Treatment, assistence and support for people with dementia and carers; the Dutch approach

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Research Programme >

EMGO+ Institute for Health and Care Research

VU university medical center

Content of lecture

- **Relevant background**
  - Some figures and care organization in The Netherlands
- **The psychosocial perspective in dementia care**
- **Experience oriented care and tailored psychosocial treatment methods**
- **Some methods in detail**
  - meeting centers support program
  - movement and psychomotor therapy
  - assistive technology
- **What could you do as professionals?**

1. Relevant background

Numbers people with dementia

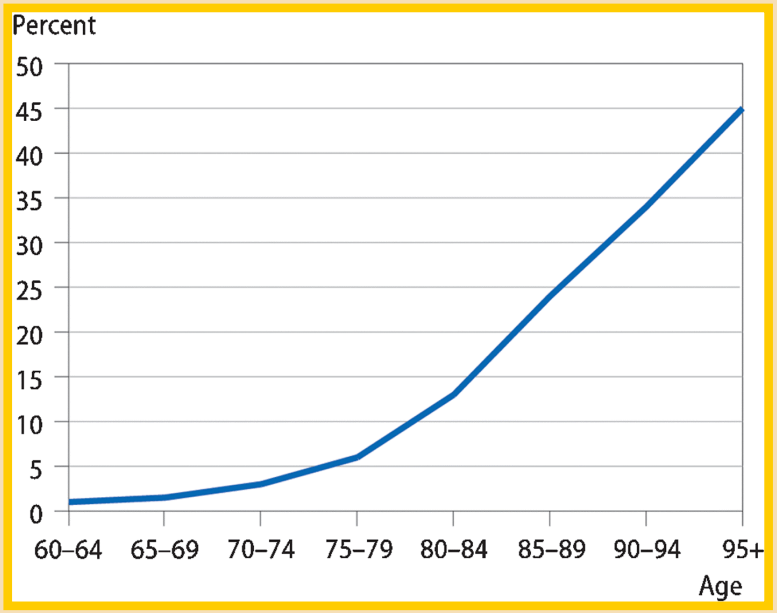
- 7% of 65 and older
- After 90 year 40-45%

- Increase between now and 2050
  Netherlands: from 230.000 naar 500.000
  Worldwide: from 36 to 115 million

- 70% lives **at home** (60% needs daily or continuous care)
- 30% in **institutional care setting** (95% needs daily or continuous care)

- costs 4,7% of all health care costs (3,2 milliard, mainly spent on institutional care)

- 60% of care at home by family carers
- 82% of carers (risk of) overburden



- people with dementia : working people
  in 2010 1: 55 → in 2050 1: 27

How do we deal with this?

