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WELCOME!!

Different Approaches of self-management facilitation for elderly in the community

Research Group Nursing, Saxion University of applied Science, Deventer/Enschede, The Netherlands

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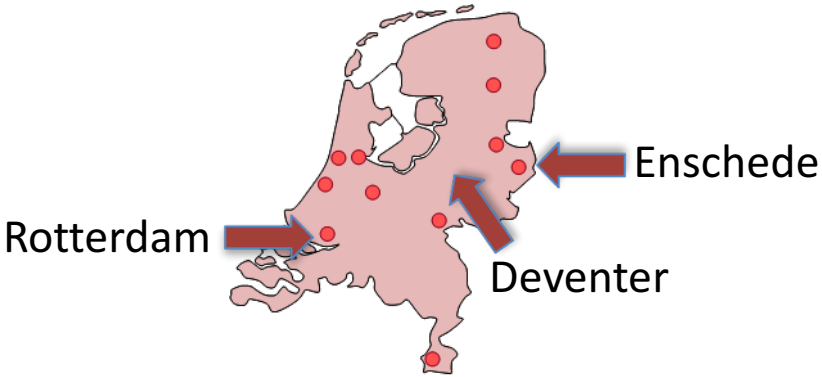
Kom verder



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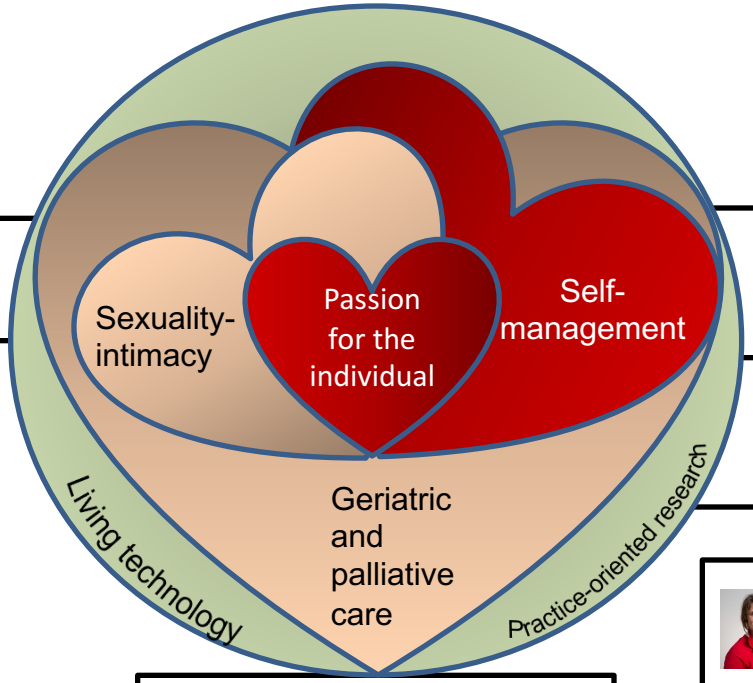
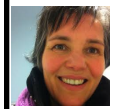
Marjolein den Ouden
Senior lecturer

Ad Bergsma
Associate professor

Esther van Loon
Senior lecturer



Jan Jukema
professsor
Per November 1th



Madeleen Uitdehaag
Associate professor

Myrna Pelgrum
Research lecturer

Researchgroup

- **Marian van het Bolscher (PhD student)**
- **Yvonne Kerkhof (PhD student)**
- **Sylvia Vonk (PhD student)**
- **Inge Geerink (research-lecturer)**

Program symposium

- 14.15 Opening

Madeleen Uitdehaag, RN, PhD, associate professor Geriatric and Palliative care

- Effects of self-management support programmes on ADL

Marian van het Bolscher, RN, MSc, PhD student, lecturer

- Tool for selection of tailored apps for people with mild dementia

Yvonne Kerkhof, RN, MSc, PhD student, lecturer

- Need for self-management related care in elderly with permanent ostomy

Sylvia Vonk, RN, MSc, PhD student, lecturer

- Digital communication tool in the community

Myrna Pelgrum, PhD, lecturer & Inge Geerink, MSc, lecturer

- 15.45 Closing

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PhD-study

VU VRIJE UNIVERSITEIT AMSTERDAM

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How to provide tailored ((I)ADL) self-management support interventions for community living older adults?

