

Situational feedback for enhancing patient self-management using mobile phones

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NIVEL



- Netherlands Institute for Health Services Research
- 200 employees: sociologists, psychologists, GPs
- Focus: Provision and use of health care services in the Netherlands and beyond
- One of the 10 research programs: (E-)communication in healthcare
- Hosts 2 European societies:
 - EUPHA
 - EACH

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Examples ongoing (E-)communication projects

- Education and recall in older cancer patients
- Historical shifts in communication
- Communication and medication adherence
- Placebo effects of communication
- Stress and communication (cortisol, hr, bp)
- Added value of group medical visits

- Tailored webbased intervention in genetic counseling for hereditary breast cancer
- Role delineation in pediatric oncology; web-based focus groups with parents, survivors and children with cancer
- Situational feedback using e-diaries in IBS

OUTLINE OF THE WORKSHOP

1. Opportunities and challenges of using electronic diaries to collect day-by-day patient data (10 min.)
Sandra van Dulmen
2. Situational feedback intervention in fibromyalgia (10 min.)
Hilde Eide
3. Situational feedback intervention in IBS (10 min.)
Sandra van Dulmen
4. Technological specifications and demonstration of the developed system in fibromyalgia (15 min.)
Erlend Eide
5. Plenary discussion about feasibility and pros and cons of the developed ICT systems.



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Opportunities and challenges of using
electronic diaries to collect day-by-day
patient data

Diary research

- On the spot
- Ecological valid (examines behavior in its natural context)
- Real-time data; no recall or retrospection bias nor distortion
- For specific within-person research questions (changes over time, also compared to others)

Diary research with PDA/mobile

- Control of alarm cues/repetition
- Log file/compliance check
- Less missings
- Electronic data file

but

- Intrusive; device must be carried constantly
- Hardware and software needed
- Difficult to handle
- Prone to technology malfunction

Electronic diaries in pain research

- Pain is not constant, but fluctuates in time
- Retrospective assessments usually generate overestimation of pain
- Pain diaries enable to examine pain variability over time
- E-diary assessments do not influence pain perception
- Respondent reactivity is low

How to reach high enough compliance?

Diary construction

- One item per screen
- Balance positive and negative items
- Branching of items
 - I took a nap today
 - Yes, for ... minutes
 - No; pass over the question
- Order of items
 - Fixed for quickly fading items (e.g. fatigue)
 - Randomized

Compliance with diary protocol

- Systematic review of studies using electronic pain diaries
- 62 included papers; 43 datasets
- Most papers written after 2000
- Mostly female chronic pain patients aged 19-65 years
- Most diaries less than 20 items
- Frequency of up to 6 times daily at fixed or prompted intervals
- Diary completion for one month at most

Morren M, van Dulmen S, Ouwkerk J, Bensing J. Compliance with momentary pain measurement using electronic diaries: A systematic review (Eur J Pain, in press)

Predictors of compliance*

- Shorter diaries
- Older patients
- Providing patients with a manual
- Using alarms to signal when a diary has to be completed
- Financial compensation

*Compliance = percentage of diary entries or percentage of completed items

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”Stimulating self-management in patients with fibromyalgia syndrome through web-based situational feedback”

Research group:

Hilde Eide, Oslo University College

Olof Kristjansdottir; OUC

Egil Fors, NTNU, St.Olavs Hospital

Arnstein Finset, UIO

Sandra van Dulmen, NIVEL

Erlend Eide, e-design, OUC

Mads Lien, e-design, OUC



Fibromyalgia syndrome - FMS

- A condition of chronic widespread pain – medically unexplained
- Psychosocial factors play an important role
- Reported symptoms: pain, fatigue, emotional distress, activity avoidance, and disability
- Many have additional psychiatric co-morbidity
- No specific treatment that has effect – multiprofessional long-time interventions best

Aims

- a) reduced pain
- b) reduced catastrophic thinking and troublesome emotional reactions to pain and cognitions
- c) quality of life
- d) stimulate improved engagement in daily activities and
- e) prevent transition to chronic disability.

