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End-of-Life Care

Mixed Methods in Public Health Research at the End of Life

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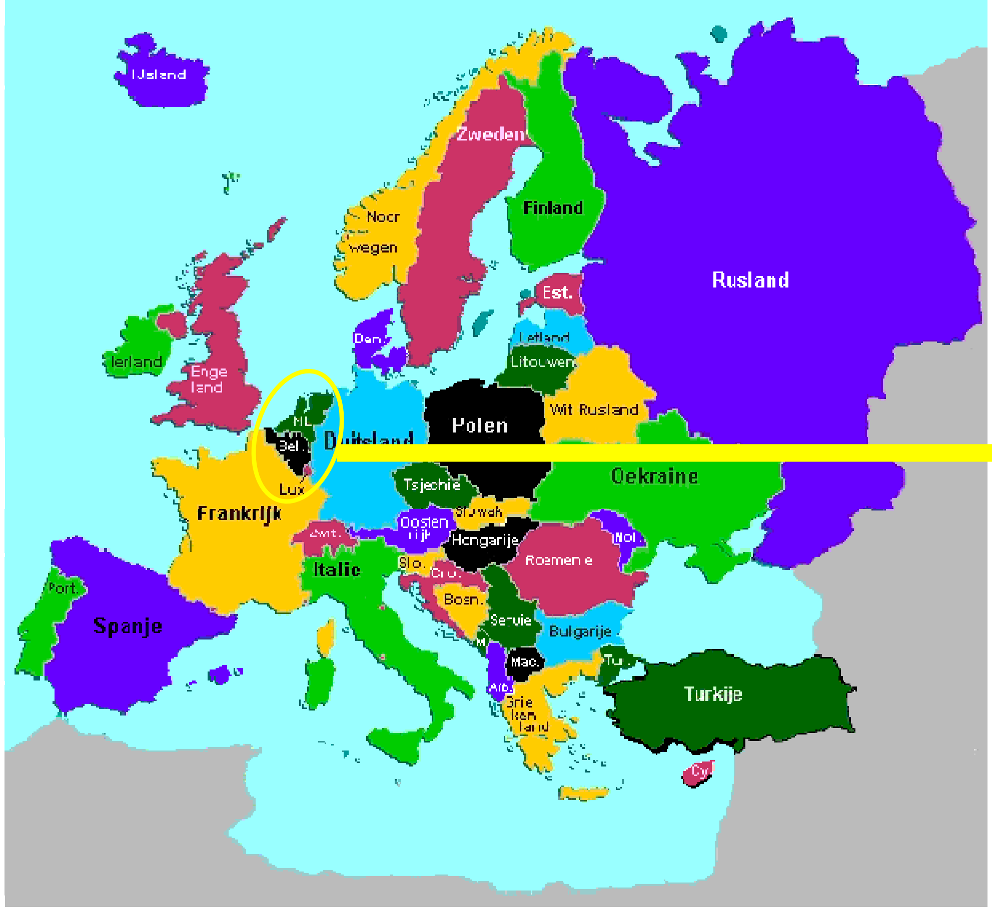
Vrije Universiteit Brussel

Europe

Belgium and the Netherlands



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End-of-Life Care

Content

1. Introduction
2. Public Health
3. Types of Mixed Methods Research (MMR)
4. Mixed Methods and the research process
5. Two Different cases:
    1. a pragmatic MMR design: the case of “End-of-life care in general practice”
    2. a conceptual MMR design: the case of “Spiritual care in nursing homes”
6. Conclusions (opportunities and risks)

Introduction

- MMR means adopting a research strategy employing more than one type of research method
- Not necessary a mix of qualitative and quantitative
- May be a mix of:
  - qualitative and quantitative methods
  - quantitative methods
  - qualitative methods

Introduction

- In the presentation we will demonstrate the use of MMR approach in public health research
- In many public health research areas MMR approaches have been applied, e.g.:
  - place of death
  - quality of end-of-life care in general practice
  - end-of-life decision making
  - Acess to PC services
  - palliative sedation
  - informing the patient and truth telling
  - doctor-patient communication at the end of life
- We will also set out some of the opportunities and risks using a MMR approach

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Public Health

PH is:

- the science and art of preventing disease, prolonging life and promoting health through all organised efforts of society

PH at the end of life is:

- the science and art of preventing suffering and promoting the quality of life of terminally ill patients at the end of life, through the organised efforts of society

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Public Health

- end of life care has become an important area of public health (WHO)
- in end of life research, there is also a growing number of public health studies:
  - Epidemiological studies, e.g.
    - place of death/place of care
    - end-of-life transitions between care settings
  - Survey studies, e.g.
    - knowledge and attitudes of GPs concerning pain treatment
    - assessment and management of symptoms
  - Health services research, e.g.
    - palliative care services in general practice
    - palliative care services in nursing homes
  - Etc.