Marian J.T. van het Bolscher-Niehuis [a], Ad Bergsma [a], Miriam M.R. Vollenbroek-Hutten [b], Anneke L. Francke [c,d]

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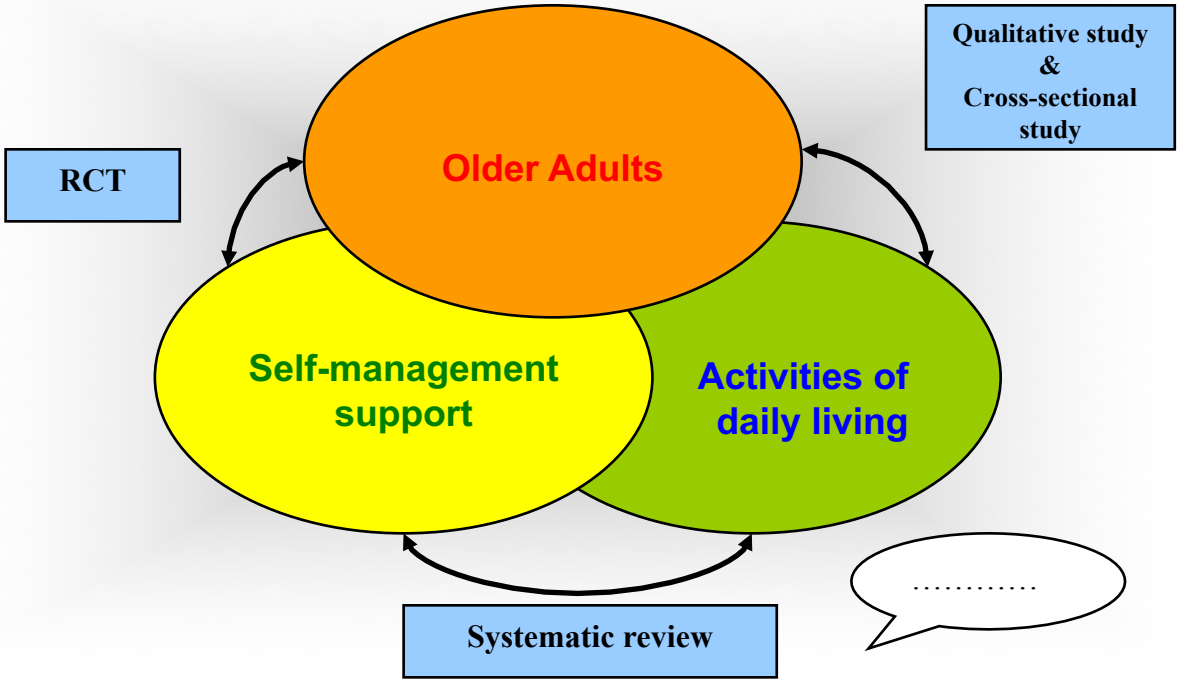
PhD-study


Qualitative study
&
Cross-sectional
study
RCT
Older Adults
Self-management
support
Activities of
daily living
.....
Systematic review

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Systematic Review

Effects of self-management support programmes on activities of daily living of older adults

(van het Bolscher-Niehuis MJ, den Ouden ME, de Vocht HM, Francke AL. Int J Nurs Stud. 2016 Sep; 61:230-47. doi: 10.1016/j.ijnurstu.2016.06.014. Epub 2016 Jun 30. Review)

Content presentation:

- Background
- Objective
- Method
- Results
- Discussion
- Conclusion

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Background

- The ability to carry out ADL decreases
- Older adults need support to manage the consequences of living with a chronic condition.
- Self-management support programmes have proven to be useful and beneficial

Evidence of effects on activities of daily living of older adults?

Objective

To identify, appraise and synthesise the evidence of the effects of self-management support programmes on ADL of older adults

Research questions:

- What evidence can be derived from existent studies?

- Characteristics of the self-management support programmes?
- Methodological quality of the relevant studies?

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Method

- Original research publications
- Searches: PubMed, EMBASE,CINAHL and PsycINFO and the Cochrane Central Register of Controlled Trials
- Inclusion and exclusion criteria
- No limitations (date, language, country)
- Methodological quality assessment

