Support of caregivers in the context of dementia – self-management and empowerment

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Outline of presentation

• Historical development of dementia care interventions
• Effectiveness of single component interventions in dementia caregiving
• Experiences of caregiving: problems in support services
• Effectiveness of care coordinator interventions.
• Dimensions of effective care
• Concept of self-management
Dimensions of dementia care – how did they develop?
Alzheimer’s disease affects the whole family...

- **Patient**
  - Social functioning
  - Cognition
  - Personality changes
  - BPSDs

- **Care burden**
  - IADL, ADL need for help
  - Depression
  - Physical symptoms (e.g. weight loss; impaired health)

- **Caregiver**
  - Microculture, roles, power, communication
  - Role changes, life changes, mourning

- **Economical burden**
  - Loneliness, social isolation
  - Stress, sleeplessness
Research on dementia care

• In early years studies tended to focus on either patient’s or caregiver’s problems
  – Patient studies focus on
    • Cognition
    • BPSDs
    • Functioning
  – Caregiver studies focus on
    • Burden of caregiving, stress, depression
    • Contents/ skills of caregiving

• >100 randomized, controlled studies on supporting dementia home care / caregiving --> mixed results
TIME SCALE

1980

COGNITIVE DECLINE, LOSS OF FUNCTIONS

PATIENT

1990

BPSDs

COGNITIVE STIMULATION

MULTI-COMPONENT INTERVENTIONS

EXERCISE

DRUGS

NUTRITION

BPSD MANAGEMENT

2000

CAREGIVING SKILLS

CAREGIVER

2011

BURDEN

RESPITE

SUPPORT GROUPS

TRAINING

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MULTI-COMPONENT INTERVENTIONS

COGNITIVE STIMULATION

BPSDs
Effectiveness of single component interventions in dementia caregiving
Effectiveness of caregiver support services – single component interventions

- Respite care: day care, home respite, respite in institution
- Support groups: peer support, educational
- Therapy: group or individual, face to face, via telephone or internet:
  - cognitive, behavioral, problem solving
- Training caregivers
  - Problem solving, lectures, personal guidance, in-home sessions, internet based
- → Caregivers are reluctant to use services
Effectiveness of caregiver support services – single component interventions

• >50 randomized trials → mostly mild effectiveness
• Target groups heterogeneous, poorly defined diagnoses
• Most interventions have small sample sizes and 20-35 % drop outs, thus low power to detect differences
• Many compare two-three active treatments
• Most promising interventions
  – Caregiver training/guidance → caregiver coping skills, QOL improved
  – Support groups → less depression
Experiences of caregiving
- findings from our qualitative studies
Caregiving leads to profound life changes

• Care status has profound effects on the whole microculture of the family: responsibilities, power in relationships, roles and communication.

• Care status often compels both the caregiver and the caree to redefine their identity; not only as caregiver / caree but also as spouses.

• Cultural expectations may limit the social life and isolate caregiving families.
Environment and meaning of home changes with caregiving...

• Care requires changes in home environment ➔ from traditional home to hospital-like ”caring arena”

• The psychological and sociological meanings of one’s own home are redefined

• Families want to retain their home and privacy as far as possible ➔ reluctant to let professionals into their home
Friction between the service system and caregiving families

• Authoritative service system often ”knows” what is best for the caree / caregiver
  
  • certain services are rigidly offered for all (e.g. respite care)

• Needs and services are often defined separately for caree / careviger → BUT needs are entangled

• The microcultures of the service system and families may confront each other:
  
  • the needs of the family may not fit into the official service system

  • Home nurses and other professionals may be experienced as a threat for autonomy and privacy of the family
How wide is friction between service system and caregiving families?
Survey of caregiving experiences (2005)

- Cross-sectional postal survey to spousal caregivers of patients with Alzheimer’s disease (AD) in Finland (N=1989)
- 75% responded
- Mean age of caregivers 78y, 63% females
Adjustment to caregiving situation

- Well or quite well adapted to the spouse’s Alzheimer’s disease 92.2%
- Satisfied with their marriage 63%
- Caregiving limits dealing with other people 63.5%
Services wished and received by spousal caregivers

- Physiotherapy
- Society's financial support
- House cleaning
- Home respite

Wished services vs. Received services
Satisfaction of the families to the services

• Only 39% of the families were satisfied with the services they received

• Only 29% found it easy to get information about available services

• Only 31% felt they could have any influence on what services they received
Caregivers’ experiences…

”Always they need ”additional information”. It is difficult to know what kind of information they need. Our needs are suspected. Without our children we would not get help.”