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Types of Mixed Methods

- MMR also means working with different types of data :
  - E.g. studying (wished) place of death by census data, registration data, survey data, interview data, etc
- different kind of sampling techniques
  - populations, large or small samples, case studies
- different kind of designs
  - retrospective, prospective
- different kind of methods for data collection
  - questionnaire, interviews, observation
- it may also involve different investigators

Types of Mixed Methods

- MMR approach can also be understood differently :
  - as implying the application of different research strategies **within** one research project
  - but also as long term strategy in case of a **research programme** of a group that is continuously studying a range of interrelated complex research questions

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The research process

- The reality of research: we are likely in 1 research to ask more than one question
- The kind of questions leads us to a choice of method(s)
- Hence, the choice for MMR is linked to the nature of the research questions

=> MMR needs to be discussed at the development of the “research design”

The research process

Developing a research design =

Wrestling with 'researchable questions'

- Do we want to know the frequency of a defined social phenomenon according to some pre-defined variables (e.g. care transitions or pain treatment)?
- Do we want to generalise those frequencies and their associations to a population (e.g. all cancer patients or all dying people)?
- Do we want to explore what people think about a particular social phenomenon and how those perceptions link to some characteristics (e.g. what is good PC, what is spiritual care)?
- Do we want to use one data collection method to study one group (e.g. physicans) and another method to study another group (e.g. patients)?

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    1. **a pragmatic MMR design: the case of "End-of-life care in general practice in the NL"**
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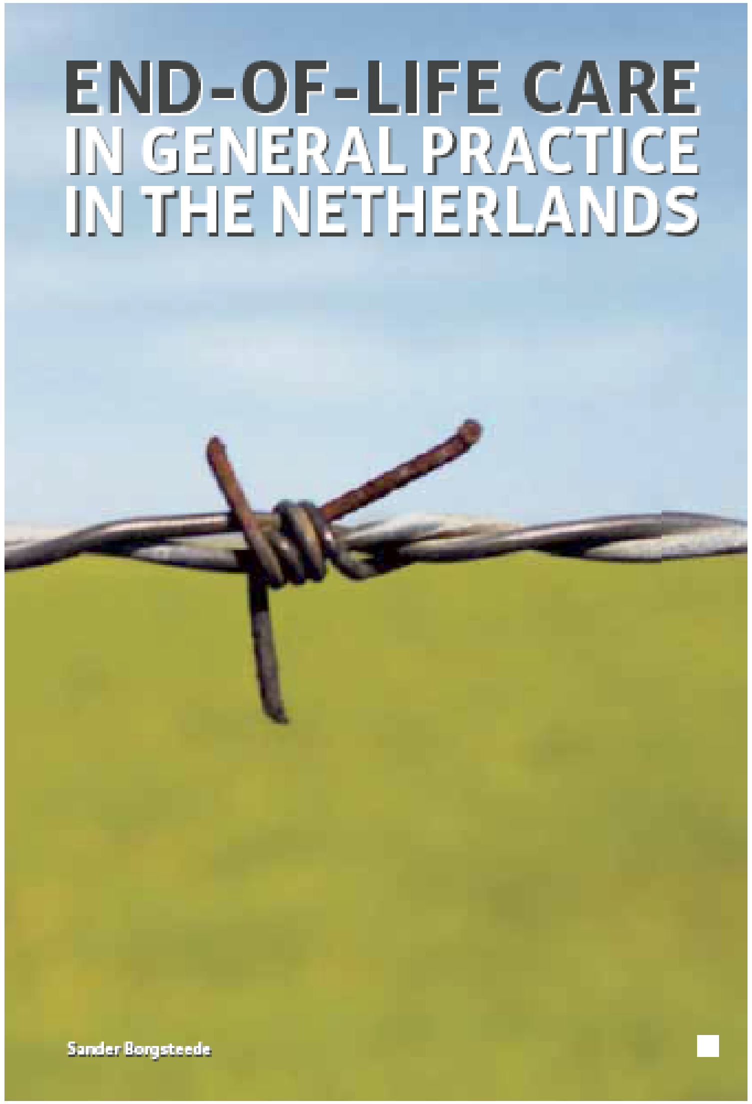
6. Conclusions