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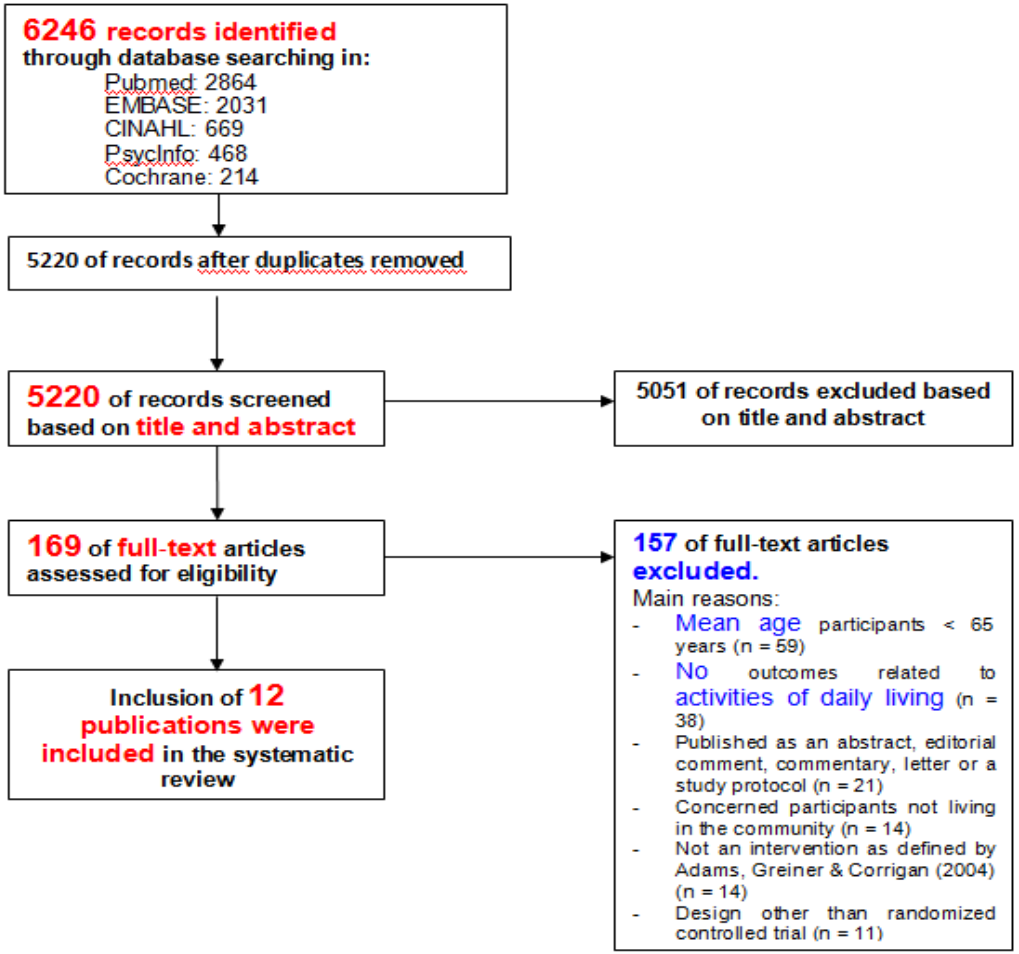
Results

Flow diagram of the searches and the selection process.



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Results

Methods of the included studies:

- Designs: RCT
- Study population:
  - Sample size varied (30-766 participants)
  - Heterogeneity mean age and types of diseases/disabilities
- Outcome variables, measurement instruments varied
- Methodological quality: low (n=8), moderate (n=3) and high (n=1)

Results

Characteristics of the programmes:

Intensity and duration:

- intensive + short programs (group sessions) (n=4)
- less intensive + long programs (individual approach) (n=5)
- intermediate duration + less intensive program (individual and/or group) (n=3)

Topics and key elements:

- Health promotion / information
- education
- coaching
- social support
- functional training / excercises.

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Results

Effects on the activities of daily living:

- Less disability in ADL (n=11)
- Statistically significant improvements (n=7)
- In some studies, the control group showed a functional decline in ADL
- Differences were maintained at follow up (after 3/6 months)
- Individually tailored coaching (personal plan/goals) works!
- The intensity and duration of the programme does not seem to affect the results

Discussion

Some considerations…

- Bias due to small sample size and/or high rates of drop-outs/lost to follow up?

- Interaction between intervention and ‘care as usual’?

- Heterogeneity and methodological quality of the included studies

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Conclusion

Take home message:

- Self-management programmes can improve ADL of older adults
- A multi-component structure should be used
- Individually tailored coaching is essential

Selecting apps for people with mild dementia; development of a requirements based assessment tool for apps enabling meaningful activities and self-management

Yvonne Kerkhof[1], Ad Bergsma[1], Maud Graff[2], Rose-Marie Dröes[3]

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Outline

- Introduction
- Research questions
- Method
- Findings
- User-requirements
- Further development

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Introduction

- Person-centred interventions
- Unmet needs meaningful activities
- Insufficient support for self-management
- Current policy

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What is known about people with dementia and touch screen technology?

- User-friendly and valuable;
- Increasement of self-confidence and engagement in daytime activities;
- Involvement in society.

(Riley et al., 2009, Astell et al., 2010, Upton et al., 2011, Meiland et al., 2012, Pringle and Somerville, 2013, Leuty et al., 2013, Nijhof et al., 2013, Lim et al., 2013, Groenewoud and de Lange, 2014, Nordheim et al, 2014; Kerkhof et al., 2015; Astell et al, 2016)

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Reflections

- Careful consideration is required to select usable apps
- Support is needed to learn how to use the touch screen and its apps

The person-centred tablet programme consists off:

- A **tool** to match individual needs, wishes and abilities of people with dementia to features of apps so that tailores apps can be selected, see Figure 1.
- A **training for people with dementia** to learn how to use the tablet.
- A **training for professionals, informal carers** (including volunteers) to support people with dementia in using the tablet (Kerkhof et al, 2016).

