It Is Time for Self-Incident-Reporting for Patients and Their Families in Every Health Care Organization: A Literature Review

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Is patients’ voice heard in patient safety incident reports?

- Nurses’ incident reports (n=785) (Haipro) 2008-2010 (Saranto et al. 2012)
- 10% of the analyzed reports contained information about patients or relatives as subjects in incident reporting
- Most often the reporter was a nurse (48 %)
- Even if the patient/relative cannot report him/herself, his/her “voice” can be heard in those Haipro-reports
- Similar findings were found in a neonatal-pediatric intensive ward where parents’ involvement appeared in four percentages (n= 2494) of critical incident reports (Frey et al. 2009)
The aim of the study

• To find out
  – What are the possibilities that patients will make reports?
  – By what means have incidents related to unintended consequences in caring processes been reported by patients or their family?
  – How common is the patient reporting system globally?

• The focus of the study is on patient self-reporting systems, and patient centrism
Database retrieval (N=940)

- Publications from Pubmed (n=628)
- Publications from Scopus (n=311)
- Publications from Cochrane (n=1)

Excluded (n=877) as irrelevant on the basis of headings, abstracts, or duplications

Included (n=63) retrieved and assessed full texts

Excluded (n=40) as irrelevant on the basis of the study focus and content

Relevant publications (n=23)

Hand search, “snowball” method, publications included (n=27)

Total number of analyzed publications n=50

Keywords used:
patient safety, adverse event, patient safety incident, patient reporting, relatives reporting, citizen's reporting, citizen's voice, patient's voice

Keywords found during the analysis:
patient participation, direct patient reporting, consumer reporting
Results

• Patient-reported incidents have not been studied widely
  – even though several patient reporting systems have been implemented
  – telephone, post, fax, e-mail, online or via pharmacy, using paper or electronic forms

• Patients are not able to spontaneously report a clinical incident
  – often reports gathered from patients using interviews or questionnaires
  – in several studies, patients were asked about adverse drug (e.g. placebo, pain killers, anti-inflammatory, or antiepileptic drugs) effects or symptoms by filling a checklist or answering a questionnaire
  – most often the data from patients were gathered post discharge
Results

• Compared to reporting in medical or nursing records, many events were not documented at all, or were poorly documented

• When comparing patients’ symptoms with adverse events identified by a physician, there were events that one of them recognized, but not both
  – both patients’ and health care personnel’s reporting of adverse events is crucial
  – combination of the information of these systems (patient and clinician based) will produce more accurate and valuable information of the events
Countries with a patient-reporting system

- 46 countries reported that they have schemes for patient-self-incident-reporting systems
- Have a patient-self-incident-reporting system in use in Denmark, the Netherlands, Sweden, the United Kingdom, Australia, Belgium, Canada, Italy, New Zealand, Norway, Malaysia, the Philippines, and the United States
- First in Australia 1964, the latest in Norway 2010 (Avery ym. 2011)
- (Finland 2012)
Countries with a web-based patient-reporting system

• Patient incident reports via Internet:
  – in the UK: patients can choose to report online, by telephone, post, fax or e-mail
  – in Norway and the Netherlands: the web-based reporting system is the only way to report clinical incidents
  – In Sweden: also via Internet (KILEN)

• In the USA, e.g. in cancer center:
  – patient reports first online, after that was implemented a wireless tablet, where the information saved was transmitted to a physician’s computer concurrently
  – brings several positive outcomes to different parties in oncology patients’ caring process, and in drug evaluation
Patient’s role in reporting system?

• Patients
  – are often experts in their diseases, which make their role very important in patient safety issues, and in preventing patient safety incidents
  – eager to participate in the development of interventions to prevent clinical incidents
  – are motivated to report incidents (e.g. preventing a similar incident from happening to other patients, and because they want to contribute to clinical research by providing information on the causes of incidents)
  – want feedback from the system administrator about their reports
Discussion

• Patients and their families perspectives and voices can been seen and heard much too little in the patient-incident reports
  – patients and their families can give valuable information concerning patient safety issues, clinical incidents, adverse drug events, adverse drug reactions, and medication errors
  – they can provide missing data which would otherwise be unavailable, but which is of high value and credit

• Most systems still gather data in a standardized way by sending feedback forms or questionnaires to patients after their discharge

• Broad surveys concerning patient reporting have been done, and there were excellent examples of well functioning systems
  – more research and experiences from those countries
Discussion

• Internet-based and spontaneous patient-self-reporting systems have evidenced positive outcomes
• Electronic databases of patient reports offer a vast amount of information that can be utilized promptly in the development of patient safety issues
Thank You for Your Interest!

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