4th Research Forum of the European Association for Palliative Care (ONLUS)

"Collaborate to catalyse Research"

Venezia Lido (Italy), Palazzo del Casinò

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www.eapcnet.org/research2006

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Computerized symptom assessment in palliative care
– current status of the PAT-C project

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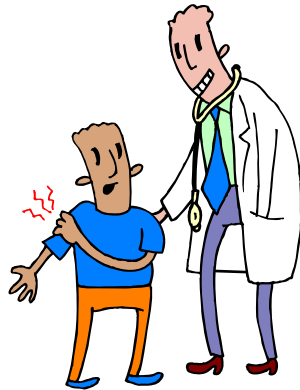on behalf of the Pain and Palliation Research group

in Trondheim, Norway

A long preparatory phase

- Background
  - A need for better, more efficient symptom assessment by computer technology
  - Initative by Stein Kaasa/Jon Håvard Loge
- Application to the NIH and EU mid-90ties

  ⟶ **No $/€!!**

- Funded by the Norwegian Research Council

The overall objective, 1

- To develop a comprehensive, computerbased tool for assessment of symptoms and functioning in palliative care

- **P**alliative **A**ssessment **T**ool – **C**omputerized

  - for use in clinic   - for use in research

The overall objective, 2

- This implies
  - the development of the actual assessment system
  - a more systematic and accurate registration
  - better, rapid information about symptoms/problems
  - better, more individualised treatment
  - continuous scientific and technological development

The international perspective

- The overall objective means widespread use
  - EAPC research network and stakeholders have contributed and will continue to do so

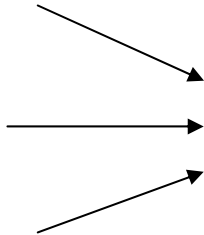- Later phases of the work is funded through the EU FP6 framework, LifeSciHealth-6!

Life sciences, genomics and biotechnology for health

Two weeks ago

- A national, clinical study was launched
  - A step forward towards the overall objective
- 9 palliative care/oncology units in Norway
- Continuous data collection for 6 months
- We aim to include 1000 patients

Objectives

- To collect large data samples on

    - Pain
    - Physical function (PF) $\longrightarrow$ For further
    - Cognitive function (CF) statistical analyses

- To test the computerized data collection
- To test the user-friendliness

8

A two step registration process, 1

- To be completed by staff
  - Karnofsky performance status scale
  - 3 items on CF
    - date, year, backwards spelling
  - Medical variables
    - diagnosis
    - treatment
    - medication

- Multiple study entries per patient possible
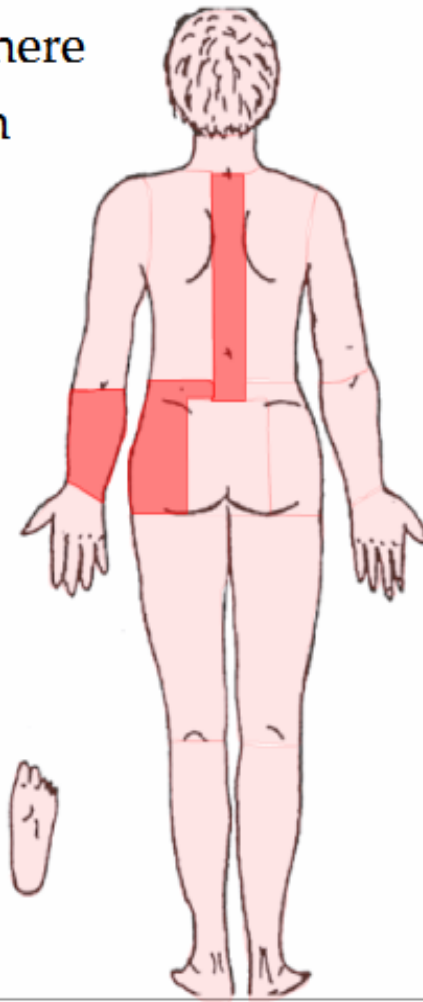
A two step registration process, 2

- To be completed by patients
  - ESAS
  - Screening of depression by a single item
    - "are you depressed?"
  - 24 items on physical function
    - mobility
  - 21 items on pain + a body map from BPI
    - intensity, interference, location, treatment, temporal pattern