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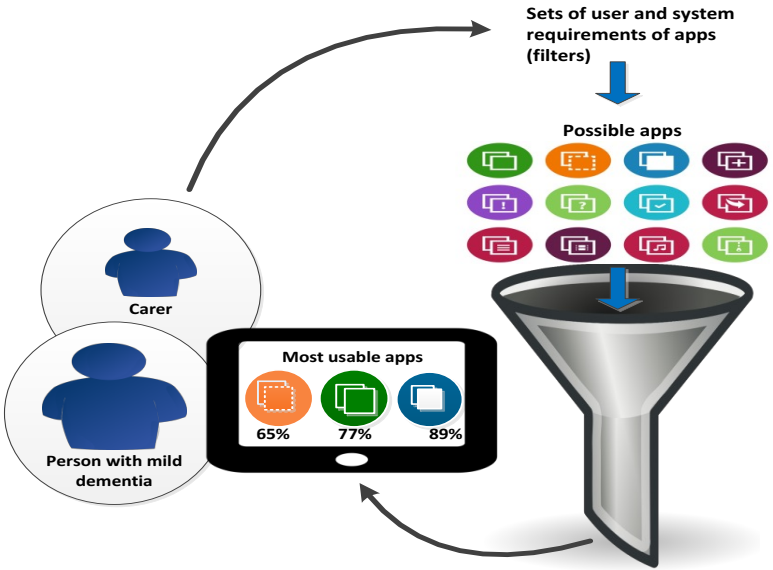
Requirements based assessment tool for customized apps




21:00
100%
Family
Videos
Music
Call
Find Home
21:00
100%
Search
Back

Research questions

What do people with dementia find important in their **choice** and **use** of apps?

1. *What kind of **self-management** and **meaningful activities** are important for people with dementia?*
2. *What are the **needs, wishes and abilities** of people with dementia in the **use** of apps?*
3. *What **user requirements** can be identified based on these perceptions?*

Method: needs study one

- Two focus groups with people with dementia (n=8)
- Two focus groups with informal carers (n=10)
- OPHI-II-NL (Graff et al, 2006; 2010; Baaijen et al, 2008)

Method: needs study two

- Two focus groups sessions with people with dementia (n=5)
- Two focus groups sessions with informal carers (n=5)
- To gain insight into current use and types of apps and newly introduced apps.

Data analysis

1. Participant characteristics
2. Transcriptions
3. Observed participants reported in field notes
4. Advantages and disadvantages of used apps noted in a diary (needs study two).

Inductive content analysis based on the principles of the grounded theory/ ATLAS.ti

Themes: needs study one

1. Past meaningful activities
2. Present meaningful activities
3. Self-management support

Quote (present MA)

"My husband has these outbursts of anger, then he becomes restless and he wants to walk away. By coincidence I noticed that music made him calm and that he enjoyed it. Because these outbursts are getting worse I made a play list in YouTube with his favourite music. Now when he becomes angry or restless I let him watch TV which shows him the play list with all these videos and then he becomes calm, engaging with the music for two hours and he says again and again how he likes it" (IC).

Quote (self-management support)

"I would like to have an alarm system, when I am at home in the evening it is medication time at seven, but I never think of it, my wife arranges this. This is the same in the morning, everything is prepared for me" (PwD).

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Themes: needs study two

1. Needs and wishes of users for:

a) Functionality of apps

b) Technical features of apps

2. Abilities of users with regard to:

a) Their physical and cognitive condition

b) The independent use of apps on a tablet

c) Skills to use the touchscreen and tablet

Quotes (functionality of apps)

"The speech and language therapist advised him to use the Diaro app. With this app it is possible to record activities by means of photos, which provide him and I with an overview of activities done during the day and this stimulates the communication between us" (IC).

"I used to play a lot of checkers competitions with my brother, but I have not played it for thirty years and now I started with it again, so nice!" (PwD).

Quote (technical features of apps)

"I was playing the word search app and when you want to go back, you had to push the pause button and I thought this was not a very clear symbol for going back. And then it might be that PwD press the pop-up window for advertising thinking that this is the button to go back" (IC)

