Evaluation of a Hyperlinked Consumer Health Dictionary for Reading EHR Notes

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The IVS-CHD

- Interventional Centre-Consumer Health Dictionary (IVS-CHD):
  - Used by patients reading their own electronic health record
  - Integrated within the EHR system at Oslo University Hospital (Rikshospitalet, Doculive system)
  - Hyperlinked terms embedded in the EHR texts
    ▪ Mouseover- definition in a pop-up box
    ▪ Can access other links at the bottom of the pop-up box
  - Contains links to a Norwegian pharmaceutical catalog (Felleskatalogen), and a Norwegian patient medical encyclopedia (Norsk Electronisk Legehåndbok)
Redigering av medisinsk ordbok

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Oversettelse

Paasitunnel er en transthorakal plassert, høyre side. Han er en operert med abdominal-leadvegg. Det aktuelle ar nera er et endurokunngrunn ved avgangene av fængene i ar og ventraale arteria iliaca communis til arteria iliaca interna.

PDO 30
COILING AV ARTERIA ILIACA INTERNA  IMPLANTASJON AV MEOT

Animsjon av utposning på hovedpulsåren i buken

Hvordan behandles aortaneurismmer?

Målet med behandlingen er rekonstruksjon av aorta hvis det er fare for at den kan spreie, det vil si hvis et aneurisme i buaorta er videre enn 5,5 cm. Dersom aneurismet har sprakket, vil akutt utsettelse være nødvendig for å redde livet til pasienten.

Behandlingen er operasjon som kan foregå etter operasjon eller ved inntaggablet av en åpen operasjon. Ved åpen operasjon fjernes den ødelagte delen av aorta og erstattes den med en kunstig åre, en såkalt larprote. Nei, aneurismen kan behandles med en inntaggablet av nevleser (stent), som settes inn fra en eller begge halslyser. Eventuell slik behandling er avhengig av aneurismsen i utseende, åre og valgavt og dermed med methoden.

Kirurgi er nødvendig ved lekkasje eller sprekkdannelse i aneurismet. Andre grunner til kirurgi kan være smerten, passasjehinder i utseende på grund av aneurismet, blodpropp avlagt fra aneurismet. Dersom kontroller viser at aneurismet roser (mer enn 1 cm per år) eller størrelsen er over 5,5 cm, så er det også grunnlag for operasjon. Dette er det størst fare for korken.
Evaluation

- Goal: Improve the patient-friendly definitions of medical terms
  - Is the consumer health dictionary seen as a useful explanatory tool?
  - What makes a good definition for patients?
  - What do patients really want help with when reading their records?

- Five participants from the thoracic surgery department
  - All were male, between the ages of 58-68
  - Diagnostic codes: cardiac transplant, carotid artery stenosis, myocardial infarction
Methods

- Data collected:
  - Patient chooses a part of the EHR to read, selects IVS-CHD terms
    - Recorded which terms patients select to have defined
    - Patient rated definitions
      - Likert item: not useful/useful (1-5)
      - Likert item: difficult/easy (1-5)
    - Patients’ comments on definitions
  - Questionnaire
    - Preferences and opinions about reading EHR records
  - Printed copy of notes from last thoracic surgical procedure
    - Underlined terms patients wanted defined
Results: Problems With Definitions

• Definitions receiving low ratings
  – Contained unfamiliar medical terms that needed to be looked up
  – Did not fit in the context of the patient’s situation and therefore did not include the necessary information for understanding what happened during a procedure
  – Were seen as too short (one word), and some were circular definitions
  – Did not explain effects, outcome information
    ▪ Patients prefer to know, for example, “the condition clears within 24 hours”
Results: General Comments and Usefulness

- All abbreviations in the EHR notes should be in the IVS-CHD
- According to patients, terms like “abdomen” should be defined
- Comments:
  - One patient said he was expecting a translation and would prefer a patient-friendly version
  - Patients were “not interested in learning”, it is the outcome and future treatment plans that they would like
  - Patients want personalized definitions and encyclopedia entries with examples from their own records
  - Terms having the potential to be misunderstood must be defined in the IVS-CHD, e.g. “negative test result” is not a bad thing
Discussion and Future Directions

• Approach: Providing definitions
  – Definitions vs. Translation can be a matter of personal preferences
  – Patients appreciated easy access to definitions
  – Surgeon-written definitions did not rate worse than the other medical dictionary/encyclopedia definitions
  – Definitions are difficult to make “general” for all patients, so far only thoracic surgery context

• Future directions:
  – Personalization of definitions
  – Integration with record content
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