”It really took time before we got the nursing home place. It took a lot of my energy ... I had to fight for it. It is not easy for an old immobile invalid:”

”I have taken care of my wife for 15 years. I ask why I am punished ? I am a 90 years old war cripple : I wash her, lift her to the wheelchair, etc. I have limited resources.”
Complexity of the service system – you need an interpreter!
Problems in present service system…

– Chain of care does not work – boundaries between organisations

– Service system is “organisation-oriented” – not patient-centeredly oriented
  • professionals may act as gate-keepers
  • .. or by doing wrong things

– Patients’ and their caregivers’ needs are not met
Effectiveness of care coordinator interventions

N=206, dementia patients and their spouses randomized into two groups:

1. Care coordinator, guidance, training, service plan, support groups, tailored services (N=103)
2. control (N=103)

Coordinators+ service workers

Postponed institutional care nearly 1 year
Admission to institution HR 0.65 (95% CI 0.45 to 0.94)
Caregivers’ depression was alleviated
Services were better adjusted to the caregivers’ needs

Callahan et al. JAMA 2006

- N=152, AT patients and their caregivers randomized:
  - 1. collaborative care (N=84): care management by primary care physician + geriatric nurse 12 mo’s, AT drugs, caregiver training (communication, coping, financial advice, AT disease, pt exercise), BPSD nonpharmacological management
  - 2. Control (N=69)
- Intervention pts have fewer BPSDs than controls (NPI - 5.6pts)
- Less distress and depression among caregivers
- No differences in use of health care services, cognition, ADL, mortality
– 406 dementia patients + caregivers randomized into
  • 1. dementia guideline-based disease management program (N=238): care managers + primary care physicians --> structured home assessment, care plans, collaboration, enhancing problem solving skills, interactive seminars for caregivers
  • 2. control (N=170)
– Higher quality of care + adherence to guidelines

- N=619 AT caregivers + pts, randomized
  - 1. Caregiver training + , address depression, burden, self-care, social support, guidance on how to get services + on BPSD management. Sessions at home, groups, telephone
  - Educated interventionists, coordinating committee

- Caregivers QOL and depression improved
- No difference in admissions to institutions
Graff et al. BMJ 2006

- rct, N=135, mild-moderate dementia, home-dwelling with caregiver
- 10 home visits by an occupational therapist during 5 weeks: tailored cognitive-behavioral intervention = guiding patient and caregiver to compensate lost skills and to adjustment
- Physical functioning (IPPP measure) improved significantly

• RCT, N=125, mild-severe dementia
• Care coordinator, geriatrian + caregiver groups; exercise rehab, tailored services
• Enhancing problem-solving skills and autonomy, family-centredness, optimism
Time in community care

During the follow-up time \( p = 0.17 \)

At 1.5 yr, 11% of Subjects with dementia in intervention group vs 24% of those in control group were In permanent institutional care \( (p=0.027) \)

Eloniemi-Sulkava et al. 2009
Cost of services

- Mean cost of services/ couple/ person years: in intervention group 15 588 € vs. control group 23 553 €
- Mean savings  7900 €/couple/year (p=0.03)
- Mean cost of intervention/ couple/ person yr was 2800€ /year

Eloniemi-Sulkava et al. 2009
Better targeting of services

- Intervention families received more physiotherapy, respite care at home and house cleaning than control families.
- Control families received more home nursing, hospital days and respite care in institutions.

Eloniemi-Sulkava et al. 2009
Trial findings

• Coordinated care, emotional support + flexible service spectrum enabled the families to continue caring of their loved ones longer at home.
• Intervention led to increased satisfaction + better concordance in needs and services
• Listening to families’ needs, empowering them and working as an interpreter between families and the service system → saved 30% in health and social services
Why did we succeed?