End-of-life care in general practice

- Any research is likely to comprise a complex of research questions
- Key research questions may be underpinned by realistic knowledge of the literature
- However, some research questions may be underpinned by pragmatic issues, e.g.
  - problems raised from the research design
  - search for meaning, e.g. how people make sense of their actions
- Hence, a pragmatic rationality may embrace a mix of methods if the research questions and the practicalities of the research context suggest it

End-of-life care
in general practice



END-OF-LIFE CARE
IN GENERAL PRACTICE
IN THE NETHERLANDS

Sander Borgsteede

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End-of-life care in general practice

- This thesis aims to investigate issues of current practice in end-of-life care in general practice in the Netherlands.
- The main aim is to study epidemiological indicators of end-of-life care in general practice with a **“quantitative design”:**
  - the needs of end-of-life patients in general practice
  - the quality of end-of-life care by the GP
- We also aim to explore the opinions of two important subjects involved: the patients and their GPs with **“qualitative interviews”**

End-of-life care in general practice

For this thesis, data from three different sources were used:

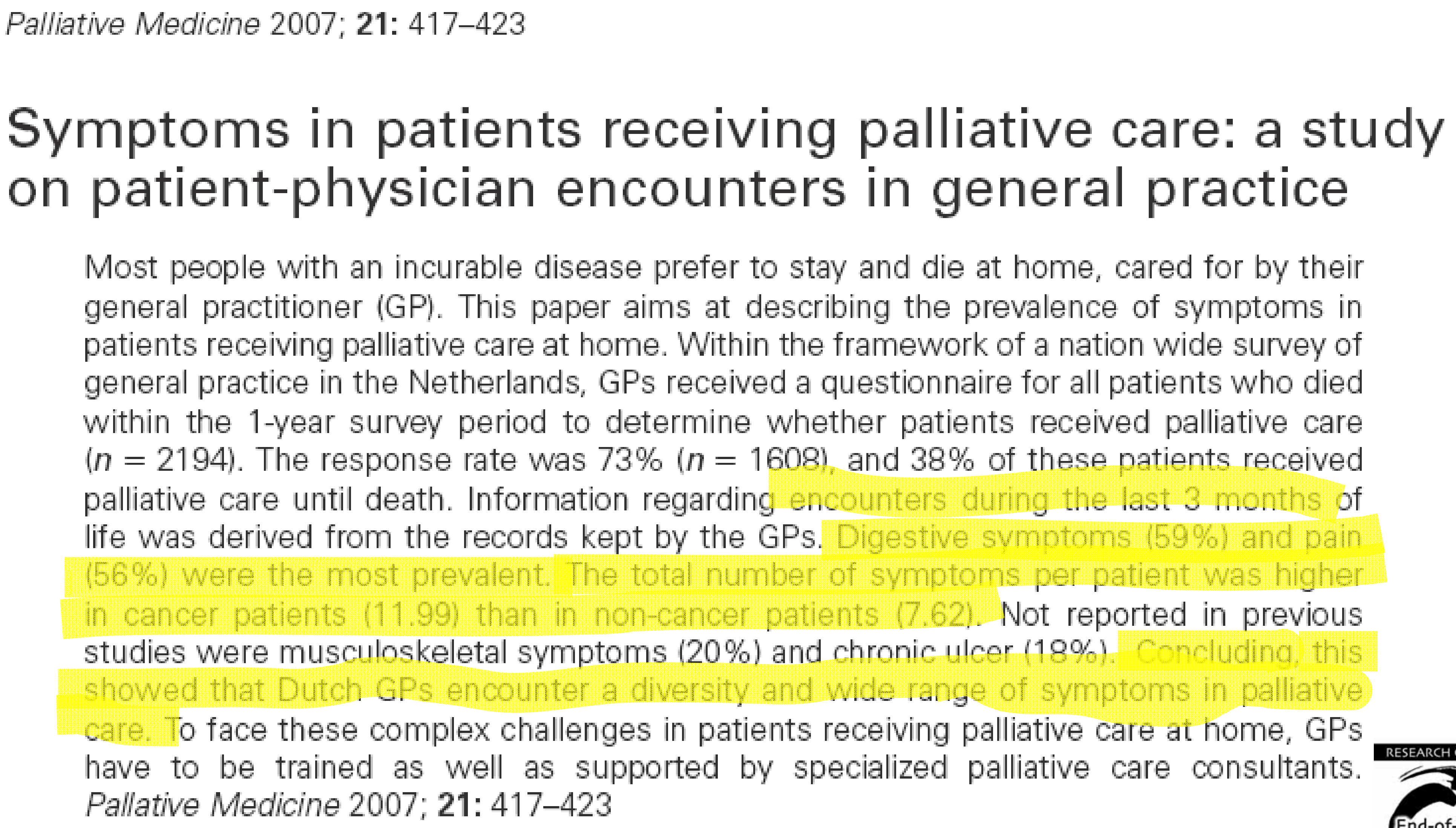
1. Quantitative registration data were collected within the framework of the Second Dutch National Survey of General Practice
2. Post-mortem questionnaire
    1. designed for this study for each patient who died during the survey year.
    2. In this questionnaire, the GPs reported the patient's underlying disease, answered questions on end-of-life care issues, and labelled each patients according to possible criteria for end-of-life care.
3. Qualitative data were obtained by interviews with 30 patients and their GPs