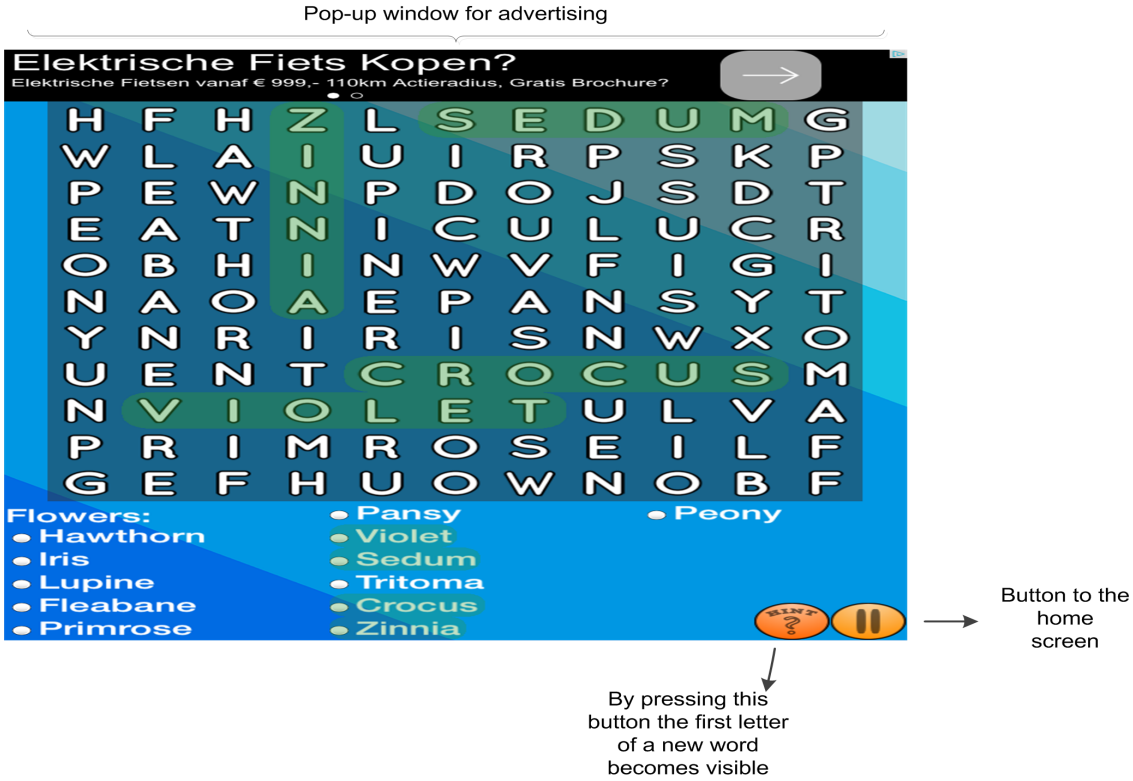

Figure 5: Word search de luxe

Quotes ((Dis)abilities)

"I cannot handle small, I cannot read it" (PwD). *"PwD I more eager to participate when apps contained less text"* (Observation researcher).

"I make the use of the tablet very simple for her, for example when we planned to buy a new chair I took pictures of chairs we like and when we got home I showed her the pictures again and again" (IC).

"Sometimes you don't know which side you have to swipe to, and sometimes it disappears too quickly and then you have to do it again" (PwD).

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User requirement (1)

Functional selection criteria *(the person wants an app that is suitable for)*

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User requirements (2)

Technical selection criteria *(the person wants an app that)*

User requirements (3)

Profiles take into account (dis)abilities of users:

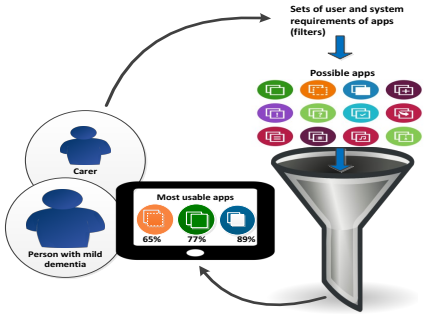
- ❑ The person has: memory problems, visual problems, language problems, etc.

- ❑ The person can use apps: independent, with support of others, etc.

- ❑ The person is capable of the following touchscreen skills: swiping, scrolling, etc.

Further development

- Operationalize and validate the technical selection criteria
- A prioritizing or ranking system
- Research present supply apps
- User requirements translation into system requirements
- Design and development of the tool



Take home message

- Pleasure and enjoyment
- Connection and belonging
- Autonomy and personal identity

(Phinney et al., 2007).

Contact

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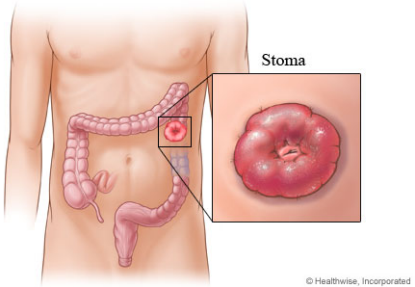
Need for self management related care in older people with a permanent ostomy

Recognition of and dealing with physical Ostomy-related problems

http://www.stomacarebelgium.be/ileostoma



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Content

- Introduction
- Aim of the study
- Methods
- Results
- Conclusion
- Q&A

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Introduction

< 2 years ostomy surgery

Goede stomazorg

Beroepsvereniging van zorgprofessionals Stomaverpleegkundigen

Stoma Zorgwijzer

Wet maatschappelijke ondersteuning (WMO)

