Care and care systems

Challenges and opportunities for European comparative research

Vechta, Germany June 22, 2006

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Background

- this presentation is based largely on author's own experiences in cross-national research projects
  - Social Protection of Older People in 15 European countries, (see Pacolet et al 2003)
  - European Clearing House for the Alzheimer Disease (see Pacolet et al xxxx)
  - PLANEC-project in the IV FP of EU (1996-1998), prime co-ordinator
  - CARMEN-network (2000-2003), see Vaarama & Pieper 2005
  - Care Keys (2003-2006), prime co-ordinator (see www.carekeys.net, Vaarama, Pieper & Sixsmith 2006))
  - European FORUM and ERA-NET

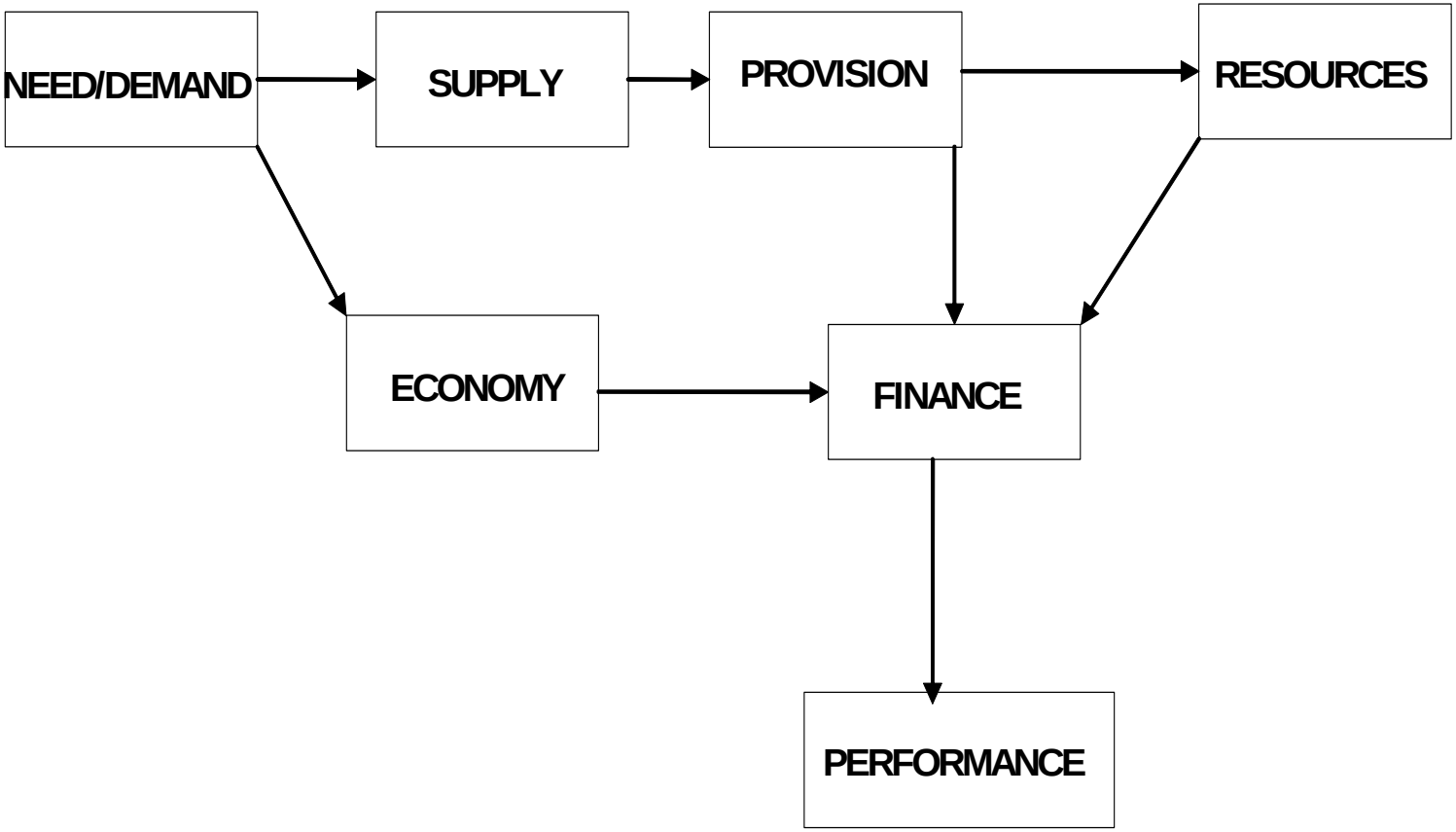
Cross-national comparative research on care & care systems

