of the consortium will raise the understanding of multimorbidity and its dynamics. In everyday life, chronic sleep disorders represent an additional burden, not only for the individual, but also for his/her social network. They are a threat to the already fragile quality of life of individuals suffering from multiple diseases (Project: INSOMNIA).

Pain is the most common complaint in old age and a major reason for reduced quality of life. As a symptom in elderly patients it generally originates from several underlying diseases and is the culmi-

nation point of various interacting illnesses (Jones & Macfarlane 2005). But little is known on how pain influences the autonomy of nursing home residents in terms of their preferences and goals and the ability to achieve them despite pain. Inappropriate drugs for elderly patients, including analgesia, may lead to a significant impairment in autonomy due to adverse drug effects and even to additional morbidity, emergency treatments, hospital admissions, and mortality (Bolbrinker et al. 2006). Hence, the influence of personal, social and therapeutic, including pharmacological resources on pain will be analysed with the aim of maintaining the autonomy of nursing home residents for as long as possible. Methods will be developed to facilitate access to the nursing home population for the purpose of continuous health monitoring using pain and autonomy as an example, including adjusted methods for people with dementia (Project: PAIN)

Synergy Effects and Added Value of Consortium Research

The added value of the consortium is put into effect via Project AMA-INTEGRATION. The central office for coordination, management, consultation, and integration is responsible not only for the duties associated with coordination and management, but also for methodological consultation and the scientific integration of the results produced by the consortium (production of added value). Here the scientific results of all projects in the consortium are continuously examined as to their quality and practical value, put together and transposed into proposals, producing as a result a set of recommendations for practitioners which will be published as a handbook.

Project AMA-INTEGRATION will support the central objectives of the consortium by encouraging synergy effects. In the first place, the consortium aims to improve the methodological basis of representative surveys on multimorbidity in the old age population. This objective will be pursued not only by those projects with an explicitly methodological focus but also in projects which emphasise analysis of resources for autonomy in the face of multimorbidity. In this context, pathways to relatively inaccessible groups of older people in particular will be tested (i.e. those living in care homes or socially disadvantaged elderly women and men) or specific survey instruments (i.e. to assess pain or sleep disorders) developed and tested as to their duration, acceptance and practicability for use in surveys. The results will be systematically documented. One instrument for consolidating synergies will be regular workshops organized by the central office of the consortium. The second area of emphasis is the analysis of the interaction between various resources in the lives of older people with multiple diseases and the protective effect of these in maintaining autonomy. Synergy effects are already inherent in the way some projects are organised. Pharmacological and long-term care theory approaches, for instance, are linked by the integration of two research institutes and gerontological and preventive research expertise synergized. A further synergy is gained from the networking between individual projects. The project on strengthening resources by the use of information and technology, for instance, utilises the research done on personal resources, since results on motivation and competencies are highly relevant to the use of a technically supported service.

It is also significant that all the project applications share a high relevance of gender specific research, the inclusion of particularly vulnerable groups in the analyses and the practical use of the results.

Novel Aspect and Future Impact

Resources which contribute to older people being able to live autonomously and independently despite multimorbidity and health impairments have not been much examined to date. Geriatric and gerontological research in recent decades has tended to concentrate on significantly increasing knowledge on diseases in old age and disease related interventions. Against this background, the research consortium aims above all to characterise those resources which are supportive to autonomy despite multimorbidity. The basic aim is to contribute to conceptualisation of multimorbidity, autonomy and quality of life in old age and develop and test instruments for assessing multimorbidity, autonomy and quality of life. An example is the examination of non-drug therapies in sleep disorders. The purely

medical treatment of sleep disorders does not require much participation (and autonomy) of patients. Conversely, non-pharmacological therapeutic alternatives (such as modification of sleep-wake regimes, occupation, and activation) strongly depend on the collaboration of a participating individual. The aim here is to improve the patients' condition through his/her own participation. Research results of practical relevance – including the use of therapies in the treatment of pain for residents in care homes, instruments for the early diagnosis of dementia in the case of very old migrants, autonomy-supporting features of socially disadvantaged neighbourhoods – are to be implemented and evaluated in the second phase of research. In addition, it is planned to collect representative population data on multimorbidity and autonomy on the basis of the standards developed, thus creating a reliable estimation of the requirements of societies undergoing demographic change as to their health, prevention and provision needs.

The consortium, which was able to gain the cooperation of interdisciplinary research capacities from major Berlin scientific institutions, has the longer-term structural aim of developing an interdisciplinary geriatric-gerontological centre in Berlin and intends to transfer the results of its research to the professional training, continuing education and further training sectors in the health sector.

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STRUCTURE OF THE PLANNED COOPERATION

Cooperation, Coordination, and Communication

The members of the research consortium have made a mutual commitment to work closely together. Modules in the organisational structure are:

(a) The Projects and Members of the Berlin Consortium "AMA". The consortium as a whole is represented by eight projects. These are made up of the central project of the Coordination Office, two projects on methodological development and four projects involved in the analysis of factors which have a protective effect on autonomy in specific health situations: pain, sleep disorders, falls, and in certain settings such as care homes, socially disadvantaged living neighbourhoods.

(b) The Spokespersons of the Berlin Consortium "AMA". The spokespersons reflect the interdisciplinary nature of the consortium and represent medicine, psychology and sociology. They represent the consortium externally.

(*c) The Central Office of the Berlin Consortium "AMA".* The role of the central office for coordination, management, consultation, and integration includes the scientific integration of the consortium's results (production of added value), consultation on methods and coordination of the consortium's internal and external communication and coordination. The Coordination Office is responsible for the consortium's external relations.