> 2 years ostomy surgery

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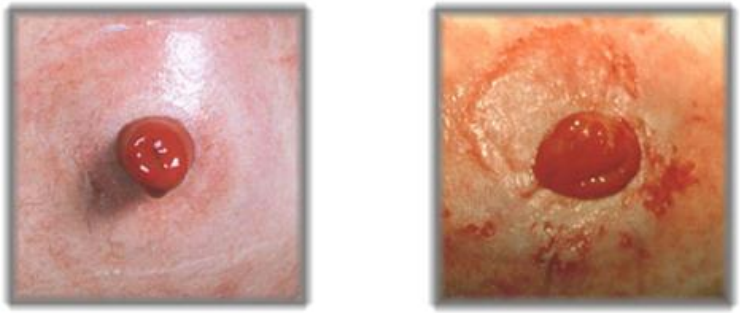
Introduction

Ostomy-related problems

Source: Stomavereniging

Physical ostomy-related problems

- Stomal (parastomal hernia, prolapse, stenosis)
- Peristomal (skin problems)



http://www.colorectal-cancer.ca/en/ostomy

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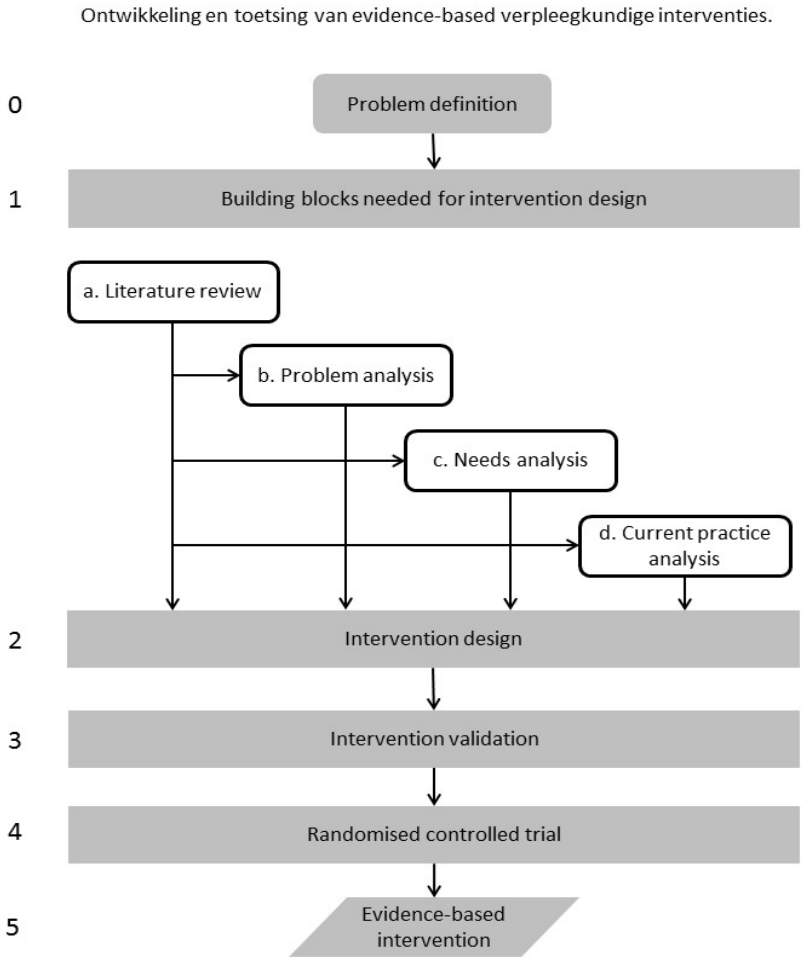
PhD study

What is the optimal care for people with a permanent ostomy (ostomates), in order to ensure lifelong sustainability of this care

To develop interventions that promote good ostomy-self-management concerning recognition of and dealing with physical ostomy-related problems

Utrechts Intervention Model

Meijel et al (2004) 'Utrechts Interventiemodel'



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- Systematic Review: Ostomy-related problems and their impact on quality of life of colorectal cancer ostomates'
  (Vonk-Klaassen, de Vocht, den Ouden, Eddes & Schuurmans, 2015)

- Exploratory (student) research

  problems, information needs, recognizing problems/ among ostomates and ostomy nurses

- National survey study (with Ostomy Association): 'Quality of ostomy care'

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Part of national survey study ‘Quality of ostomy care’

- Digital semi structured questionnaire
- 17 open & close-ended questions: ostomy-related problems
- Members Ostomy Association N=5542
  Response 28% (n)=1554

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Population

Inclusion criteria (n=972)

- Adult
- Permanent ileostomy, colostomy
- Constructed > 1 year
- Received ostomy care past 12 months

Population

Table 1. Baseline Characteristics n= 972

Characteristic	Frequency (n)	Percentage (%)
Gender (male)	580	60
Age (years)		
18- 44	43	4
45-64	336	35
65- 84	564	58
85+	35	4
Education		
Low	171	18
Middle	410	42
High	294	30
University	79	8
Other	26	3
Reason construction ostomy		
Colorectal cancer	593	61
Ulcerative colitis	143	15
Crohn's disease	85	9
Other*	159	16
Most recent ostomy creation		
Colostomy	670	68
Ileostomy	304	32
Take care of ostomy themselfs	939	97
Help received at daily ostomy care from:		
Partner	24	2
Home care	9	1
Perceived health now compared to health before ostomy		
Better	359	37
The same	316	32
Worse	301	31
Perceived general health		
Excellent	60	6
Very well	159	16
Good	516	53
Moderate	214	22
Poor	31	3