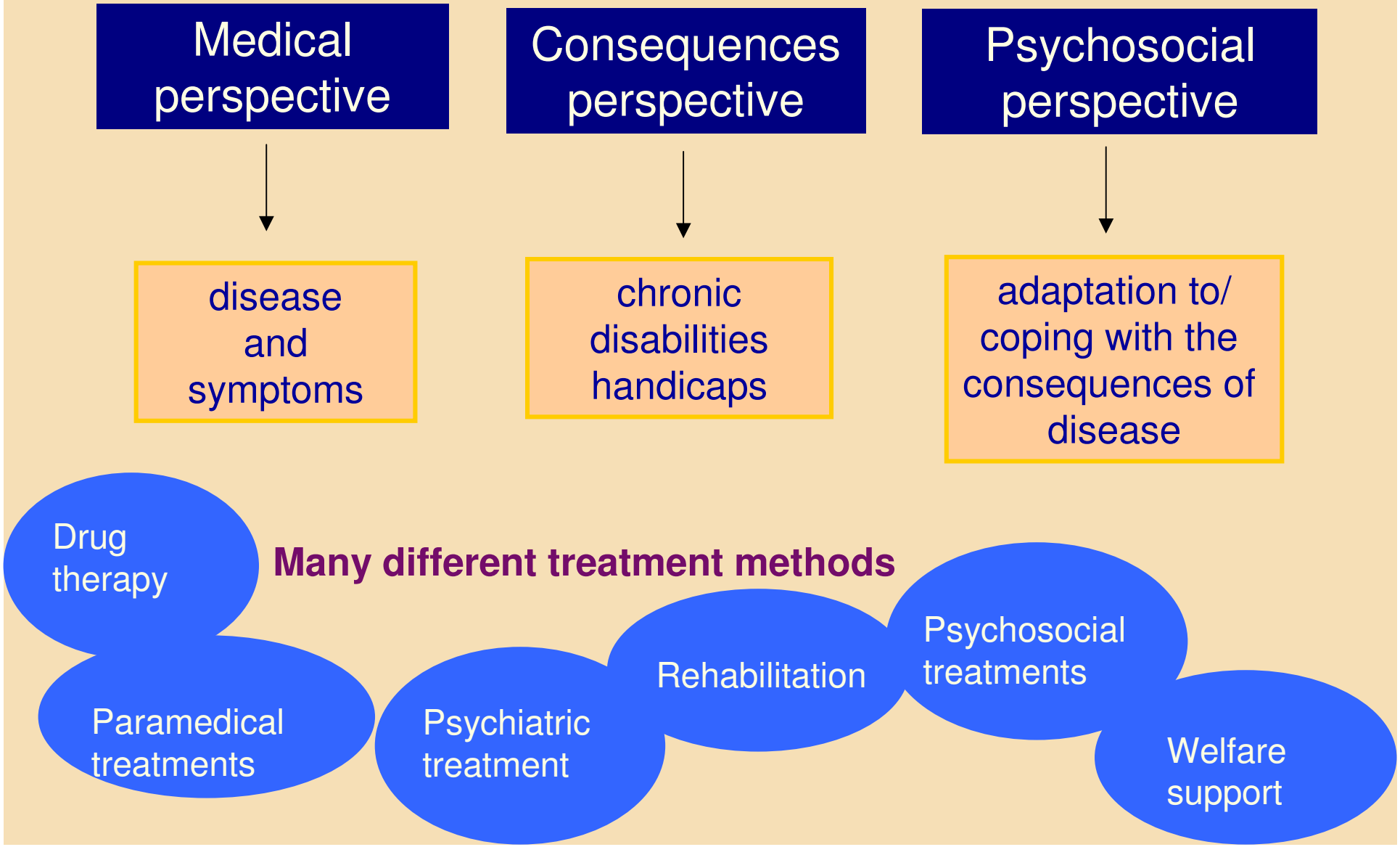
Improving Dementia care

- More (cost-)effective care
- Delivering care more efficiently

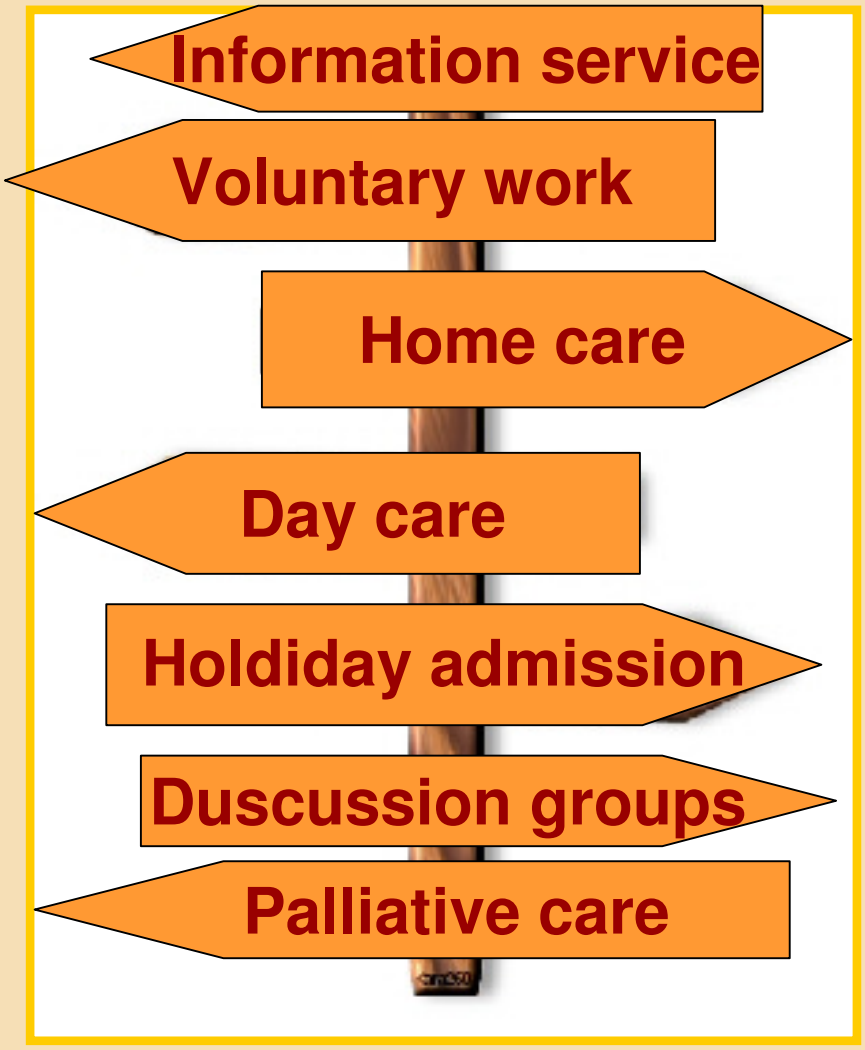
Cheaper

More people can benefit!