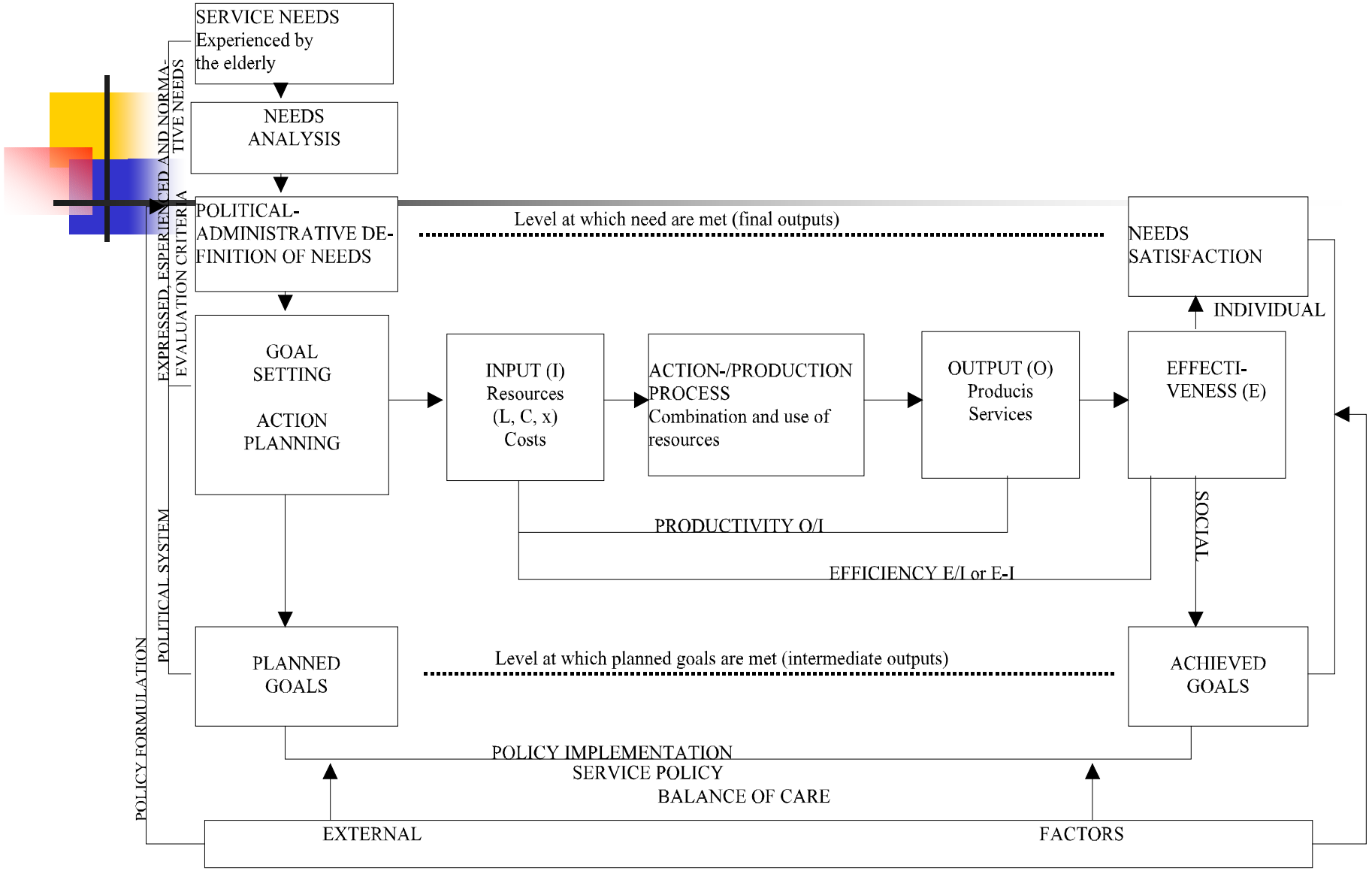
- Key elements
  - cross-national
  - care
  - system
  - comparative
  - research
- each word is complex...

