Nationwide continuous monitoring of end-of-life care via representative GP networks in Europe - EURO SENTIMELC

Meeting of the Primary Palliative Care Taskforce
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Introduction

- Provision of high quality palliative care is a priority in Europe and beyond
  - Clinical
  - Public health

- Scarcity of population-based nationwide data that monitor and compare circumstances and quality of care and dying in the final months of life in different countries
EURO SENTIMELC

- Monitoring end-of-life care through representative Sentinel GP networks in different European countries
- Started in 2004 in Belgium and in 2005 in the Netherlands; continuing registrations since then
- since 2009-2011: Belgium, Netherlands, Spain, Italy
- 2014: Belgium, Netherlands, Spain, Italy, France
Design of the EURO SENTIMELC study

- Mortality follow-back study
- Data collection through nationwide representative networks of general practitioners (epidemiological surveillance systems)
- Continuous weekly registration of all deaths
  - part of GP practice
  - ≥18 years old
  - Standardised registration form in all countries
- Selection of “the dying”, for whom end of life care is a realistic consideration
  - “Was this death sudden and totally unexpected?” yes / no
- Exclusion of nursing home deaths in the Netherlands
Selection of publications using EURO SENTIMELC data

- **Preferred place of death, Ko et al 2013 Eur J Cancer**
- **EoL decisions, Evans et al 2013 PLOS ONE**
- **Transitions at the EoL, Van den Block et al 2007 JAMA**
- **EoL care in Belgium, Van den Block et al 2008 Arch Intern Med**
- **Dying from cancer in Europe, Meeussen et al 2011 J Clin Oncol**
Study aim

to describe and compare the quality of palliative care in primary care in several European countries via representative networks of general practitioners
New registration: Quality indicators (QIs) for primary palliative care (from 2013/2014)

Study of existing international literature on QIs for palliative care and the recently developed QI sets in Belgium and the Netherlands (Claessen et al 2011 J Pain Symptom Manage; Leemans et al 2013 BMC Palliat Care)

Nine domains of quality of palliative care

Selection of indicators for each domain that are measureable in a retrospective way by GPs as respondents

Expert consultation to evaluate indicators in terms of usefulness and relevance in primary palliative care on a 9-point scale

Based on median scores the highest scoring indicators were selected (1-2 per domain) → 16 indicators assessed through the registration form
Core set of 16 indicators covering 9 domains

1. Physical aspects of care
2. Psychological, social and spiritual treatment and care
3. Information, communication, planning and decision-making with the patient
4. Information, communication, planning and decision-making with the family and friends
5. Information, communication, planning and decision-making with other care providers
6. Type of end-of-life care
7. Coordination and continuity of care
8. Support for family/friends and informal carers
9. Structure of care
Advantages of monitoring end-of-life care through GP sentinel networks

- Low cost, high flexibility, and high gain for public health and research
- Developed specifically as a research and policy tool
- Not all care-related information is available from medical files and death registers
- Cross-national comparisons and benchmarking
- Many existing and stable GP sentinel networks in Europe with long-standing involvement in epidemiological surveillance
- Electronic registration possible
- Flexibility in topics studied
- Weekly registration → recall bias limited
For further information...

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EURO SENTIMELC studies at the EAPC Congress 2013

• Lara Pivodic, Presentation ‘Burden on family carers and difficulty in covering costs of care at the end of life: a cross-national retrospective study via representative networks of general practitioners’

• Winne Ko, Poster Discussion ‘Factors Associated with Dying at the Place of Wish: A Cross-country Comparison of Cancer Patients with the EURO SENTI-MELC Study 2009-2010’