Treatment development in dementie 1970- 2010



Dementia care fragmented



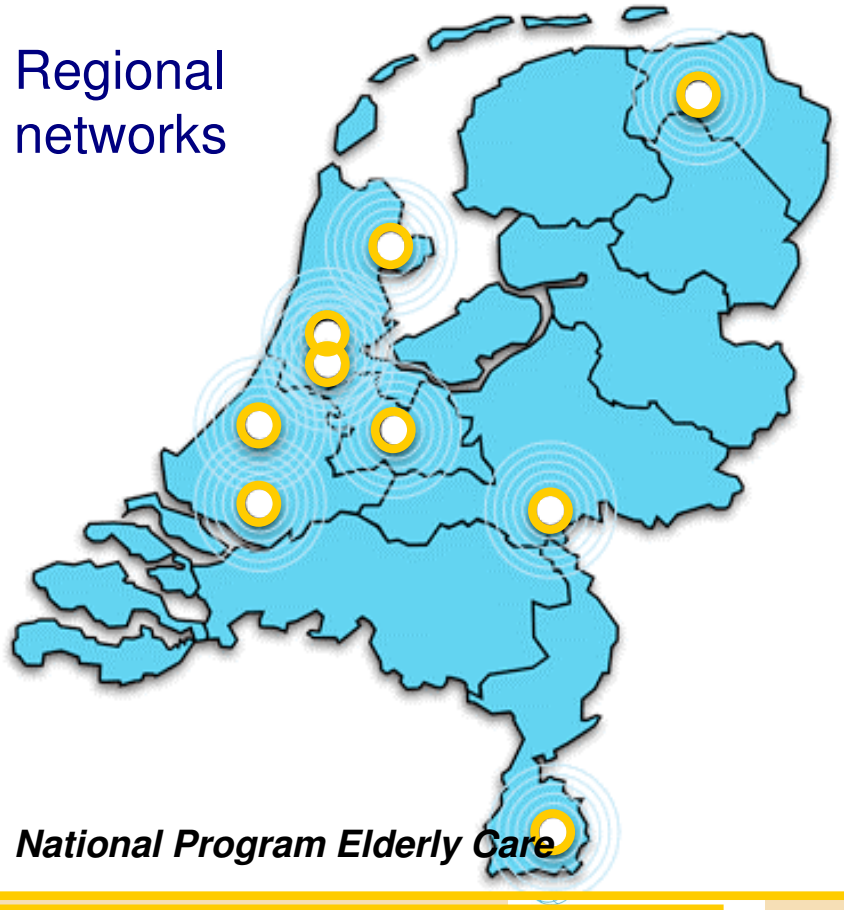
Finding the right service?

More (cost)effective and efficient

Close cooperation within chains of Dementie care

Multidisciplinary teams of care & welfare

Regional networks



National Program Elderly Care

Care coordination by casemanager from beginning to end of disease

Aim: Coordination, efficiency, continuity

More (cost-)effective and efficient

By means of promoting 'standard of care' regarding

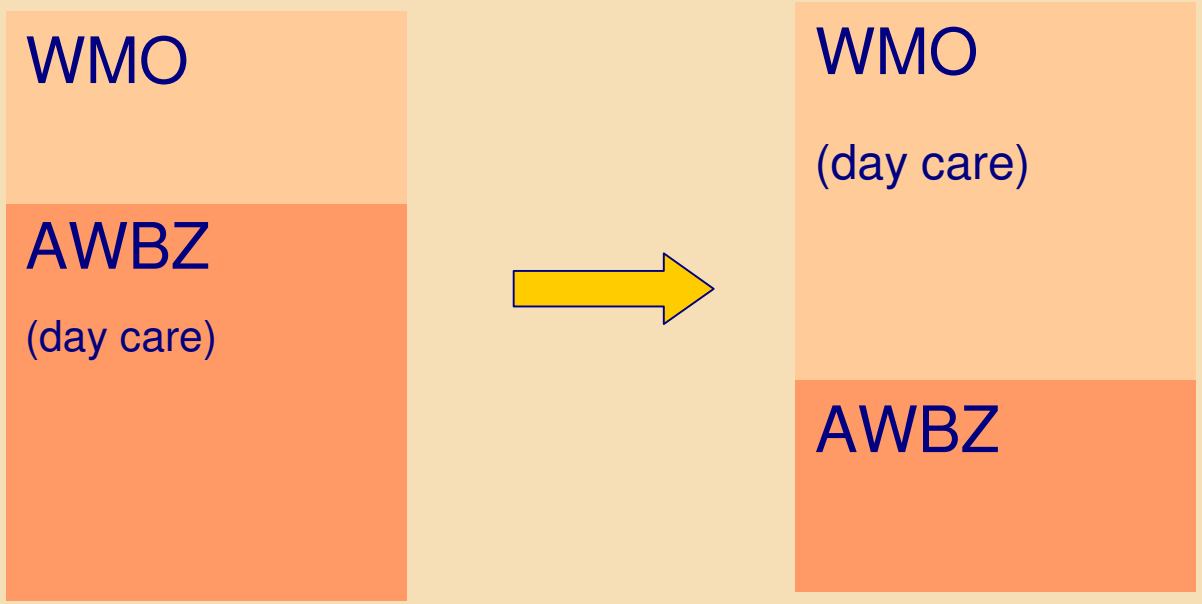
- ✓ Early diagnosis
- ✓ Timely interventions
- ✓ Evidence-based and personalized care
- ✓ Driven by the individual needs → demand oriented
- ✓ Efficient solutions for presently unmet needs
- ✓ Preventing crises /admission to hospitals
- ✓ Delaying admission to nursing home
- ✓ Remain at home longer