E.g. word 'Cross-national'

- a mix of systems, cultures, values, languages, terms, care products, processes....
  - regimes
  - cultural, normative issues
  - institutional contexts, laws, benefits
  - languages
  - etc....

E.g. words 'Care' & 'Care system'





where inputs (I) are capital (C), labor (L) and non-material resources (x)

Typical obstacles for cross-national research

- inadequate training to conduct studies that cross national boundaries and compare different cultures
- unawareness of
  - the limitations of comparative research methods
  - inadequate knowledge of the contexts in which comparisons are being conducted
  - inadequate knowledge of the conceptual frameworks within which the researchers from different countries are operating
  - absence of shared conceptual framework
  - problems of consistency and comparability – different policy systems
  - technical and methodological problems
- these problems can be avoided by careful and detailed planning of the research which involves the entire research team

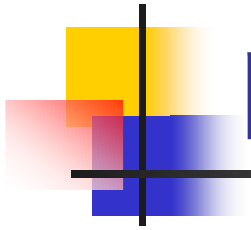
Cross-national research into care of older people

- should involve detailed comparisons of social and economic conditions of old age
- availability of data vary greatly between countries
- patterns of services vary
- knowledge of services availability, quality and costs vary
- classification and categories are closely tied to respective health and welfare structures
- how to get information on relative effects of different levels of service supply on actual welfare outcomes for the individuals?

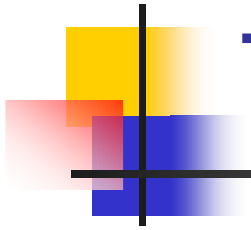
Studying Long-Term Care

- understudied area
- lot of obstacles
  - lack of theoretical frameworks
  - difficult access to data
    - statistics, secondary, new
  - lack of valid and reliable instruments
    - Quality of life - current measures do not fit for frail old people
    - Quality of care - measures often protected heavily or are commercial
    - Quality Management of LTC - little is known about this

How to solve and prevent problems



- Common research protocol necessary
  - Common theoretical framework and terms
  - Common research questions
  - Common ethical principles
  - Common methods
  - Common instruments
  - Common practical research procedure (detailed)
  - Common data
- these should be clear to ALL participant researchers since the beginning of the research
- often good to do first time in the proposal stage and second time in the beginning of the real work in the project



Theoretical approaches

- inductive - from loosely defined concepts toward verificated ones
- deductive - applying a general theory to a specific case in order to interpret certain aspects
- demonstrative - confirm and refine a theory
- these all can appear in the lifetime of a research project lasting many years
- it is important to have a common theoretical framework to guide the study, but it is demanding to create in multi-disciplinary projects

Constructing models of care options of frail elders

- statistical methods
  - multivariate analyses
- qualitative
  - Vignette (reliability problematic)
  - Model families/cases
  - Focus groups
  - Delphi
- combination of quanti-quali offers a possibility to deepen the research

