Research for the Care of Patients

Dutch Experiences with General Practice-based Networks

Presentation at the Séminaire

‘Requeil de données épidemiologiques en médecine générale, santé publique et santé au travail’

At the occasion of PhD Awarding Aline Ramond-Roquin
Angers, 04 September 2014

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Past president of Wonca
Objective of this presentation

• Present Dutch Primary Care Databases
  o Nijmegen experience, history

• Illustrate Methodology, Present Examples
  o Longitudinal data, episodes illness and care
  o Person centered structure
  o Benefits analysis ‘full’ episodes
  o Collaborative outcome studies, flow ‘care over time’

• Context Dutch Healthcare
  o Contributing to its development
Characteristics of the Dutch health care system

- Access to health care through general practice
- Primary care link community - health care system
- Gate keeper, navigator function
- Specialists, hospital, after GP referral only
- Personal listing with a practice, GP
- Practice population defined, and ‘known’
- Primary care the link to society: gouvernance, societal impact
Ecology of Medical Care\textsuperscript{1,2}:

1. White et al. NEJM 1961
2. Green et al. NEJM 2001

Dutch healthcare
- ‘structures’ ecology model
- Need to understand model
Practice-based Research Networks, the Start 1967: Nijmegen Continuous Morbidity Registration (CMR)

- Frans Huygen, inaugural chair general practice Nijmegen
- General practice in the academic arena:
  - The ‘Incident of German Measles’
- The Nijmegen CMR
  - Highlight health problems community
  - Need empirical data real life family practice
  - In-fighting to change
  - Research agenda
‘Nijmegen Continuous Morbidity Registration’ (CMR)

- CMR:
  - Oldest FP database, Netherlands
  - PBRN Department Family Medicine
  - Research Capacity Building
  - Longitudinal Research – patient careers/time


- Data and Study Objectives
  - ‘If we knew what we were doing, we would not call it Research’ (Albert Einstein)

- Caveat: pre-computer experience
Most Common Health Problems in Family Practice

Acute, ‘everyday’
- Respiratory tract infection
- Functional complaints
- Dermatitis
- Urinary tract infection
- Tonsillitis
- Myalgia neck, shoulder, arm
- Ear wax
- Minor trauma
- Low back pain
- Vaginitis

Chronic
- Obesity
- Hypertension
- Chronic nervous complaints
- Deafness
- Malignancy
- COPD
- Chr. Isch. Heart disease
- Myocardial infarction
- Hyperlipemina
- Psoriasis
Context of data collection: Dutch Family Practice

• Primary care led system
  ✓ Every Citizen personal FP
  ➢ All episodes start with that FP
• Most health problems treated in primary care
  ✓ 90+ % 1989 => 96+% 2002
  ➢ FP records basis individuals’ health (care)
• FP data collection longitudinal
  ✓ Personal continuity
  ➢ Person- and context factors
  ✓ System continuity
  ➢ Population characteristics
  ➢ Use of secondary/tertiary care

ECOLOGY OF MEDICAL CARE *

* White et al NEJM 1961
  Green et al NEJM 2001

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Episodes Recording: Longitudinal Data, Continuity of Care

Practice

Database

time
Episodes Recording: Longitudinal Data, Continuity of Care

Practice

Visit 1: new health problem

time

Database
Episodes Recording: Longitudinal Data, Continuity of Care

Practice

Visit 1: new health problem

Database

Recorded episode 1
Episodes Recording: Longitudinal Data, Continuity of Care

Practice

Visit 1: new health problem

Visit 2: new health problem
  review problem 1

Database

Recorded episode 1
Episodes Recording: Longitudinal Data, Continuity of Care

Practice

Visit 1: new health problem
Visit 2: new health problem
review problem 1

Database

Recorded episode 1
Recoded episode 1

Recorded episode 2
Episodes Recording: Longitudinal Data, Continuity of Care

Practice

Visit 1: new health problem
Visit 2: new health problem
review problem 1
Visit N: new health problem
review health problem 1