……

- ✓ Institutional care in human proportion
  (large scale care → small-scale living)

Cheaper

Dementia care costs



AWBZ: Exceptionel Medical Expenses Act pays long term care for people with severe disabilities caused by chronic illness or age (Own contribution max € 2.097,40/year)

WMO: Social Support Act reimburses costs for domestic help, adaptations to the home, social participation of people with chronic diseases **(no specialized care)**

Basis Health insurance: reimburses e.g. GP-visits, hospital, dentist, medication, medical transport (own risk € 170)

2. Psychosocial perspective in dementia care

Medical perspective

disease and symptoms

Consequences perspective

chronic disabilities handicaps

Psychosocial perspective

experience of/ adaptation to/ coping with the consequences of disease

experience oriented care/ psychosocial treatment

How to make psychosocial care more (cost-)effective?

How can we help people to stay at home?

Experience oriented care / Psychosocial treatment

Aim: More effective assistance in dealing with the consequences of dementia

⇨ **Attention for the personal experience**

⇨ **Attention for individual adaptation problems**

⇨ **Attention for individual quality of life**

⇨ **Attention for carer capacity**

⇩

Tailored evidence based care/ best practice

Attention for personal experience of dementia

1. Are people aware that they have dementia?

Variations in awareness: varying from no awareness to variable and full awareness, and sometimes awareness without expressing any emotions

(Bahro et al., '95; Cotrell & Lein, '95; Hutchinson, '97; Phinney '98)

Approximately two third of people is aware of the disease and one third is not aware – no hard evidence

(Swaab, 2010)

2. What do people experience in their daily life?

Loss of abilities, also from independence and self esteem, uncertainty, other world of experience, anger, anxiety, frustration, changed social relations and roles …

→ STRESS

(Clare, 2002; Steeman et al., 2007; De Boer et al., 2007)

Coping strategies

Denying
Minimizing problems
Emphasizing competence
Trying to stay involved
Avoiding social contacts
Overly depending on others
External attribution of problems
Keeping up a façade
Confabulating
Using humor

Intellectually and emotionally exhausting!

(Dröes, 1991; Clare 2003; Steeman et al., 2007; De Boer et al., 2007)

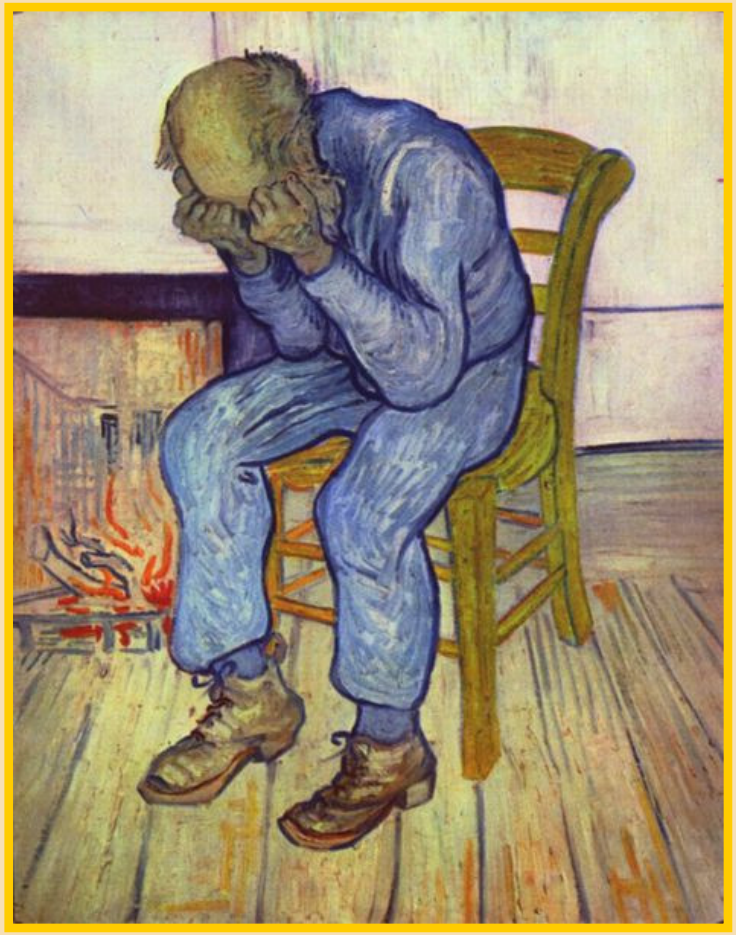
Disruptions of mood and behaviour

anxiety

depressed

agitation

rebellious



suspicious

restless

apathy

delusions

- Caused by a combination of biological, psychological and social factors
- Inadequate or ineffective coping and crises

Attention for individual adaptation problems

- How does the person experience his disabilities?
- Can he/she maintain emotional balance?
- Is the self image changed?
- How do people cope with the uncertain future?
- Does the person experience understanding from family and friends?
- Does the person accept help from others?
- ….

In what area does the person need assistance?