* e.g. Bowel polyps, (Slow transit) Constipation/ Obstipation, Incontinence, Bladder cancer, Diverticulitis

- 60% male
- 58% 65-84 years
- 68% colostomy
- 61% colorectal cancer
- 97% ostomy self-care

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Aim

To describe the experiences of ostomates to recognize and deal with physical ostomy-related problems

1) perceived physical ostomy-related problems
2) recognizing and dealing with (symptoms of) problems and the effect on ostomates
3) needs of ostomates dealing with (symptoms of) physical ostomy-related problems

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Results
Perceived physical ostomy-related problems

Problems caused by the ostomy in the last 12 months	Frequency (n)	Percentage (%)
No physical problems	325	33
Physical Problems	**667**	**67**
Leakages	349	**36**
Skin problems	229	**24**
Parastomal hernia	179	18
Retraction	51	5
Prolapse	59	6
Stenosis, dehiscention, necrosis, peristomal fistula	39	4
Fatique	250	26
Saddle pain	156	16
Constipation	132	14
Diarrhoea	132	14
Pain	76	8
Weight gain	54	6
Weight loss	37	4
Oedema	40	4
Dehydration	28	3
Inflammation	33	3
Other physical problems *	80	8

Table 2. Perceived (physical) ostomy related problems of ostomates
*Less fysical condition, backpain, myalgia, pancaking

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Results
Recognizing and dealing with (symptoms of) problems and the effect on ostomates

Table 3. Solving problems

question 11 n=667 (67% experienced a problem) Were you able to judge at the last appeared problem if you could solve this on your own	**frequency**	**percentage**
Not at all	113	17%
A little	71	11%
Quite a bit	211	31%
Completely	272	41%

Results
Recognizing and dealing with (symptoms of) problems and the effect on ostomates

No effect: 20%

"*After 14 years you are used to these problems*"
[man, ileostomy, leakages]

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Results
Recognizing and dealing with (symptoms of) problems and the effect on ostomates

Effect

1. effect on psychological wellbeing

2. complaint (mostly physical)

   pain, fatigue, less active, skin problems, less sleep, problems at work

3. consultation with a health care professional.

   ostomy nurse, surgeon, general practitioner

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Results
Recognizing and dealing with (symptoms of) problems and the effect on ostomates

Not (completely) knowing

"I was desperate, because no one could help and I felt alone" [woman, colostomy, leakages-skin problems- obstipation-pain]

"I felt extremely vulnerable and unhappy when leakages occurred" [woman, ileostomy, leakages-saddle pain]

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Results
Recognizing and dealing with (symptoms of) problems and the effect on ostomates

Not taking action

"*I was in doubt whether to call the emergency number of the general practitioner for complaint of constipation. In the end, I waited too long which resulted in a hospitalization*"
[woman, ileostomy, leakages-skin problems]

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Results
Recognizing and dealing with (symptoms of) problems and the effect on ostomates

(Largely) knowing what to do

"*I can still manage it on my own. I feel good, because it gives me a sense of control and independence.*" [man, colostomy, skin problems]

"*It gives me strength and trust that I can manage it on my own*"
[woman, ileostomy, leakages, skin problems]

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Results
Recognizing and dealing with (symptoms of) problems and the effect on ostomates

Knowing what to do and still feeling:

"*I am still anxious when you feel something that you cannot explain*"
[woman, colostomy, parastomal hernia]

" *Having a stoma, you always have to anticipate on potential problems*"
[man, colostomy, leakages-skin problems-saddle pain]

Results Needs of ostomates

Contact professional

- 90% knows when to contact a professional
- Professionals contacted: Ostomy nurses (55%), surgeons (29%), general practitioners (17%)
- 39% no regular appointments
- 84% content with frequency appointments

Regular contact ostomy nurses desirable

"*I would prefer aftercare after the period of one year of the construction of the stoma. Even if it is contact by email of telephone once a year, so they can check whether you are still okay. Then you know who to contact and it will decrease the threshold to contact if you experience symptoms*" [woman, colostomy, saddle pain, pain]

On their own initiative

"*I only visit them {health care professionals} when I have a problem that I cannot take care of myself*" [woman, ileostomy, leakages retraction-saddle pain]

Information

Table 4. Information about ostomy-related problems

	Information given by			
	Ostomy nurse after care n= 972 n(%)	**Ostomy nurse of supplier, manufacturer** n= 466 n(%)	**Nurse home care** n=65 n(%)	**Nurse nursing home** n=3 n
Information about				
Recognizing ostomy problems	220 **(23)**	52 (11)	10 (15)	2
Preventing ostomy problems	297 **(31)**	80 (17)	12 (18)	2
What to do when a problem occurs	324 **(33)**	84 (18)	20 (31)	2
Where, how, or whom to contact if a problem occurs	468 (48)	110 (24)	32 (49)	2
I do not know anymore	168 (17)	94 (20)	16 (25)	1

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Conclusion

- 67% problems
- Great impact psychological wellbeing
- Self management insufficiënt
- Need for information recognizing and treatment
- Self diagnosis and self treatment (if possible)
- Consult professional (flexible)

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Future steps

- More research: develop and validate interventions

- Self diagnosis instrument for ostomates
  Delphi research ostomy nurses & ostomates

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Q&A ?

