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## Care in the last months of life

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2011

### **document version**

Publisher's PDF, also known as Version of record

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### **citation for published version (APA)**

Abarshi, E. A. B. (2011). *Care in the last months of life: End-of-Life Care registration in the Netherlands by a Network of General Practitioners.*

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## SUMMARY OF DISSERTATION

This is a research on patient care in the last months of life via a representative network of general practitioners. Data from GPs on all patients in the network aged > 1year, whose deaths had been non-sudden and expected, were collected between 2005-2008 through registration forms which were filled within one week of dying. Data were collected on demographic characteristics, place of death, nature and purpose of care, wishes of patients and some other aspects of end-of-life care.

Chapter 2 examined how long before death the patients who were likely die in the near future were recognised, from a selection of non-sudden and expected deaths. Our results showed that most patients died at home or in a care home (twice as many as those who died in hospital). Recognising death before a patient's last week of life was found to be related with fewer hospital deaths, more GP-patient contacts in the last week, more deaths in a preferred place, and more GP-patient discussions about specific end-of-life issues in the last seven days of life. Cancer was the main reason for recognising death in the near future, and recognising death in the near future preceded aspects of end-of-life care, i.e. GP-patient discussing end-of-life topics such as possible complications, physical problems, psychosocial problems, and palliative care options. We reasoned that if GPs could systematically recognise the dying phase, particularly among non-cancer populations at home, there would be more desirable end-of-life care outcomes. A practical tool that has been used for facilitating this practice in the UK is the Gold Standards Framework (GSF).

Chapter 3 explored the incidence and timing of GPs discussing ten end-of-life issues - primary diagnosis, incurability of illness, life expectancy or prognosis, possible medical complications, physical symptoms, psychological problems, social problems, spiritual or existential problems, palliative care options and treatment burdens with terminally ill patients. We found that physical and psychological problems were discussed most frequently; while social and spiritual problems were least discussed with GPs. Having cancer, being educated and absence of dementia were important correlates of GPs ever discussing the ten issues with their patients before death. Generally, issues were discussed more often with younger, female, more educated, and mentally competent patients, and those with a clear palliative care treatment goal. Primary diagnosis and incurability were discussed more frequently with men than women. Although patient-needs were not assessed in this study, our data shows that current practice in the Netherlands does not completely reflect the new models of palliative care, which dictate that supportive care be given alongside curative therapies. Cancer was the main reason for GP-patient communication about all end-of-life issues in all the three time intervals.

Chapter 4 examined GP awareness of patients' preferred place of death in the last months, and the incidence of patients dying in a preferred place. Forty-six percent of the patients had GPs who were not aware of their preferred places of death. Of those GPs that were aware of their patients preferred POD, most had informed by the patients themselves. Four-fifth of the patients with known preferred POD died there. A higher social status, having a palliative care or life-prolongation treatment goal, and using palliative care services were associated with higher GP-awareness odds. We concluded that there is a potential for improving awareness among GPs, of patient wishes such as preferred POD. Such awareness can be enhanced when palliation is an active part of end-of-life patient care.

Chapter 5 examined the nature and prevalence of care setting transitions in the last 3 months of life, and the results showed 690 patients made 709 transitions in the last 3 months, which involved a hospital two out of every three times, covering 43 distinct care trajectories within the two-year study period. The commonest trajectory was home-hospital (48%). Two out of every three transitions involved hospital at some point. Having a transition in the last 30 days of life was associated with being male, having multi-morbidities, and absent GP-awareness of a patient's preferred place of death. Terminal hospitalisation for the last 7 days of life, was associated with age ( $\leq 85$  years), infection, and absent palliative care treatment goal. We observed that transitions to hospitals were relatively frequent, though most 'non-sudden and expected' deaths occurred at

home. We therefore conclude that timely recognition of the palliative phase of dying, is important in minimizing abrupt or frequent transitions before death.

Chapter 6 compared the frequency of GP visits and palliative care service utilisation in two European countries, and identified associated factors. GP visits were more frequent in the Netherlands than in Belgium: the mean number of GP visit in the last week of life was 5.1 vs. 3.2 (home) and 4.4 vs. 2.3 (care home). Conversely, palliative care services were more often used in the last three months of life in Belgium than the Netherlands: 78% vs. 41% (home) and 39% vs. 5% (care home). Having more frequent GP visits at home were associated with cancer-related deaths in the Netherlands and Belgium. The differences between countries remained consistent despite correcting for possible confounders. They appear to have resulted from existing policies and the organisation of healthcare in the two countries, but these should be studied in some more detail.

Chapter 7 examined the oldest old and GP end-of-life care. Many of the oldest of old in the Netherlands reside at home and in residential care homes, and remain under the care of their GPs, (unlike those cared for by specialists in nursing homes and hospitals). There were more women than men, more patients with heart failure than cancer, less hospital and home deaths, and more residential care home deaths among the oldest old (>85y) compared with the younger old group (65-84y). Comparatively, fewer oldest old patients received PCS, and more preferred to die in a residential care home than the latter. Age was independently associated with using palliative care services: the oldest old received PCS less often (OR=0.7), and were treated with a palliative-centred goal more often (OR=2.4) than the younger old; but was not related to dying in a preferred place, i.e. independent of other characteristics. This results shows age to be independently associated with receiving PCS in the Dutch community. And although the GPs did recognise the "palliative phase" in the oldest old, their involvement of specialist teams for them was somewhat less.

Chapter 8 is the last chapter and it provides the discussion of all findings in a general context. In conclusion, the non-sudden and expected nature of death resulting from advanced progressive illnesses (e.g. cancer, heart failure, COPD, end-stage renal disease, AIDS), and advanced ageing allows for better care management at the end of life. Monitoring the pattern of GP recognition of the need for palliative care, communication of salient issues with patients, their awareness of place of death preferences, and the knowledge of transitions between care settings, could provide cues for forward planning and adequate end-of-life care provision by all concerned.