Randomized controlled trial

- Duration: 5 weeks
- 3 diaries per day
- Meeting with the therapist at the start; establish therapeutic alliance, identify patient's aims and establish overall agenda for the treatment
- Week 1: Only registration
- Week 2- 5: 3 registrations per day and one situational feedback 5 days per week

Intervention content

- Based on CBT-principles shown to be effective
- Motivation according to Prochaska en di Clementes "stages of change model" is known at the begin
- Acceptance principles will also be taken into account in the responses
- Work with troublesome cognitions and activity avoidance

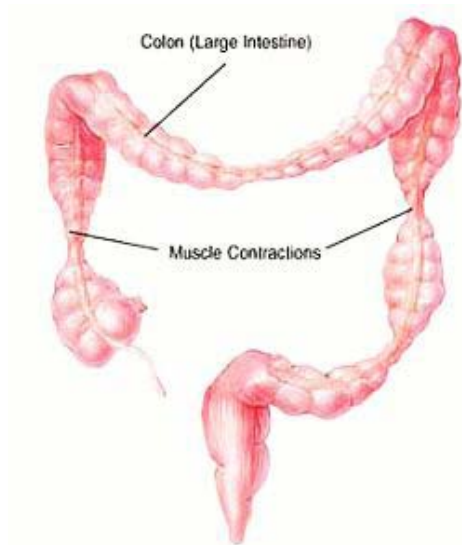
Situational feedback foundation

Daily registrations and fluctuations of:

- Pain (every time)
- Emotions (morning and evening)
- Current, recent and planned activity (morning and random)
- Satisfaction with activities (morning and random)
- Quality of sleep (morning)
- Pain cognitions (positive and negative) (morning and random)

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Situational feedback intervention in irritable bowel syndrome (IBS)



How to solve IBS complaints?



Characteristics of IBS

- Affects around of primary health care patients (m:f = 1: 2)
- Primary complaint: recurrent abdominal pain
- Secondary complaints: abdominal bloating, abdominal rumbling, flatulence, diarrhea or constipation
- A lot of a somatic and psychiatric comorbidity (musculoskeletal complaints, fibromyalgia, mood disorder, reduced global health)
- Reduced psychosocial functioning and quality of life (working disability, frequent health-care visits, medication use)
- No somatic abnormality; no effective medical treatment
- Referral rate 16%

Symptoms of IBS reported by 8% of Norwegian adults (Vandvik et al, 2006)



Psychological factors related IBS

- Dysfunctional cognitions
 - catastrophizing thoughts
 - somatic attributions
- Dysfunctional behaviour
 - avoidance of food, drinks and social contacts
- Dysfunctional emotions
 - fear for serious underlying disease
 - difficult to reassure

Stimulating self-management in IBS

- Cognitive-behavioural intervention
- Usually once or twice per two weeks
- Intervene on cognitions and behaviour without delay
- Reinforce and stimulate more positive thinking and behaviour

Ongoing RCT (until end of 2008)

- 60 IBS patients, recruited via GPs, internet and patient organisation
- 30 experimental PDA patients; 30 usual care control group
- Control group, questionnaires at baseline, 5 weeks and 3 months
- Experimental group, same questionnaires and electronic diaries for 5 weeks including situational feedback for 4 weeks

E-diaries

- One morning, one evening e-diary, two throughout the day
- Inquiries about current activities and plans, IBS and other complaints, thoughts and feelings
- In between day diaries situational feedback from psychologist/researcher