The promises and risks of using statistics

- if reliable, system level comparisons possible
- but - are the figures measuring same thing and are they comparable?
  - statistical products are dependent on history, culture and administrative structures that are NOT identical
  - differences in classification and aggregation systems
  - changes over time in definitions and systems

Language & cultural issues

- often underestimated as a problem
- in research on care, a common taxonomy is necessary to ensure comparability, where the care services are given with functional specifications
- usually part of the State of the Art analysis, which normally starts a comparative research

An example

- a list of single care products within the care of older persons (next slide)
- the names may be the same in different countries, but the contents of the service may vary a lot
- therefore, each should be given with a functional specification in the native language AND in the language of the comparative research (e.f. in Finnish and in English)

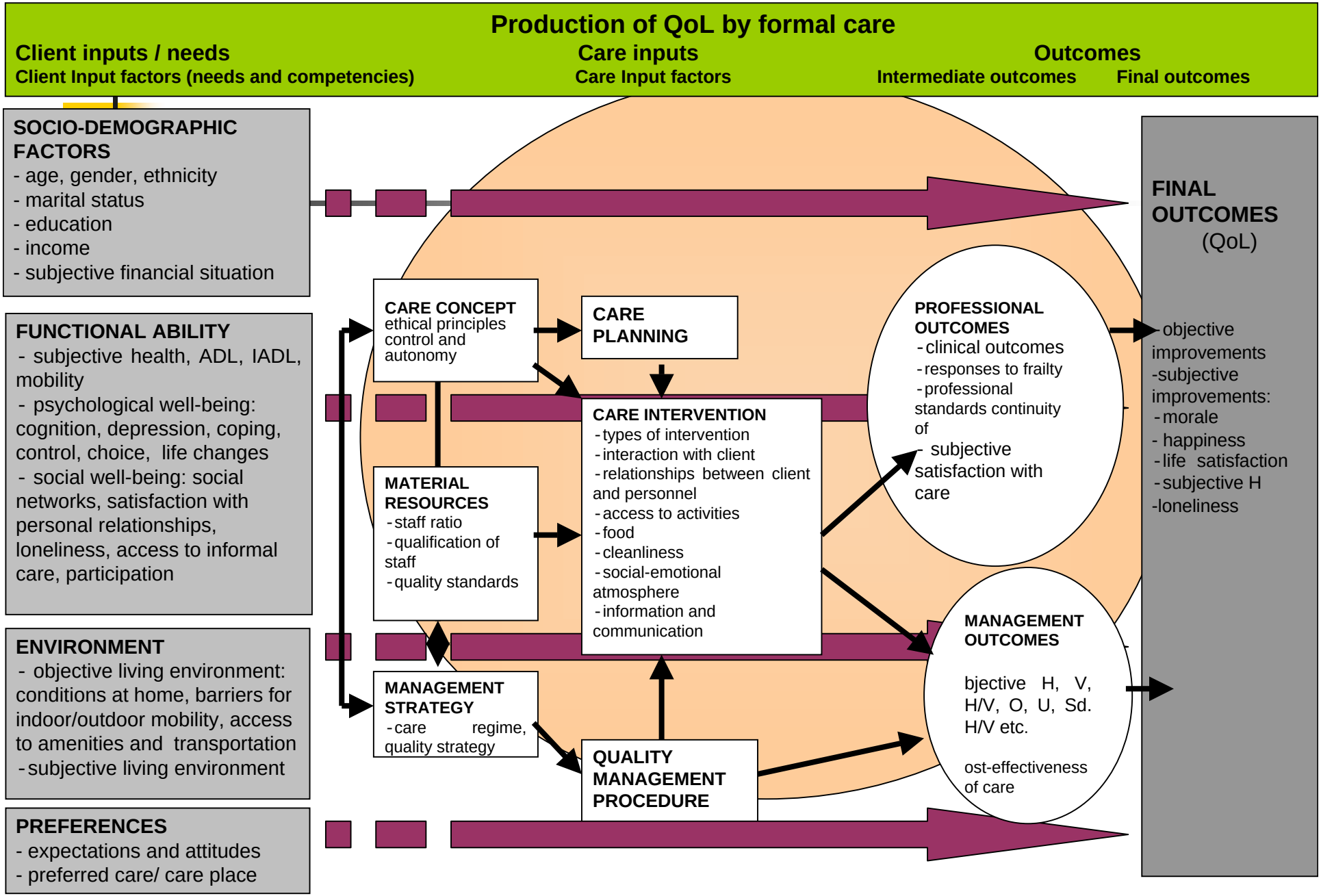
- 1. Home renovation/improvements subsidies/loans
- 2. Sheltered housing/service housing
- 3. Old age homes/residential care
- 4. Nursing homes
- 5. Acute inpatient care, specialised hospital, somatic
- 6. Acute inpatient care, specialised hospital, psychiatric
- 7. Long-term inpatient care, specialised hospital, somatic
- 8. Long-term inpatient care, specialised hospital, psychiatric
- 9. Acute inpatient care, primary care (e.g. health centre hospitals)
- 10. Long-term inpatient care, primary care (e.g. health centre hospitals)
- 11. Home help
- 12. Home nursing/district nursing (including health advisory services)
- 13. Rehabilitation ward
- 14. Outpatient visits, primary care
- 15. Outpatient visits, specialised care
- 16. Transport services
- 17. Day centres for the elderly
- 18. Day hospital care for the elderly
- 19. Alarm service