End-of-life care in general practice

Main research questions:

- **“What is the prevalence of pain and other symptoms in patients receiving palliative care at home?”**

End-of-life care in general practice



Palliative Medicine 2007; **21:** 417–423

Symptoms in patients receiving palliative care: a study on patient-physician encounters in general practice

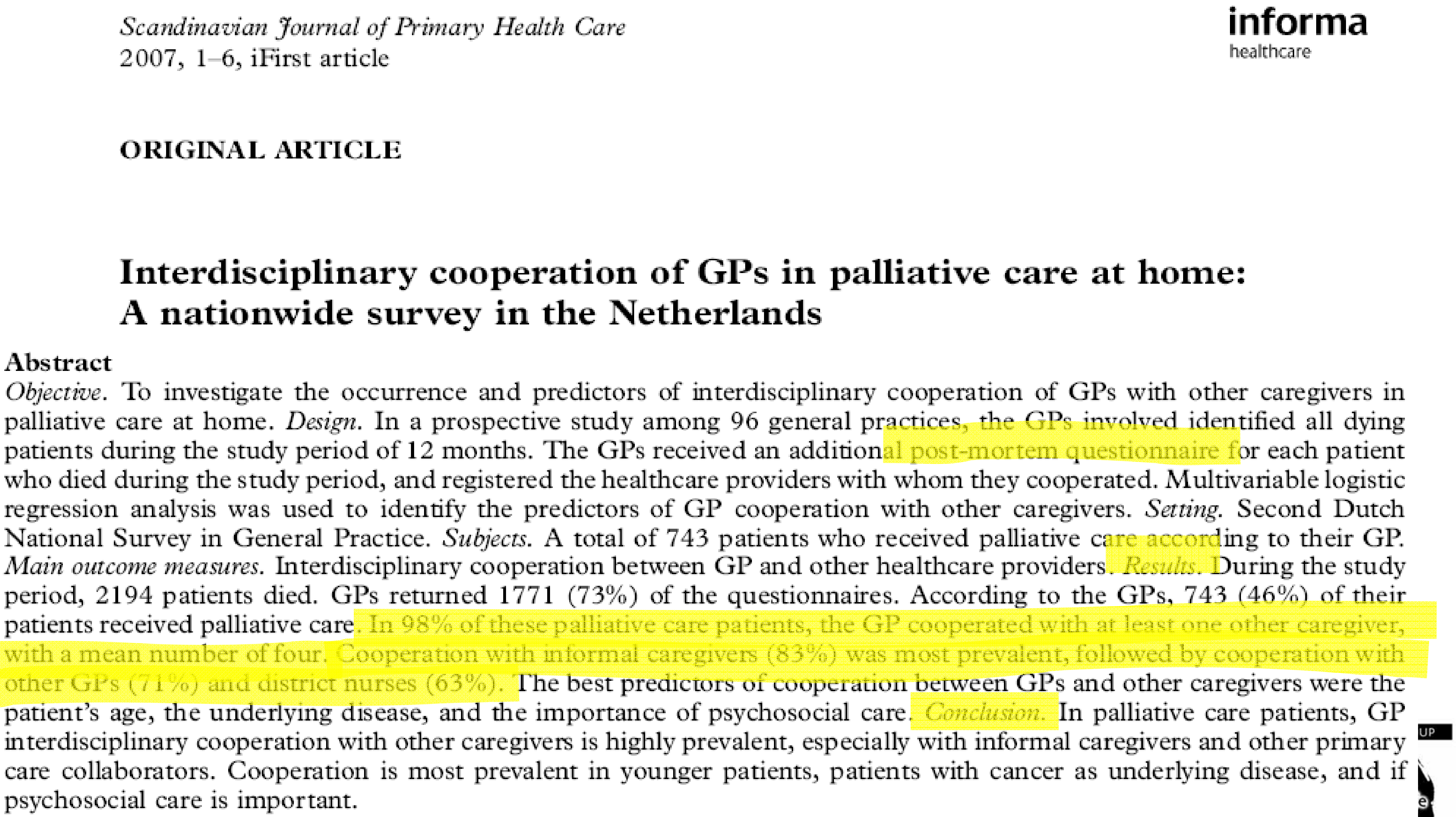
Most people with an incurable disease prefer to stay and die at home, cared for by their general practitioner (GP). This paper aims at describing the prevalence of symptoms in patients receiving palliative care at home. Within the framework of a nation wide survey of general practice in the Netherlands, GPs received a questionnaire for all patients who died within the 1-year survey period to determine whether patients received palliative care (n = 2194). The response rate was 73% (n = 1608), and 38% of these patients received palliative care until death. Information regarding encounters during the last 3 months of life was derived from the records kept by the GPs. Digestive symptoms (59%) and pain (56%) were the most prevalent. The total number of symptoms per patient was higher in cancer patients (11.99) than in non-cancer patients (7.62). Not reported in previous studies were musculoskeletal symptoms (20%) and chronic ulcer (18%). Concluding, this showed that Dutch GPs encounter a diversity and wide range of symptoms in palliative care. To face these complex challenges in patients receiving palliative care at home, GPs have to be trained as well as supported by specialized palliative care consultants. *Pallative Medicine* 2007; **21:** 417–423

