Health Information Technology Department
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In the Name of God

Mashhad University of Medical Sciences

A EUROPEAN VENOUS REGISTRY: PITFALLS AND OPPORTUNITIES

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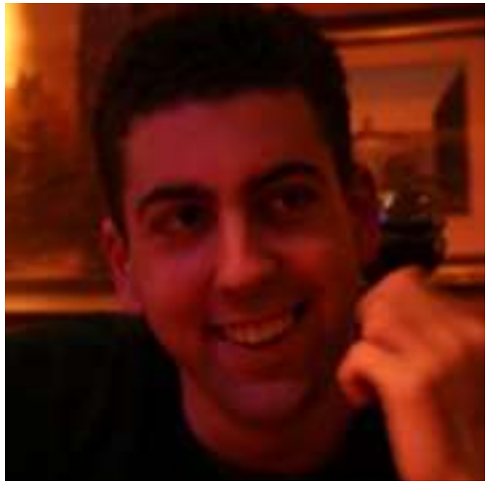

Introduction

Treatment choices and major decisions are based on randomized controlled trials (RCT's).

RCT's are the only way to decide which therapy or diagnostic tool is best suited for a specific type of patient or disease.

BUT this is not completely true

Introduction

patients have the right to know and demanding detailed statistics on their physician and their treatment in order to make sure they receive the “best” treatment.

RCT’s cannot provide this information because they are fragmented.

- **This lack of information influences:**

- Costs
- quality of care
- importance to health insurance companies, hospitals and physicians

Introduction

In the field of venous disease :

- Dedicated venous stenting
- Catheter directed thrombolysis
- New treatments of i.e. the May-Thurner syndrome

Most of these results are coming from complicated multicenter RCT’s.

Many Aspects Of Venous Disease Are Still Unknown:

- “Natural” development and progression
- The true QoL effects of various treatments in daily practice
- “Best” treatments

Introduction

Registries are a better way to gather medical research data.

- A prospective registry should be :

capture outcomes and collect information on the complete population .

- And gives :

▪ insight in the real-life effects

▪ applications of medical techniques

▪ treatments and advances

Introduction

Registries can be used to:

- improve the quality of care
- reduce costs
- improve the patient safety
- allow quicker introduction and evaluation of new treatments and techniques.

Registry (Medical)

Systematic collection of a clearly defined set of health and demographic data for patients with specific health characteristics, held in a central database.

- Denmark (Danish National Patient Registry)
- Australia (National Joint Replacement Registry)
- UK (National clinical audit & registries)
- Netherlands (Dutch Institute for Clinical Auditing)

Method

literature search in order to:

gain a better understanding of the factors that lead to success.

NCBI’s Pubmed was used with the following search terms:

#1: (registry[ti] OR registries[ti])

#2: (clinical[ti] OR medical[ti] OR patient*[ti])

#3: (validity[tiab] OR accuracy[tiab] OR quality control[tiab] OR data collection[tiab])

Method

212 articles were identified → 25 were selected

Used: descriptive and review articles on data quality/validity/collection

Excluded: detailed analyses and results of specific registries and trials.

Results

Current registries: American Venous Registry (AVR)

These poor results are not applicable to the AVR alone and can be attributed to a number of factors:

- It’s complicated to add data to a registry.
- Data has to be entered twice; into the electronic medical record (EMR) and into the registry.
- Required registry parameters do no correspond with clinically used parameters

RESULTS

Current medical registries rely on two methods for acquiring data:

- Manual data collection; mainly with case record forms (CRF)
- Automatic data collection; usually extracted from the electronic medical record (EHR/EMR)

The Role Of The Electronic Health Record

The definition of an EHR is very similar to that of a registry.

EHR (electronic health record):

A systematic collection of electronic health information about individual patients or populations.”

Most EHR implementations suffer from poor design are:

- lacking user-friendliness
- Do not lead to improved efficiency

The Role Of The Electronic Health Record

Problems for creating a true registry:

- Incompatibility between different vendors
- Lacking standards of communication between EHR’s.
- Structural data gathering is not facilitated, exporting and analyzing data stored in the EHR is cumbersome.

Five Factors

Five factors seem to be required in order to create a true, nationwide and all-compassing venous registry.

1. Integration In The Daily Workflow Of Physicians

- increase acceptance among physicians and efficiency.
- time savings

2. EHR And Registry As One System

The perfect venous registry should be the result of an intuitive and smart EHR interface, without double entry, gathering research data

2. EHR And Registry As One System

the registry is created separately from the EHR, Associated advantages are:

- Auto enrollment on specified diagnosis
- Real time data collection

3. Data Quality And Completeness

To ensure a high quality data, validity and completeness data:

Training for the physicians who enter data in the EHR/Registry.

Other factors:

- Completeness of data
- Predefined data fields for easy entering, to reduce type errors and fulfill the registry definitions.

4. Data Standardization

Data collection needs to be standardized for two reasons:

A: assure and control quality , accuracy, completeness

B:compare outcomes between different providers

5. Collaborative Data Gathering

- improve the compliance.
- compare different treatment options at different locations.
- create prognostic models which aide in validating and optimizing individual treatments.

DISCUSSION

- registries generally have poor compliance
- RCT’s are expensive

Various steps are being taken to create a better registry ,BUT:

lack of collaboration between various organizations active in the EHR/registry.

- when unity between different countries:

specialties and institutes to start building a true European venous registry.

CONCLUSION

- The perfect future venous registry should encompass the following features:

1. Integration in the daily workflow of physicians
2. EHR and registry as one system
3. Data quality and completeness
4. Data standardization
5. Collaborative data gathering

Thanks for Your Attention

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