Presentation slides HEC / MIE 2016

Dataset: September 2016

6 authors, including:

Hanife Rexhepi
University of Skövde
15 publications 7 citations

See profile

Asa Cajander
Uppsala University
74 publications 577 citations

See profile

Rose-Mharie Ahlfeldt
University of Skövde
50 publications 134 citations

See profile

Isto Huvila
Uppsala University
112 publications 335 citations

See profile

Some of the authors of this publication are also working on these related projects:

HIBA - Taking Health Information Behaviour into Account: implications of a neglected element for successful implementation of consumer health technologies on older adults
View project

Deployment of Online Medical records and E-health services (DOME) View project
Patient Empowerment Meets Concerns for Patients

A Study of Patient Accessible Electronic Health Records in Sweden

Christiane Grünloh, KTH Stockholm & TH Köln
Hanife Rexhepi, University of Skövde
Åsa Cajander, Uppsala University
Rose-Mhari Åhlfeld, University of Skövde
Gunilla Myreteg, Örebro University
Isto Huvila, Uppsala & Åbo Akademi University
Journalen

• 2012: County Council of Uppsala gave patients access to their EHR
  - appointment booking
  - medical notes
  - drug prescription
  - lab results
  - diagnoses
  - referrals
  - access log

• Secure login e-ID

• 16 counties included today, more will follow

• DOME: Deployment of Online Medical Records and E-health service
Electronic Health Record (EHR): Journalen
Motivation

"Nätjournal can be dangerous"

Records online strengthens the power of the patients in care

"Nätjournalaler is a democratic tool!"

Stop nätjournalerna!
Interview study

- 12 physicians (onco, ortho, emergency, internal)
- 15+15 patients from oncology
- 6-12 months after the launch
- Ethical Approval
- Semi-structured interviews (45-60 min)
- Transcribed
- Thematic analysis
Results

- reading before physician
- suspected diagnosis
- receiving bad news (unprepared, without physician present)
- medical terms

Anxiety
Results

Physicians

- reading before physician
- suspected diagnosis
- medical terms

Patients

- receiving bad news (unprepared, without physician present)
- preferred bad news through "Journalen" instead of waiting
- partial understanding not seen as problematic
- want to have a choice how to receive news

Anxiety

- direct access to test results reduces anxiety

Suspected diagnosis: reading before physician, receiving bad news (unprepared, without physician present).

Medical terms: suspected diagnosis.

Preferred bad news through "Journalen" instead of waiting.

Partial understanding not seen as problematic.

Want to have a choice how to receive news.

Direct access to test results reduces anxiety.
Results

Anxiety

- increased phone calls
- more questions during visits

Workload

- changing way of writing
- demand changes of inaccuracies / errors
Results

Anxiety

- increased phone calls
- more questions during visits
- changing way of writing

Workload

- no calls due to lack of understanding
- no calls / requests to demand corrections
- don't want to be a burden
- demand changes of inaccuracies / errors
- ask at next visit, friends, look online
Results

Anxiety

Workload

Usefulness

- no usefulness due to assumed lack of understanding
- no usefulness due to assumed anxiety
Results

Anxiety

- increased sense of control
- memory aid
- information in timely manner
- increased understanding of their health condition

Usefulness

- prepare for the next visit
- enhanced shared decision making
- increased sense of control

Workload

- no usefulness due to assumed lack of understanding
- no usefulness due to assumed anxiety

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Conclusion

- Physicians' expectations and patients' experiences were different --> perceived usefulness differed accordingly

- Physicians' expectations based on general assumptions about patients' capabilities and their lack of medical knowledge

- Patients had not experienced the negative aspects of online access anticipated by physicians
  - online access to medical records did not generate substantial anxiety, concerns or increased phone calls
  - Patients respectful of physicians’ time

- Patients perceived access to their online medical records as central to their coping with their disease
Limitations & Future Work

• Number of participants
• Actual experience of physicians
• Follow-up interview study with physicians & nurses
• National patient survey implemented in *Journalen* (> 580,000 users)
Questions?

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