A practical example of a cross-national project - Care Keys

- under the V FP of EU/Quality of life, years 2003-2006
- 5 countries (Fin, EE, Ger, Swe, UK, until 2004 also ES)
- budget 2,8 million Euro
- on pooled, representative database (n=1500 old LTC clients)
  - research on care-related QoL in old age from the perspectives of the clients, professional care and care management
  - development of instruments to measure quality of life and quality of care of old care-dependent people, and for management of LTC of older people
- see www.carekeys.net

Care Keys Research Protocol

- Defined how research is to be conducted
  - Theoretical framework and concepts
  - Research design
  - Sampling procedure
  - Research instruments
  - Data collection procedure
  - Data saving procedure
  - Analysing methods
  - Division of labour
  - Schedule and milestones


Production of QoL by formal care
Client inputs / needs
Client Input factors (needs and competencies)
Care inputs
Care Input factors
Outcomes
Intermediate outcomes
Final outcomes
SOCIO-DEMOGRAPHIC FACTORS
- age, gender, ethnicity
- marital status
- education
- income
- subjective financial situation
FUNCTIONAL ABILITY
- subjective health, ADL, IADL, mobility
- psychological well-being: cognition, depression, coping, control, choice, life changes
- social well-being: social networks, satisfaction with personal relationships, loneliness, access to informal care, participation
ENVIRONMENT
- objective living environment: conditions at home, barriers for indoor/outdoor mobility, access to amenities and transportation
- subjective living environment
PREFERENCES
- expectations and attitudes
- preferred care/ care place
CARE CONCEPT
ethical principles
control and autonomy
CARE PLANNING
MATERIAL RESOURCES
- staff ratio
- qualification of staff
- quality standards
CARE INTERVENTION
- types of intervention
- interaction with client
- relationships between client and personnel
- access to activities
- food
- cleanliness
- social-emotional atmosphere
- information and communication
MANAGEMENT STRATEGY
- care regime, quality strategy
QUALITY MANAGEMENT PROCEDURE
PROFESSIONAL OUTCOMES
- clinical outcomes
- responses to frailty
- professional standards continuity of
- subjective satisfaction with care
MANAGEMENT OUTCOMES
bjective H, V, H/V, O, U, Sd. H/V etc.
ost-effectiveness of care
FINAL OUTCOMES
(QoL)
- objective improvements
-subjective improvements:
- morale
- happiness
- life satisfaction
- subjective H
-loneliness