End-of-life care
in general practice

Main research questions:

- **“What is the extent and the level of GP cooperation with other caregivers in palliative care at home?”**

End-of-life care in general practice



Scandinavian Journal of Primary Health Care
2007, 1–6, iFirst article

informa
healthcare

ORIGINAL ARTICLE

Interdisciplinary cooperation of GPs in palliative care at home: A nationwide survey in the Netherlands

Abstract

Objective. To investigate the occurrence and predictors of interdisciplinary cooperation of GPs with other caregivers in palliative care at home. *Design.* In a prospective study among 96 general practices, the GPs involved identified all dying patients during the study period of 12 months. The GPs received an additional post-mortem questionnaire for each patient who died during the study period, and registered the healthcare providers with whom they cooperated. Multivariable logistic regression analysis was used to identify the predictors of GP cooperation with other caregivers. *Setting.* Second Dutch National Survey in General Practice. *Subjects.* A total of 743 patients who received palliative care according to their GP. *Main outcome measures.* Interdisciplinary cooperation between GP and other healthcare providers. *Results.* During the study period, 2194 patients died. GPs returned 1771 (73%) of the questionnaires. According to the GPs, 743 (46%) of their patients received palliative care. In 98% of these palliative care patients, the GP cooperated with at least one other caregiver, with a mean number of four. Cooperation with informal caregivers (83%) was most prevalent, followed by cooperation with other GPs (71%) and district nurses (63%). The best predictors of cooperation between GPs and other caregivers were the patient's age, the underlying disease, and the importance of psychosocial care. *Conclusion.* In palliative care patients, GP interdisciplinary cooperation with other caregivers is highly prevalent, especially with informal caregivers and other primary care collaborators. Cooperation is most prevalent in younger patients, patients with cancer as underlying disease, and if psychosocial care is important.