Practical/cognitive adaptation
- Dealing with disabilities
- Develop an adequate care relationship with professional carers

Emotional adaptation
- Preserving an emotional balance
- Maintaining a positive self image
- Preparing for an uncertain future

Social adaptation
- Stay in contact with family and friends
- Dealing with a day care/institutional environment

(Dröes, 1991)

Adaptive tasks

These **adaptive tasks** are commonly experienced in chronic diseases (Moos & Tsu, 1977)

and confirmed in dementia (De Lange, 2004; Clare 2003; Steeman et al., 2007; De Boer et al., 2007, Van der Roest et al, 2007)

Attention for individual quality of life (QoL)

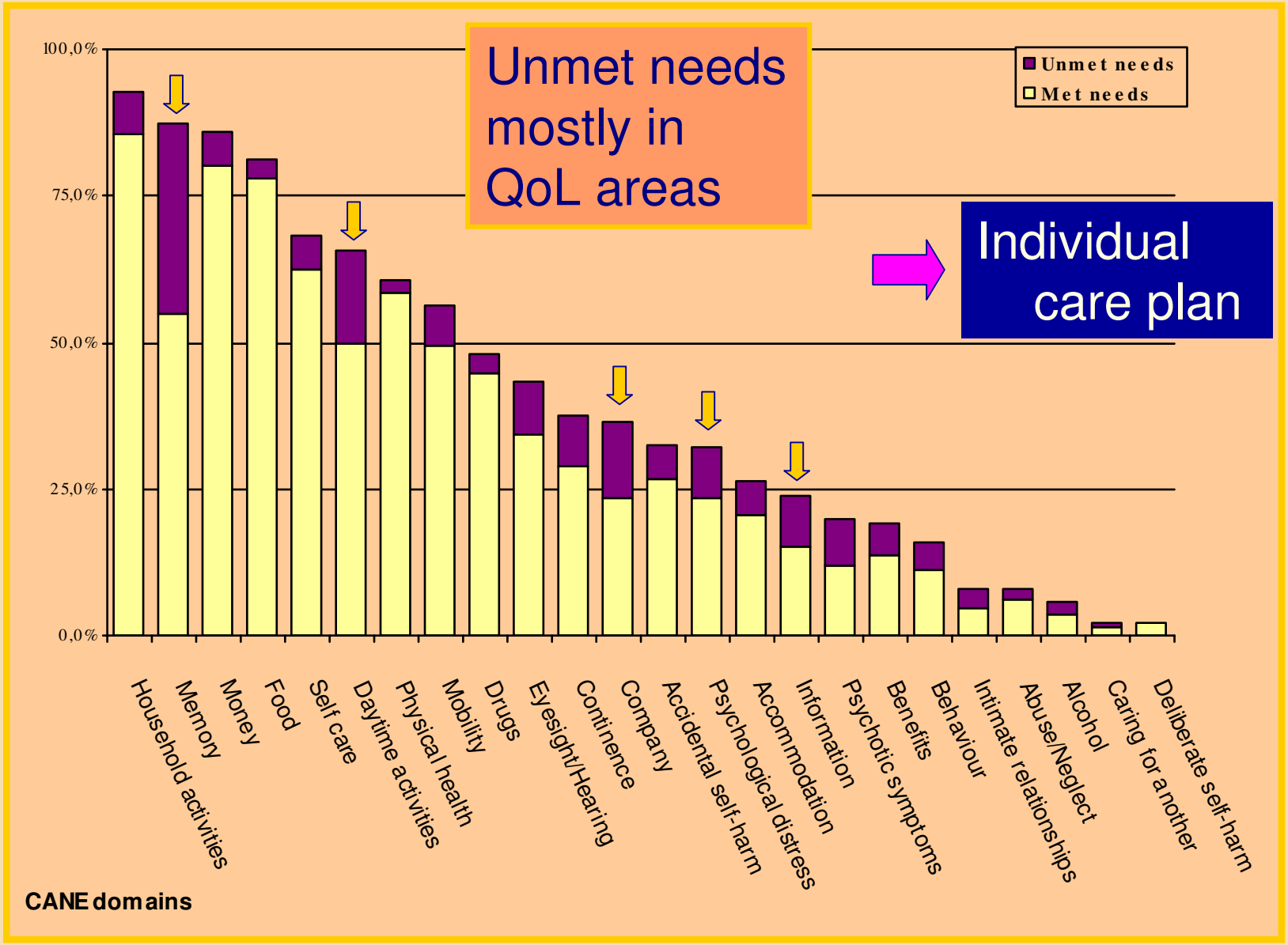
QoL in dementia concerns not only **health,** but also

- Feeling happy
- Having social contacts
- Feeling useful
- Feeling at home
- Enjoying activities
- Self esteem
- Freedom and perceived autonomy
- Adequate treatment and care when ill
- Safety, while remaining privacy

Individual variation

(Leo Cahn working group KvL bij dementie; Dröes et al., 2006)

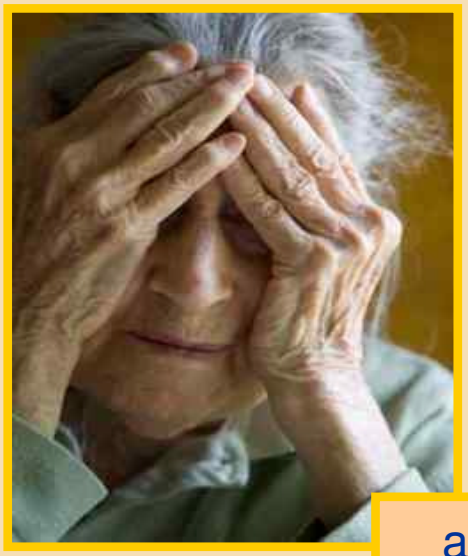
Individual differences in care needs



Solutions for unmet needs in dementia?