Database

Recorded episode 1
Recoded episode 1

Recorded episode 2
Episodes Recording: Longitudinal Data, Continuity of Care

Practice

Visit 1: new health problem
Visit 2: new health problem
review problem 1
Visit N: new health problem
review health problem 1

Database

Recorded episode 1
Recorded episode 2
Recoded episode 1
Continued recording episode 1
(Prevalence affix)
Recorded episode N
Episodes Recording: Longitudinal Data, Continuity of Care

Practice

Visit 1: new health problem
Visit 2: new health problem
Review problem 1
Visit N: new health problem
Review health problem 1

Database

Recorded episode 1
Recorded episode 2
Recorded episode N

Recorded episode 1
Recorded episode 1
Continued recording episode 1
(Prevalence affix)

FPs code, recode
Use of referral information
Clinical judgment
Coding & classification rules
Study Designs with this database

- **Index patient and/or health problem(s)**
  - Point in time (incidence, prevalence)
  - Look forward: Historic Cohort
  - Look backward: Case Control

- **Recruit control groups**
  - Sex, age, social class, practice, morbidity
  - Set ‘dummy’ diagnosis, for observation time

- **Retrieve additional information**
  - Morbidity, mortality
  - Optional: records, interviews, questionnaires

- **Establish Time Window**
  - After diagnosis
  - Prior to diagnosis
Research into the Community: partnership with practices (PBRN)

- Bring practice to research
- Bring research to practice
- Relation university
- Practice basis academic staff
Example Cohort Study: Depression in family practice (1994)

- Increased public awareness of depression
  - chronic, recurrent nature
- Availability antidepressants
  - Promotion early detection, proactive (drug) treatment
- Most literature
  - Referred patients
  - Short term observations
- Lack of insight
  - Prognosis depression in primary care
- Historic cohort analysis CMR Database after a first life episode depression
  - Recurrence rate, quality of life, psychiatric health status
  - 10 year+ observation after first episode
Number of episodes during first 10 years after diagnosis

Percentage of patients

Number of episodes
Perceived health and quality of life, health status
(> 10 years after (first) episode depression, compared healthy controls)

• Patients with depression (major depression 79 %)
  - Frequent mental health symptoms
  - Impaired quality of life
  - Impaired mental and physical health status
  - ‘Coping’: ‘Learning’ experience

• Patients with recurrent nervous-functional symptoms
  - Comparable to patients with depression on all aspects
  - Poorer ‘coping’
The Language and Terminology PHC: International Classification of Primary Care ICPC

- Developed by Wonca
  - 1987, WICC
  - Henk Lamberts, Maurice Wood
- Primary care focus
  - Specificity of generalist
- Relation with other classifications
  - ICD (relation WHO, family classifications
  - SNOMED
- International Standard
  - Europe, Australia
  - The Netherlands: standard EMR

Professor Chris van Weel

• Specialist literature
  ➢ Premature death, increased risk CV morbidity
  ➢ Case of tight metabolic control
  ➢ Case of pro-active treatment

• Primary care experience
  ➢ Health problem of the elderly
  ➢ Risk overtreatment
  ➢ Case of masterly inactivity

• Empirical data: long term outcome diabetes mellitus FP
  ➢ Historic cohort analysis CMR
Historic Cohort Analysis DM type-2

- All new cases CMR-database diabetes mellitus 1967-1989
- Verification of diagnostic criteria (WHO, 1985): 265
- Non-diabetic controls, matched at time of diagnosis:
  - Sex, age, social class, practice
- Outcome from time of diagnosis – 1989:
  - Mortality
  - Cardiovascular Morbidity
- Mean observation period 6.8 year (8 months – 22 years)
22-year Mortality in type 2 diabetic patients