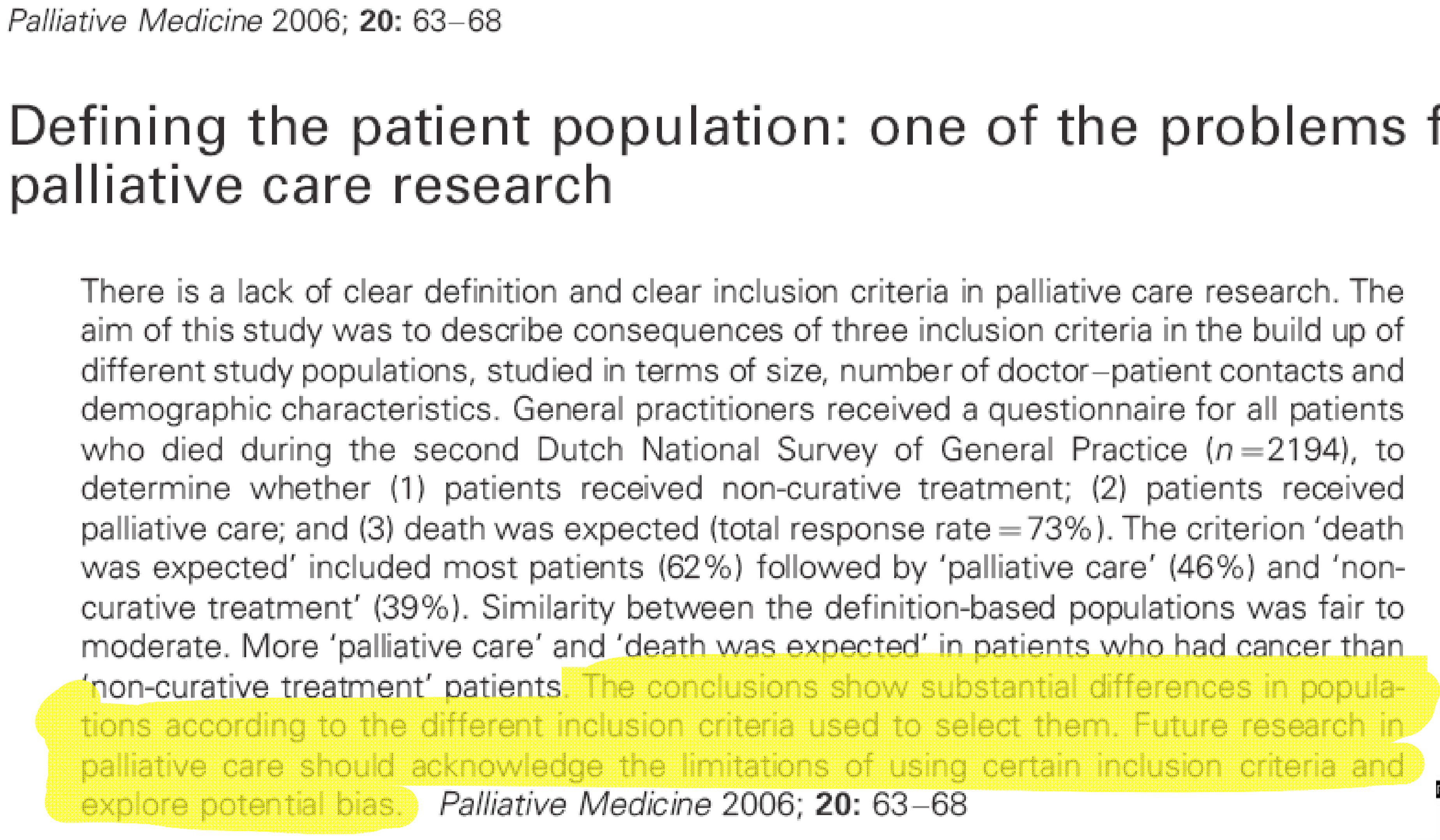
End-of-life care in general practice

- A problem we encountered when we had to define inclusion criteria for the design of our study was that there is no generally accepted research definition of “palliative care”.

- This led to the research question:

  “What are the consequences of using different inclusion criteria on the selected palliative care populations in terms of size, number of doctor-patient contacts and demographic characteristics?”

End-of-life care in general practice



Palliative Medicine 2006; **20:** 63–68

Defining the patient population: one of the problems for palliative care research

There is a lack of clear definition and clear inclusion criteria in palliative care research. The aim of this study was to describe consequences of three inclusion criteria in the build up of different study populations, studied in terms of size, number of doctor–patient contacts and demographic characteristics. General practitioners received a questionnaire for all patients who died during the second Dutch National Survey of General Practice ($n = 2194$), to determine whether (1) patients received non-curative treatment; (2) patients received palliative care; and (3) death was expected (total response rate = 73%). The criterion 'death was expected' included most patients (62%) followed by 'palliative care' (46%) and 'non-curative treatment' (39%). Similarity between the definition-based populations was fair to moderate. More 'palliative care' and 'death was expected' in patients who had cancer than 'non-curative treatment' patients. The conclusions show substantial differences in populations according to the different inclusion criteria used to select them. Future research in palliative care should acknowledge the limitations of using certain inclusion criteria and explore potential bias. *Palliative Medicine* 2006; **20:** 63–68

