

## Journal Watch

### **Nationwide monitoring of end-of-life care via the Sentinel Network of General Practitioners in Belgium: the research protocol of the SENTI-MELC study.**

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#### **Abstract:**

**Background.** End-of-life care has become an issue of great clinical and public health concern. From analyses of official death certificates, we have societal knowledge on how many people die, at what age, where and from what causes. However, we know little about how people are dying. There is a lack of population-based and nationwide data that evaluate and monitor the circumstances of death and the care received in the final months of life. The present study was designed to describe the places of end-of-life care and care transitions, the caregivers involved in patient care and the actual treatments and care provided to dying patients in Belgium. The patient, residence and healthcare characteristics associated with these aspects of end-of-life care provision will also be studied. In this report, the protocol of the study is outlined. **Methods/Design.** We designed a nationwide mortality follow-back study with data collection in 2005 and 2006, via the nationwide Belgian Sentinel Network of General Practitioners (GPs) i.e. an existing epidemiological surveillance system representative of all GPs in Belgium, covering 1.75% of the total Belgian population. All GPs were asked to report weekly, on a standardized registration form, every patient (>1 year) in their practice who had died, and to identify patients who had died “non-suddenly”. The last three months of these patients’ lives were surveyed retrospectively. Several quality control measures were used to ensure data of high scientific quality.

#### **Comments:**

Strengths/uniqueness: This paper describes the construction of a retrospective questionnaire and its completion by physicians participating in a sentinel GP network in Belgium. The study is a mortality follow-back study with demonstrable efforts made to ensure representativeness. The domains of data collected are appropriate and well described. Data is collected by the GPs using death certificates, institutional medical records and medical records kept by themselves. Efforts to reduce recall bias and to otherwise maximize data quality are laudable.

Weakness: The reader is told that GPs are highly accessible and routinely consulted. Patients nonetheless spend much time in institutions during the last three months of care and therefore may not have any contact with the GP during this time. Much of the data requested is qualitative and therefore must be inferred from chart review. For example, the desired place of death and intent of care provided. These variables are known to change during the trajectory of care and furthermore may not represent a consensus between the patient, family and health care providers. Other mortality follow-back studies involve surveying the caregivers themselves which may help understand these concepts. The location of care can be estimated according to the instructions. Yet this data is available administratively in many instances and therefore need not be estimated. Finally, 37% of deaths are categorized as sudden or unexpected. While it is true that patients with terminal illnesses can die suddenly or unexpectedly, excluding these patients has not been justified.

Relevance to Palliative Care: Despite the limitations, this article is relevant to policy makers. There is a need to increase the knowledge of the place of care, type of care and determinants of care. This study includes the protocol and questionnaire used to capture information in Belgium and is purportedly under consideration by several other countries in Europe. Consideration of its use in Canada may possibly require modifications to the questions regarding euthanasia and would be strengthened by addressing the weaknesses. Finally, patients that die suddenly, hit by automobiles for example, can live in the ICU for days or weeks – a population and setting equally deserving of attention.