Information and memory support

Day activities



anxiety / safety

company

(Van der Roest et al, 2009)

Attention for carer capacity

Dutch National Dementia Programme

14 problem areas identified

where carers need support

for example:

- Dealing with behaviour changes
- Loss
- Dangerous situations
- Miscommunication with professional carers
- Resistance against admission in nursing home

(Meerveld et al, 2004; Peeters et al, 2007)

3. Experience oriented care and tailored psychosocial interventions

Definitions

Experience-oriented care

Starting point → experience of the person of his situation, his disease and abilities,

→ his individual needs and wishes

Offered care attuned to ind. experience, needs and wishes

Tailored psychosocial treatment

Interventions → to support the person's adaptation/coping process and treat adaptation problems

→ to decrease or prevent behavioural and mood disruptions

→ to maintain **quality of life**

Working model psychosocial treatment

Analysis adaptation / coping proces

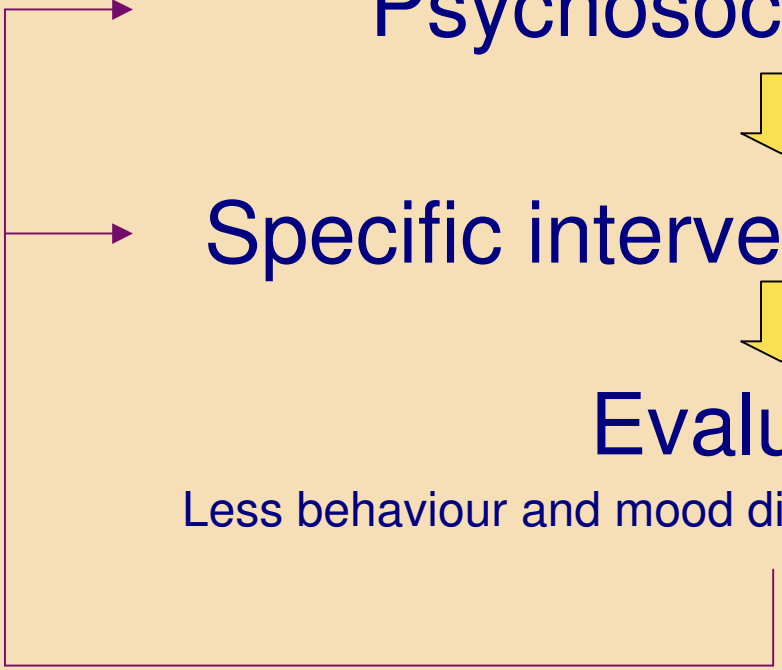
Problematic adaptive tasks – unmet needs/wishes –coping strategy – explanation of behavioral and mood disruptions

Psychosocial diagnosis

Specific intervention strategies

Evaluation

Less behaviour and mood disruptions, more quality of life



Adaptive tasks and care strategy

Experienced Problem(s)

Cognitive adaptation → **(Re)activation**

- Dealing with disabilities
- Developing an adequate care relationship with professional carers

Emotionele adaptatie → **Improving affective functioning**

- Maintaining an emotional balance
- Preserving a positive self image
- Coping with an uncertain future

Sociale adaptatie → **(Re)socialisation**

- Maintaining social relationships
- Coping with a day care/institutional environment

Care strategy

Psychosocial treatment methods

Institutional setting

- Supportive psychotherapy
- Psychomotor therapy
- Behaviour therapy
- Normalising living pattern
- Activity groups
- Reality orientation
- Music therapy
- Reminiscense
- Validation
- Emotion-oriented care
- Snoezelen
- Aroma therapy
- Simulated presence therapy,
- Pet therapy, ICT ……etc

At home / day care

- Cognitive rehabilitation
- Cognitive stimulation therapy
- Activity groups
- Animal therapy
- Reminiscence
- Physical exercise
- Combined programmes
- Assistive technology
- Occupational therapy
- Skill training carers
- Casemanagement
- Respite care

Evidence based / best practice?

What & When?

1970-2007		Problematic Adaptive tasks/ Adaptation areas						
Studied methods in Nursing homes Severity of dementia		1 disabilities	2 emot	3 self image	4 future	5 environment	6 care-relation	7 social relations
Psychomotor therapy	M-MS	X	X	X			X	X
Normalising living pattern	M-MS	X	X			X		X
Behaviour therapy	M-S	X	X			X	X	
Activity groups	M-MS	X	X			X		X
Music therapy / Art therapy	M-VS		X	X			X	X
Reminiscence	M-MS	X	X					X
Realiteitsoriëntation	M-MS		X			X		X
Emotion-oriented care	MS-S		X	X			X	
Animal therapy	M-MS		X			X		X
Snoezelen	M-VS		X	X				
Simulated presence therapy	S-VS		X					X
Education family visits	MS-S		X					X

M=mild MS=moderate severe S=severe VS= very severe

(Van Mierlo et al., 2009; Dröes et al., 2010)

What & When?