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Introduction

- Myrna Pelgrum-Keurhorst, PhD
- Inge Geerink, MSc
- Project “Sterven op de plaats van voorkeur”= dying @ site of preference

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Content

- Aims project
- Role research
- Self management & communication tool
- Longer at home: a virtual nursing home. A study by Bachelor Nursing students

Aims project

- Studies best practices in palliative and end of life care to improve care (patients and professionals)
- Including role of technology (apps, medical tools) to improve self management and quality of life for palliative and end of life patients

Role of research

- Role research Bachelor Nursing
- Practice oriented studies

Self-management & communication tool

- Chances in Dutch health system: elderly longer at home.
- ⬇community nurses versus ⬆elderly/patients
- Proper use of technology; increase safety feeling by patients and more important care potential
- OZOverbindzorg communication tool

Tool OZOverbindzorg

- Home care organization and GP invite clients to participate in OZOverbindzorg
- Mutual communication (not urgent) and coordination of care through computer program
- Cliënt or care giver - own page
- Quick communication: pharmacy, community nurses
- Empowerment & improved feeling of safety

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contactpersoon Mantel Zorger 1

zoek | zoekterm

profiel | berichten | agenda | case management | zorgleefplan | instrumenten

rapporten | deelnemers | historie

Vragen - test

U kunt reageren op een vraag of de reacties op die vraag. Vul uw reactie in en klik op **reactie versturen**

gesteld door	Huis Arts 1
vraag voor	Wijhe, Apotheek (Apotheker)
gesteld op	17-02-2016

toelicht door vraagsteller	**jkfjdkfjdkj**

meer details ☐

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Interview study

- Semi-structured interviews
- 8 home care nurses
  - 4 without experience with the tool
  - 4 with experience with the tool
- 5 care givers
- Inductive thematic approach

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Findings (1)

- Stimulates (perceived) self-management in frail elderly
- Applicable in daily palliative home care
- Strengths:
  - Low barrier communication tool
  - Empowerment
  - Improved continuity of care

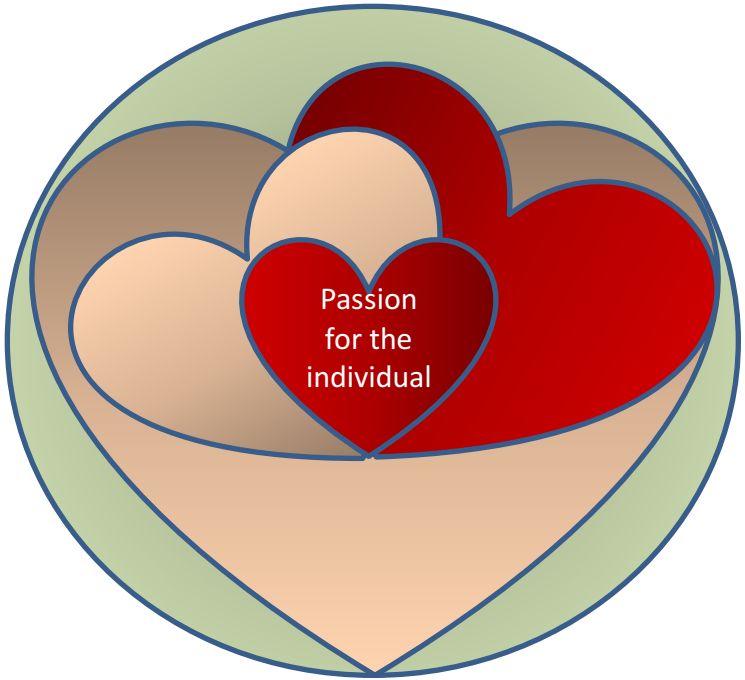
Findings (2)

- Weaknesses:
  - Care support and indicators for prioritising messages
  - Follow-ups of care
  - Palliative tools not available (e.g. identification palliative phase)
  - Application in emergency situations

Conclusion

- Reveals possibilities of virtual care
- Yes, virtual support can be personal
- Limited use in palliative care
- Successful for frail elderly, however:
- Further development required for daily application in palliative care

TAKE HOME MESSAGE



- Passion for the individual is the central value in self-management facilitation for elderly in the community
- Individually tailored (sometimes digital) care!