- Increased mortality diabetes mellitus
- Increased cardiovascular morbidity
  - Mortality
  - Cardiovascular Morbidity
- Diabetes in primary care matters: lower life expectancy, QoL
- Implications for practice:
  - Supervision and control
- Move from practices’ role:
  - From data collecting to practice building on data (EBM)
- Essential Practice Based Research Network (PBRN)
Research into the Community: partnership with practices (PBRN)

- Bring practice to research
- Bring research to practice
- Relation university
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Practice based Diabetes Monitoring
Audit & Feedback

Monitoring - 3 monthly - annual

Type 2

46,500

Dpt P&CC, Radboud Univ
Audit Feedback

Monthly Meeting FPs
## Outcome of care DM with audit and feedback

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<th>1999, n=594</th>
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<tr>
<td>Annual review %</td>
<td>73</td>
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<tr>
<td>HbA1c available %</td>
<td>50</td>
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<tr>
<td>Mean %</td>
<td>8.3</td>
<td>7.1</td>
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<td>RR available %</td>
<td>72</td>
<td>83</td>
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<tr>
<td>Mean mmHg</td>
<td>150/84</td>
<td>150/82</td>
<td></td>
</tr>
<tr>
<td>Chol available %</td>
<td>69</td>
<td>83</td>
<td>0.001</td>
</tr>
<tr>
<td>Mean mmol</td>
<td>6.2</td>
<td>5.4</td>
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</tbody>
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Research Capacity building background: ‘the death of the clinician-researcher’

• 1986 – 1996 capacity building through MRC program
  – Focus on GPs and relevant (clinical) problems in primary care
  – Four year full-time researcher, outcome PhD
  – Department/professor of general practice as applicant, supervisor
  – Primary care – secondary care collaboration

• Since 1998 combined specialty – research training
  – Comprehensive programme, 6 – 7 years
  – Outcome specialty qualification and PhD
  – Flexible timing of its clinical and research parts

• At basis: Collaboration Universities – Dutch College GPs
  – guidelines development programme
Fig 2  Number of research publications (15% sample) by authors from primary care in journals with ISI impact factor per billion dollar gross domestic product spent on research (GERD).

Glanville J et al. BMJ 2011;342:bmj.d1028
Fig 3 Mean number of research publications by authors from primary care (2001-6, 15% sample) per billion dollars gross expenditure on research and development (GERD) and by journal impact factor.

Glanville J et al. BMJ 2011;342:bmj.d1028
PHC Development:
in, by, from, through, with community
Primary Care Development
journey through unfamiliar grounds

The traditional model: guidance to lead deficient practice
Primary Care Development
journey through unfamiliar grounds

The reality: guidance and practice are resources in their own kind

Empirical wisdom
Practice

Guidance
Knowledge
Primary Care Development
journey through unfamiliar grounds

The challenge for patient care: to connect different worlds

Research

Empirical wisdom

Practice

Knowledge
Health Care Development
journey through unfamiliar grounds

The challenge for patient care: to connect different worlds

Empirical wisdom
Practice

Research
Knowledge

COMMUNITY
CONTEXT
CONTINUITY
Health Care Development
journey through unfamiliar grounds

The challenge for patient care: to connect different worlds

Community Diagnosis
Needs and Values
Priorities
Evidence for people and populations

Two Key Publications Monitoring Diabetes Mellitus Nijmegen

Grauw WJC de, Lisdonk EH van de, Gerwen WHEM van, Hoogen HJM van den, Weel C van. **Insulin therapy in poorly controlled type 2 diabetic patients: does it affect quality of life?** *Br J Gen Pract* 2001;**51**:527-32

Publications Depression CMR Nijmegen


Publications Monitoring Diabetes Mellitus NMP Nijmegen


Grauw de WJC, Gerwen van WHEM, Lisdonk van de EH, Hoogen van den HJM, Bosch van den WJHM, Weel van C. Outcomes of audit-enhanced monitoring of patients with type 2 diabetes., *J Fam Pract* 2002; **51**:459-464


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Continued recording episode 1
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