(d) Methodological Consultation of the Berlin Consortium "AMA". The methodological consultation comprises qualified support for epidemiological, biometric and statistical methods in the interest of obtaining valid results in the projects involved with quantitative research. Methodological cooperation is available for all levels of planning, execution, evaluation and interpretation. Additionally there will be consultation on the qualitative methodology in the consortium projects. This central consultative function on methods is part of the responsibility allocated to the central office and will align methodological processes throughout the whole consortium.

(e) The Advisory Council of the Berlin Consortium "AMA". The role of the Advisory Council is to oversee research with regard to practice orientation. The Advisory Council is made up of representatives from clinical and applied partner institutions and from senior self-help organisations.

(f) Support for Young Scientists by the Berlin Consortium "AMA". The consortium and the existing graduate research school "Multimorbidity in Old Age" will collaborate together closely in building up an interdisciplinary group of graduates to promote future generations of gerontological and geriatric scientists. There will be a flexible approach to exchanges between the consortium and the graduate school and to creating graduation opportunities within the school.

Added Value

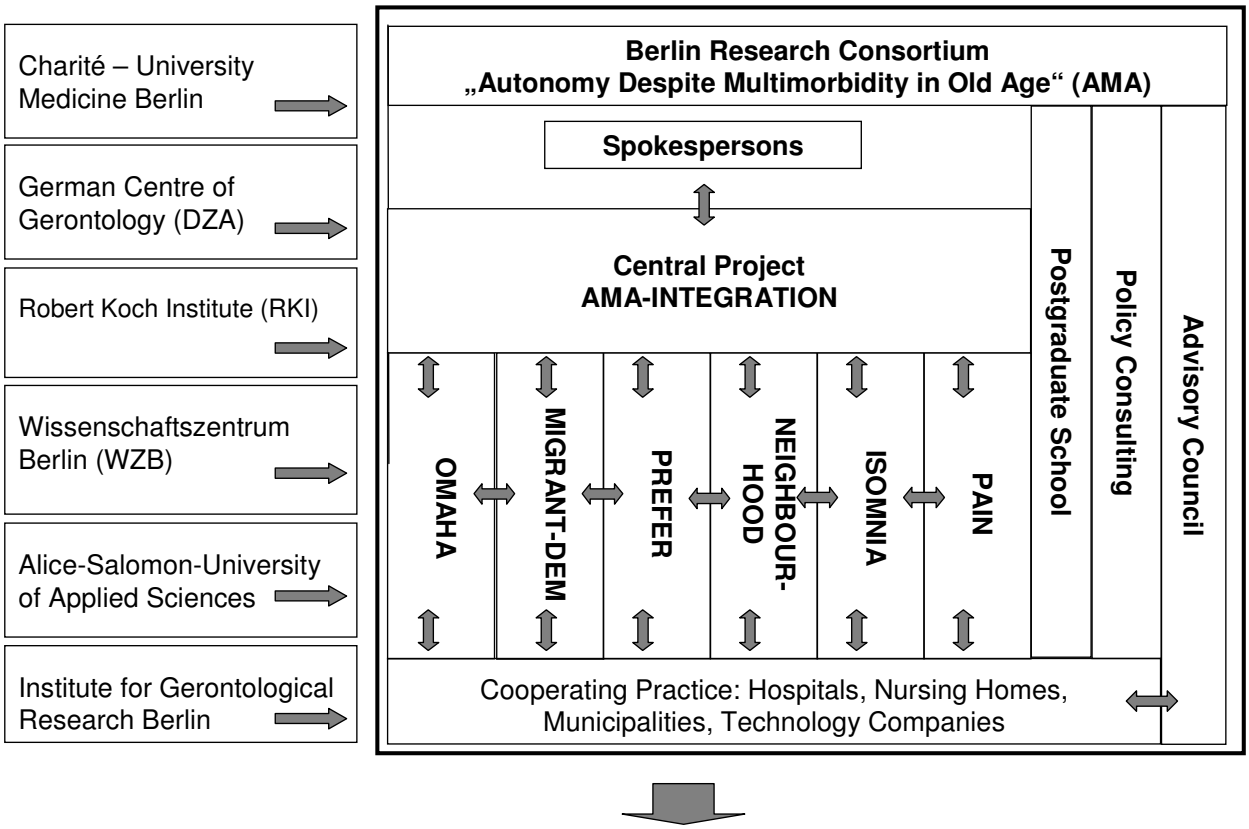
The Berlin research consortium "Autonomy Despite Multimorbidity in Old Age" (AMA) will integrate the work of national and international scientific experts from various disciplines from universities, specialised tertiary institutions and extramural research bodies. Close cooperation with various practice-oriented bodies (clinics, residential and non-residential care providers etc) is part of the work of the consortium. The longer-term structural plans of the consortium foresee the development of an interdisciplinary geriatric-gerontological centre (IBeGZ) in Berlin. This objective will be reached by means of the following measures:

(a) Establishment of institutions made up of contiguous research groups. These groups will start to emerge in the conception phase of the consortium. In the second phase of the application these research groups should form the core of applicants.

(b) Development of data bases for interdisciplinary use which can also facilitate ongoing health monitoring. Working with the data bases should link the consortium more closely in interdisciplinary tasking and research work in the second project phase.

(c) Linking of the research consortium with a graduate school and interdisciplinary advanced education programmes. Some of the partners in the consortium are currently mentors in the "Multimorbidity in Old Age" graduate school (www.gradmap.de). This group will work together very closely with the consortium, meaning that dissertations will be assigned in the context of consortium work, young scientists will work as school graduates in the consortium. Consortium and graduate school should form a unit, with the school supplying the future scientists for the consortium and young graduates working in the consortium. Ultimately this should promote careers in the gerontological professions.

The Network Structure of the Berlin Research Consortium



Aim: Interdisciplinary Berlin Geriatric-Gerontological Centre

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