End-of-life care in general practice

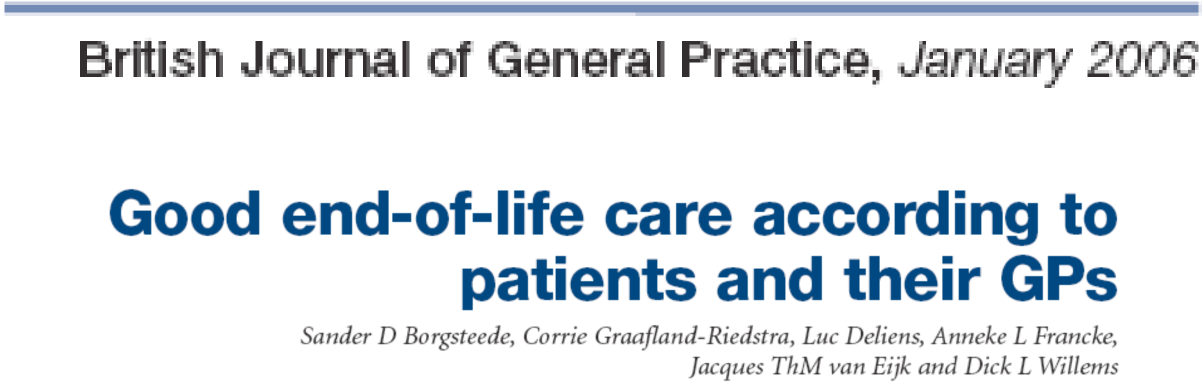
Qualitative interviews:

- We explore the opinions of the patients receiving end-of-life care and their GPs with qualitative interviews concerning two topics.

- First, we analyse their experiences with end-of-life care with the next research question:

> **“What are the aspects valued in end-of-life care at home by patients and their general practitioners?”**

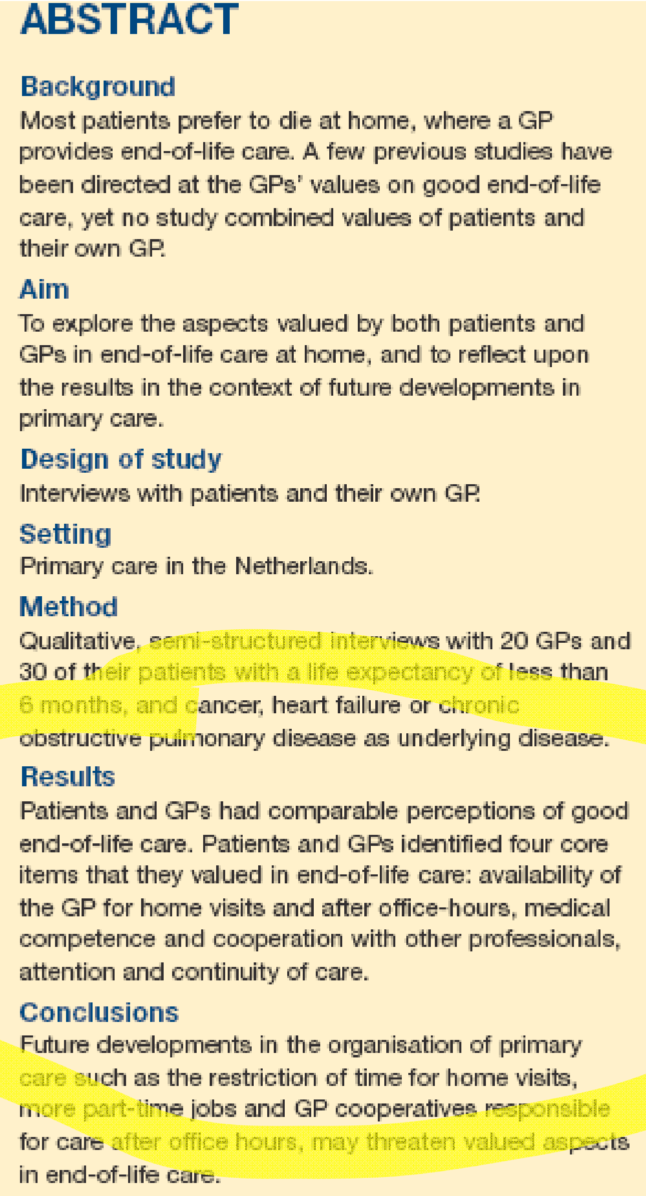
End-of-life care in general practice



British Journal of General Practice, *January 2006*

Good end-of-life care according to patients and their GPs

Sander D Borgsteede, Corrie Graafland-Riedstra, Luc Deliens, Anneke L Francke, Jacques ThM van Eijk and Dick L Willems



ABSTRACT

Background

Most patients prefer to die at home, where a GP provides end-of-life care. A few previous studies have been directed at the GPs' values on good end-of-life care, yet no study combined values of patients and their own GP.

Aim

To explore the aspects valued by both patients and GPs in end-of-life care at home, and to reflect upon the results in the context of future developments in primary care.