• Conscious principles of intervention ➔ not WHAT we did BUT HOW we did it!
  – family centeredness
  – empowerment of caregivers: listening + taking seriously their needs ➔ physiotherapy, house cleaning, respite at home = tailored services
  – trusting + accepting that they knew their needs better than we did! = CO-OPERATION

• Empowerment led also to caregivers’ improved mastery, problem-solving skills and self-efficacy
Why did we succeed?

• Immediate intervention when needed – proactive to be prepared to confront crises/ complications
• Supporting normal family life, respecting their autonomy and privacy
• Acting as an interpreter between the family and the service system ➔ good communication skills:
  – alliance with both the families and the service professionals
  – patience
  – reliability
Dimensions of effective interventions
<table>
<thead>
<tr>
<th>Problems in normal service system</th>
<th>Improved care</th>
<th>Studies implementing principle</th>
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<tbody>
<tr>
<td>Authoritative service system: Caree/ caregiver are passive objects for services</td>
<td>Family-centred service, Supporting empowerment, Respecting autonomy and developing cooperation Supporting self-efficacy+ mastery and problem solving skills</td>
<td>Mittelman et al. 1996 Graff et al. 2006 Vickrey et al. 2006 Belle et al. 2006 Eloniemi et al. 2009</td>
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<td>Caree and care-giver are met as separate subjects</td>
<td>Supporting the family as a whole</td>
<td>Mittelman et al. 1996 Teri et al. 2003, Graff et al. 2006, Belle et al. 2006, Eloniemi et al. 2009</td>
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<td>Multidimensional effects of the disease on caree and caregiver are not met</td>
<td>Tailoring services, implementing effective elements from prior trials</td>
<td>Mittelman et al. 1996 Eloniemi et al. 2009 Callahan et al. 2006 Vickerey et al. 2006</td>
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What is self-management?
What is self-management?

• Self-management is patient’s ability to organize his/her life under the influence of a chronic disease, to engage in activities and to use knowledge to protect and promote health.

• In self-management professionals support patients in a patient-centered way to manage their care. This includes support of patient’s autonomy, decision making, problem solving skills and responsibility.

• In self-management health professionals act as coaches rather than as experts, and they respect the patients’ every-day know-how. Self-management is based on partnership.

• Central concepts are patient’s empowerment, support of self-efficacy and mastery
Is there evidence of effectiveness of self-management?

• Several self-management programmes have shown their effectiveness in rct’s
  – Asthma
  – Hearth failure
  – Osteoarthritis
  – less hospital admissions, decreased mortality
Implementation of self-management in dementia care

- Identifying problems and resources
  - Listen, inquire, assess
    - Tailored together with the family according to their preferences and life situation
    - Respect autonomy and support family in their decision making
    - Means are agreed together

- Care plan

- Self-management

- Follow-up
Also ”wrong choices should be accepted…

- Pt/caregiver is autonomous when he/she can act according to his/her free will and make own choices
  - Pt/caregiver always has the final decision
  - Pt/caregiver has enough information to make competent decisions
  - Decisions and actions are in line with pt’s/caregiver’s values and principles
How to support self-management?

• Positive feedback
• Caregiver/pt has a feeling of an equal relationship with professionals: dares to ask questions, feeling of self-efficacy
• Power to make decisions and responsibility are in balance
• Knowledge, ability to find information and to solve problems
Self management capabilities

• Empowerment
  – Self-awareness to feel equal with professionals
  – Courage to doubt aloud, to tell about every-day problems, to ask questions, and to demand for help

• Self-efficacy, mastery
  – Problem solving skills, self-awareness to make own decisions and take responsibility for them
  – Planning one’s own actions, make objectives for them and make plans for the future
Take home messages

• There are still many problems in the process of caring demented people and their families

• Families are left very much alone to sail in a strange ocean when sent to open care after diagnostics

• Empowerment of caregiving families, family centredness, true cooperation, and support of self-management skills may lead to better satisfaction, longer times living at their own homes
Supporting self-management in dementia families – randomized controlled trial 2011-3

- Psychosocial group rehabilitation for recently diagnosed dementia patients and their spouses
- N=160; Groups of 10+10 meeting 8 times, 4 hours/wk, 8 wks
- Objective-oriented, main aim to empower families and support their self-management skills
- Takes advantage of group dynamics; professionals act as coaches rather than as group leaders
- Programme is built in cooperation with families
- Positive, future-oriented work + resource-oriented work
Thank you for your attention!