Diary completion overall

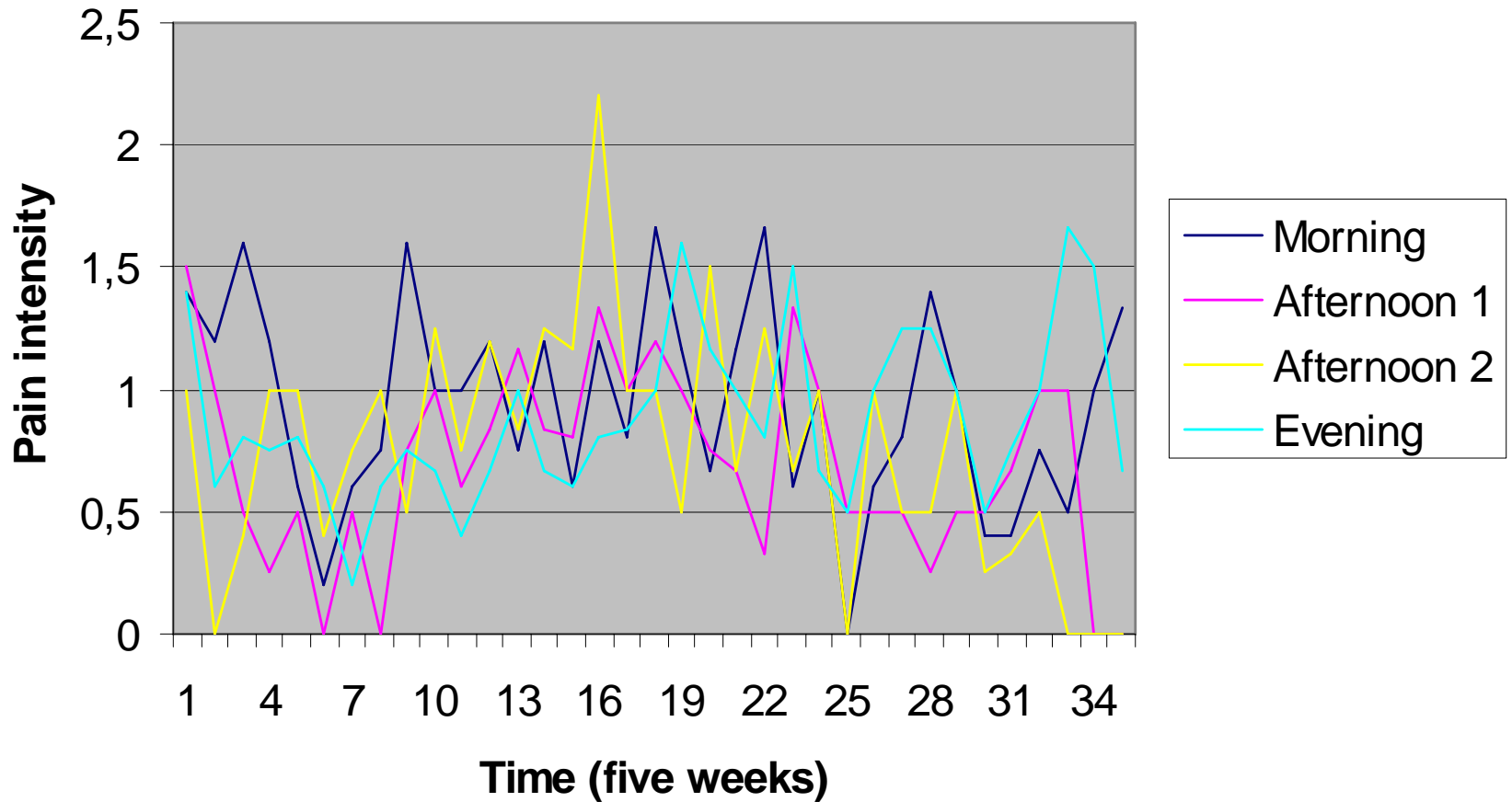
- So far, 30 patients included
- Complete records of 6 experimental group patients
- Total number of measurements per patient is 140 diaries
- Percentage completed diaries:
 - Patient 1: $117/140 = 84\%$
 - Patient 2: $119/140 = 85\%$
 - Patient 3: $117/140 = 84\%$
 - Patient 4: $63/140 = 45\%$
 - Patient 5: $69/140 = 49\%$
 - Patient 6: $122/140 = 87\%$
- Overall: $607/840 = 72\%$ (80% should be the minimum)

Diary completion per diary

- Morning: $173/210 = 82\%$
- Afternoon: $262/420 = 62\%$
- Evening: $172/210 = 82\%$