PAT

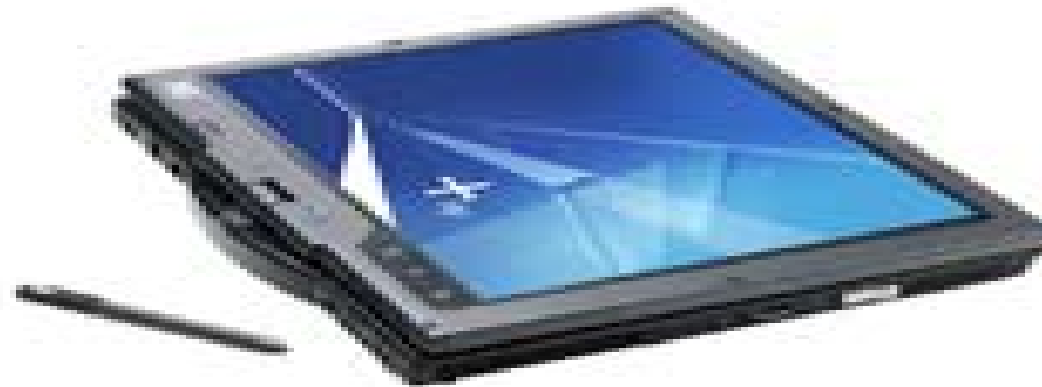English ▼

Indicate areas where you have pain

The software content

- Based on
  - literature studies
  - expert reviews
  - clinical studies
  - creation of item banks

  for identification of relevant items
- Further analyses
  - by IRT, Item Response Theory
  - or Case Based Reasoning

Hardware

- **Laptop with 12"- screen**
- **Digital pen**
- **A more accurate data collection**
- **Automatic registration of time**

User-friendliness

- Considerations to overcome limitations of age, poor eyesight, or limited dexterity
  - Touch sensitive screens
  - Large bold fonts
  - Strong contrast between background and text
  - One question displayed at the time

The first display

PAT

English

Choose action:

New Consultation   Backup data

Shut down

v. 0.9.20

Part of the registration

Reason for aborting the answering

- ⬭ Became tired

- ⬭ Too difficult

- ⬭ Took too long

- ⬭ Didn't understand
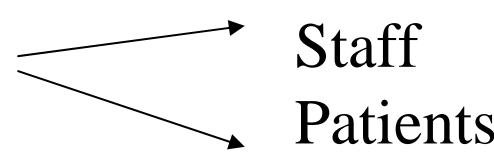
- ⬭ Other

Back

Abort

Need for assistance

A pilot study

- In April in Trondheim
- Objectives:
  - To test the userfriendliness

  - To test the applicability $\longrightarrow$ Staff
    Patients

The pilot study, 1

- Palliative Medicine Unit
- Out-patient clinic: 43 patients
  - 11 were asked, 8 consented to participate
- In-patient clinic: 18 patients
  - 15 were asked, 12 consented to participate
- N=20, F: 6, M: 14
- Mean age: 61 yrs (32 - 81)

Preliminary pilot results, 1

- Mean time for completion: 26 minutes
  - Are you used to working with computers?
    - Yes: 11   No: 9
  - Would you prefer paper and pencil to the computer?
    - Yes: 3   No: 11   Doesn't matter: 5
  - Was the text easy to understand?
    - Yes: 19
  - What do you think about the time of completion?
    - Too long: 1   OK: 18

The pilot study, 2

- Why were not all patients asked?
  - Logistics, staff and equipment
  - Opinion of nurses!

- Gatekeeping - an obstacle to research
  - at various levels
    - ethical commitees/declarations
    - institutional
    - individual
  - ethical considerations do apply
  - patients and family have the right to respond to invitations to participate in research!

Preliminary pilot results, 2

- Quotes from staff

  - *" The patient is too sick today, you should not go in and ask for participation "*

  - *" The patient is in too much pain, she is not in shape today"*

  - *" Maybe some other day"*

  - *"I think this is too demanding for him"*

  - *"The patient is new to me, I do not know him so well. We have to learn to know him better before we can decide"*

  - *"He is too confused today"*

  - *"We would like to spare the patient for this"*

  - *" It's been enough for this pasient today, it is just too much to ask, but maybe some other day"*

Conclusion

- **We have started!**

    - **We are optimistic!**

- **We look forward to the work that's ahead and to the international cooperation!**