The 3D Quality Matrix

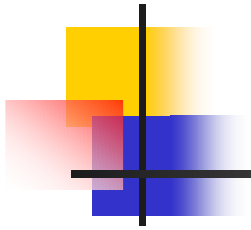
(Øvretveit 1998, Vaarama & Pieper 2005)

Evaluation perspectives	Inputs (e.g)	Process (e.g)	Outcomes (e.g)
Client Quality	client care & quality expectations care environment	dignity, care/ interaction quality, informal care inclusion	satisfaction with life/care, pain relief, self-esteem
Professional Quality	staff qualification, motivation, quality standards	good professional care, continuity, courtesy	meeting professional standards, no mistakes, satisfaction
Management Quality	sufficient resources, structures for quality, legal framework	needs-led supply, efficient resource use, conflict resolution	good horizontal and vertical TEFF, H/V, sound working community

Methods in Care Keys

- Multidisciplinary research (sociology, social policy, psychology, nursing science, medicine, economics, statistics)
- Triangulation (theoretical, methodological, data)
- Close dialogue between practice and research
- Literature reviews, cross-walks between diverse instruments, exploration with diverse instruments, modelling and statistical analyses, Delphi panels and focus groups with users

Common ethical principles



- Permissions to use research instruments
- Permissions to contact clients or relatives
- Permission to use care documentation as an information source
- Permission to use register data
- Data protection rules (by country and within EU)
- Training of client interviewers
- Ethical principles interviews
  - instruments shall fit to be used with old people
  - special conditions (hearing, vision, cognition)

Common research instruments

- Condition 1: suitable for use with frail old people
- Condition2: well validated
- these conditions posed problems, so we needed
  - first to test many instruments to find the fitting ones
  - for lacking areas, we had to develop and validate our own data collection instruments
  - Translate the instruments and get approvals
  - Pilot the instruments and refine them
  - Still a lot of missing data due to the variation in care plans and documentation

Example: What instrument we used at which cognition level?

MMSE or CPS	Measurement	Source of information
I. CPS 0-2 (MMSE 19-30)	WHO-QOLBREF & PGMS	client interview
II. CPS 3 (MMSE 15-18)	PGMS & (WHO-QOLBREF IF the client can do it)	client interview
III. CPS 4-6 (MMSE 0-14)	QUALID & Cornell Depression Scale	client observation, interview of relative

CK Results in brief

- strong connections between quality of care (QoC), care management (QM) and care documentation (DoC) with subjective quality of life (QoL) of the old clients
- determinants of QoC and QoL vary in home care clients and in clients in the institutional care
- dimensions of QoL in old LTC clients are similar to those in older adults in general, but variables vary, demonstrating the special needs and living situations of care dependent old people
- 10 quality indicators from client perspective, 10 for professional quality, 10 for care management specified for both HC and IC
- implemented partially in software taster MAssT (ww.carekeys.net)

Difficulties we faced

- different care systems, different meanings
  - IC vs. HC, Informal care
  - 'Social care model' vs. 'Medical model'
  - management of care
- measurement of QoL, QoC, QM
  - not standardized measures for LTC or measures heavily protected - it took one year to develop and pilot the instruments for our research
- differences of scientific interests among research team
  - it took time to reach consensus on research topics and define the instruments
- differences in research team qualifications
  - good division of labor necessary
- the project was extremely complex - next time we try something easier

Publications

- Vaarama, M., Pieper, R., Sixsmith, A. 2006. Care-related quality of life in old age. The concept and empirical exploration. In: Mollenkopf, H. & Walker, A. 2006: Quality of life in old age. Springer Science and Business Media. New York. (In print).
- Vaarama M, Pieper R, Sixsmith A. 2006. Care-related quality of life in old age. Key-findings of the European Care Keys research. Springer Science and Business Media. New York. (Forthcoming in November 2006)

Thank you for your attention !