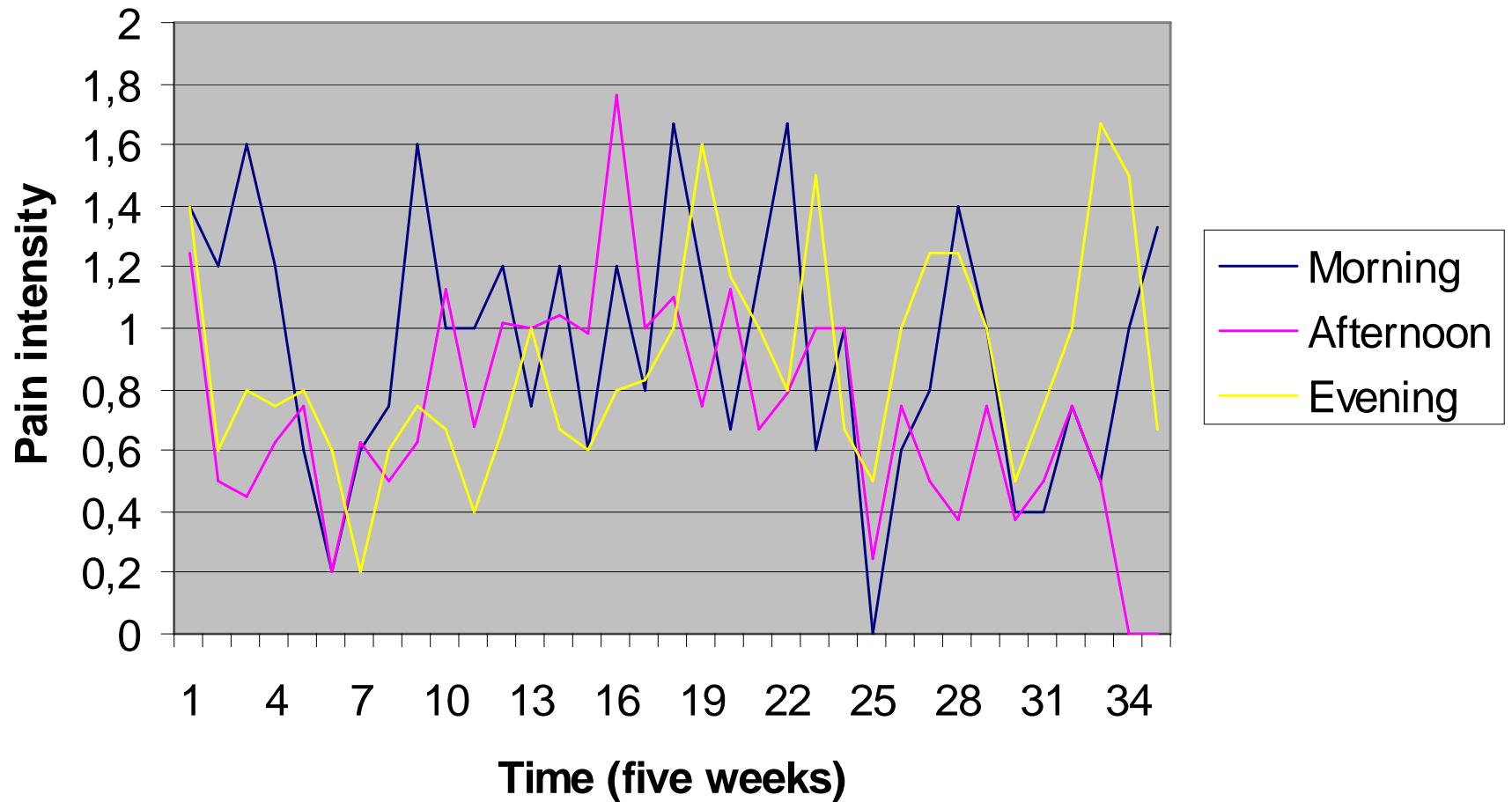
Given these percentages we decided to skip one afternoon diary

Fluctuation of pain in IBS patients



Also, the afternoon measurements proved quite similar

Fluctuation of pain in IBS patients



Abdominal pain

• No	251 (41.6%)
• Little	222 (36.8%)
• Heavy	<u>130 (21.6%)</u>
	607 (100 %)



Other complaints

- Abdominal rumbling 302 (50.1%)
- Abdominal cramps 194 (32.2%)
- Bloating 174 (28.9%)
- Flatulence 138 (22.9%)
- Muscle pain 128 (21.2%)

Disturbed by pain and complaints

- No 159 (60.9%)
- Little 73 (28.0%)
- A lot 29 (11.1%)



Cognitions

- Ongoing concerns about food 208 (80.0%)
- Avoidance behaviour 116 (44.6%)
- Thoughts focused on the pain 31 (11.9%)

Feelings

- Tired 118 (45.4%)
- Relaxed 100 (38.5%)
- Cheerful 91 (35.0%)
- Depressed 31 (11.9%)
- Frustrated 28 (10.8%)

More results yet to come...