1970-2007		Adaptive task / Adaptation problem						
Studied method	Severity of dementia	1 disabilities	2 emot	3 self-image	4 future	5 environment	6 care-relation	7 social relations
Supportive psychotherapy	M-MS	x						
Cognitive stimulation	M	x						
Validation	MS-S		x					
Structuring activities	MS-S	x						
Aroma therapy	S-VS							x
Person centered showering	S-VS						x	

(Van Mierlo et al., 2009; Dröes et al., 2010)

- Focus mostly on effects on <u>emotional</u> and <u>social</u> functioning
- Less attention for
  - coping with disabilities
  - preserving a positive self image
  - coping with an uncertain future
  - adequate care relationship with professional caregivers
- Development and research is needed and more attention in care practice!

4. Example of evidence based practice

Combined support in

Meeting Centers Support Program

Meeting Centers Support Program

Person with dementia

- Social club
  -creative and recreational activities
  -psychomotor group therapy

Carer

- Informative meetings
- Support group
- Care coordination

For both

- Consulting hour
- Monthly meeting
- Social activities

Theoretical framework: Adaptation-Coping model

Practical/cognitive adaptation
- Dealing with disabilities
- Develop an adequate care relationship with professional carers

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(Dröes, 1991)

Adaptive tasks

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Psychosocial diagnosis

Problematic adaptive tasks

Care strategies for person with dementia

- (re)activation
- (re)socialisation
- improving affective functioning

Support strategies for carer

- information
- practical help
- emotional support
- increasing social network

From film ‘Meeting centers for people with dementia and their carers’

Results effect multicenter study (n=11 centers)

Compared to regular day care the MCPS participants showed:

Persons with dementia*:*

- Less behavioural problems (inactivity and unsocial behaviour)
- Less depressive symptoms
- A higher self-esteem
- Delay of nursing home admission

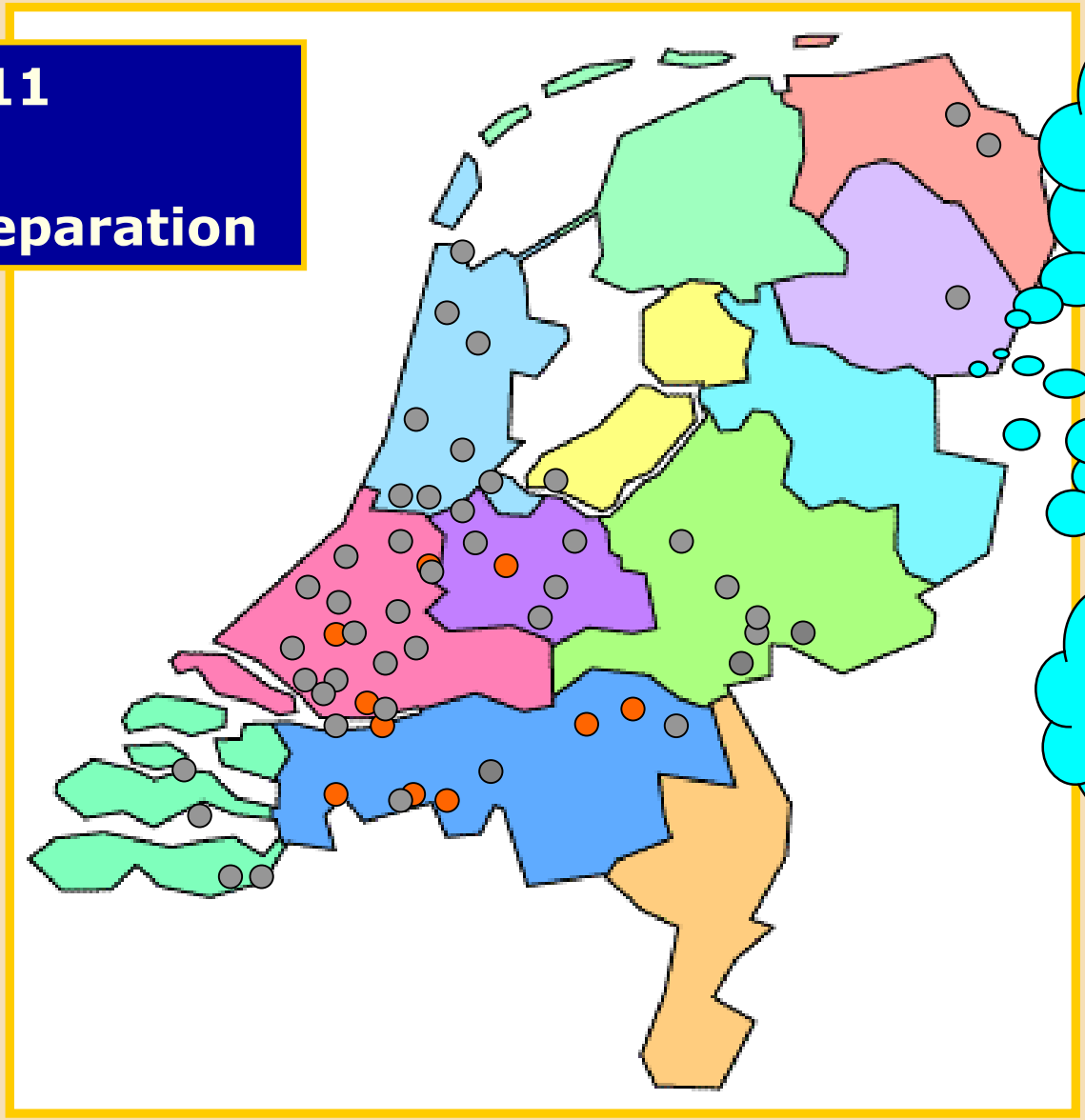
Carers:

- Less psychosomatic complaints in lonely carers
- Less feelings of burden after 7 months participation

(Dröes et al, 2000; 2004a,b; 2006)

Meeting centers in The Netherlands +

Sept 2011
N=75,
25 in preparation



ARUBA (1)
PARAMARIBO (1)

BELGIUM
(1)

ITALY/ER
(20)

5. To conclude:

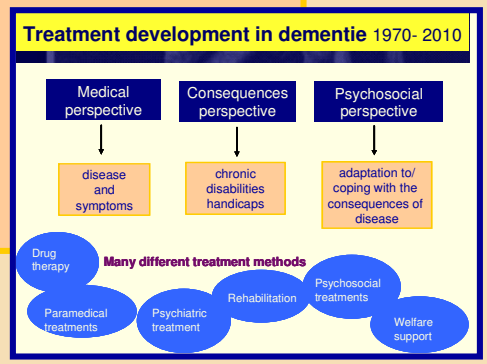
What are characteristics of the Dutch model?

The Dutch model of dementia care

Multidisciplinary approach in dementia care chains

- medical treatment perspective
- rehabilitation perspective
- psychosocial perspective

} casemanager



Psychosocial treatment perspective

Attention for personal experience, adaptation problems, individual quality of life, carer capacity

Tailored care and support

for person with dementia and carer, preferably combined, using evidence based methods and best practice

Thank you for your attention!

Correspondance

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If there is time left

Two other examples of psychosocial treatment

- Movement and psychomotor therapy
- Assistive technology

Movement and psychomotor therapy

Main therapeutic perspectives

- Cognitive and neurophysiologic

  Aim: stimulation of informationprocessing system / neurophysiologic processes

  Methods: physical education, sport, games

- Psychodynamic

  Aim: restore emot. balance by experiencing success, fun and contact/trust

  Methods: sport and games, hobby, dancing on music

* Reactivation *

Memory: reminding, recalling

Perception: orientation person, space, time

Language: (non)verbal

Action: locomotion, reaction, concentration

Initiative and choice

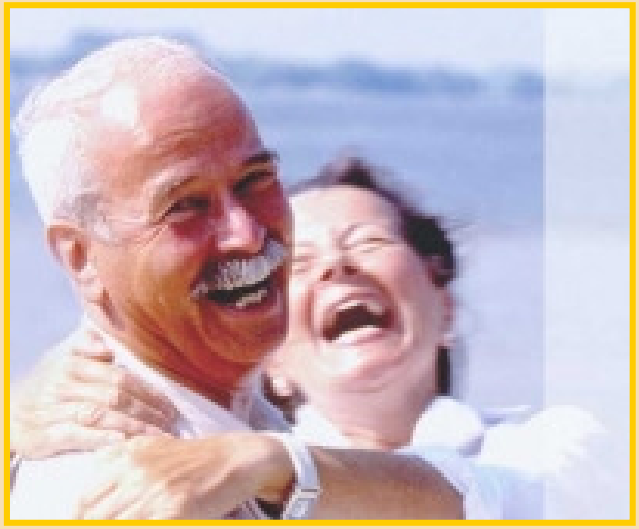
* Improving emotional functioning *

Preserving a positive self image

Experience own potential

Strenghtening sense of identity and

Sense of control



Maintaining an emotional balance

Success and fun

Mental relaxation

Abreact emotions

* Resocialisation *

Communication

Cooperation

New contacts

Research

Effect studies 'Psychomotor Activation Programme' (psychodynamic perspective) in people with mild to moderate severe dementia

Positive effects on affective functioning / <u>nursing homes</u>
RCT, 3x45min/wk, 9mnd

- increase of satisfaction
- less agressive behaviour
- less night time restlessness
- improved sleep

N.B. During therapy sessions improvement of
⇧ memory, lifeliness and initiative (Dröes, 1991;1996)

Positive effect on cognitive and social functioning / <u>care homes</u>
RCT, 3x45min/wk, 3 mnd

(Hopman et al., 1999)