Design of study

Interviews with patients and their own GP.

Setting

Primary care in the Netherlands.

Method

Qualitative, semi-structured interviews with 20 GPs and 30 of their patients with a life expectancy of less than 6 months, and cancer, heart failure or chronic obstructive pulmonary disease as underlying disease.

Results

Patients and GPs had comparable perceptions of good end-of-life care. Patients and GPs identified four core items that they valued in end-of-life care: availability of the GP for home visits and after office-hours, medical competence and cooperation with other professionals, attention and continuity of care.

Conclusions

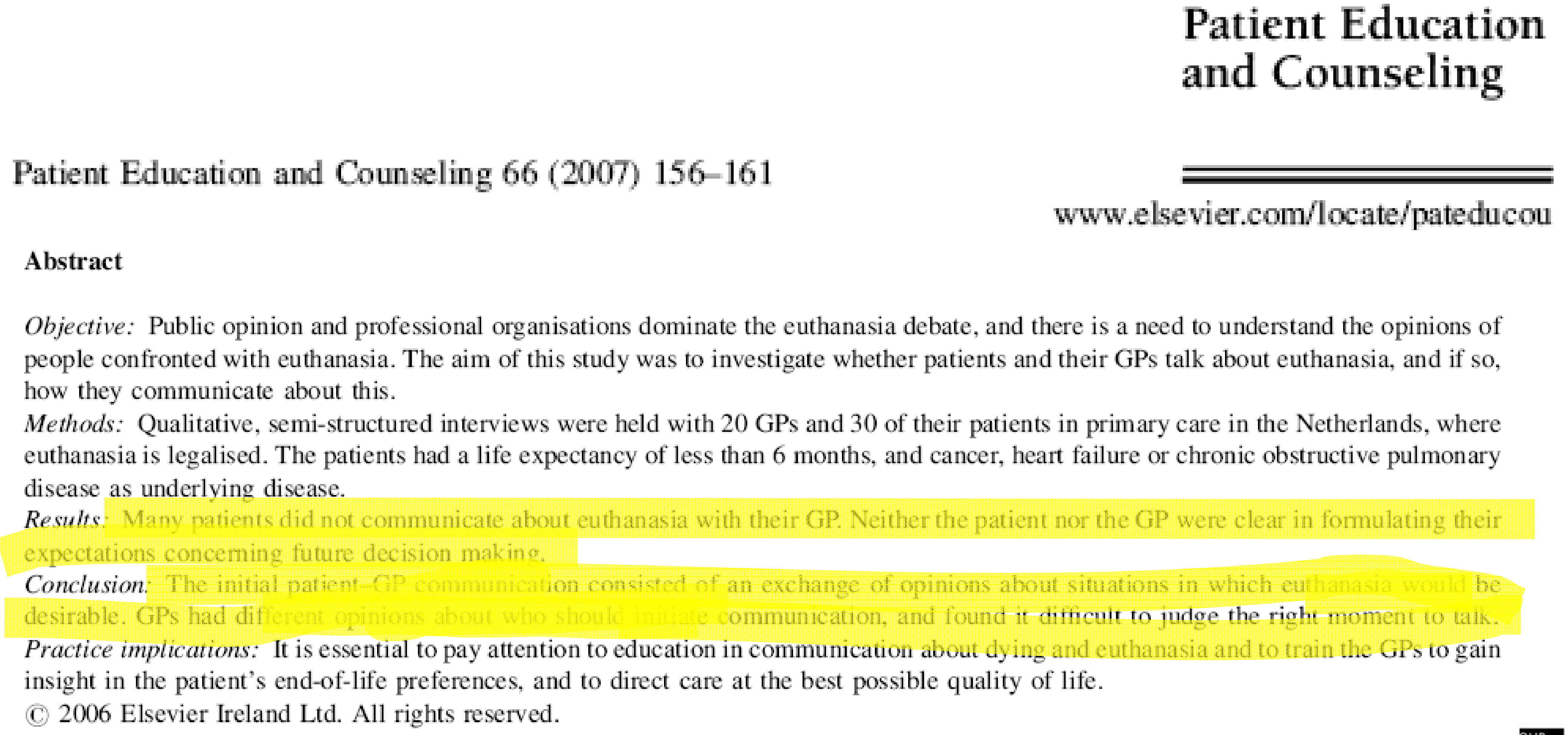
Future developments in the organisation of primary care such as the restriction of time for home visits, more part-time jobs and GP cooperatives responsible for care after office hours, may threaten valued aspects in end-of-life care.

Qualitative interviews II:

- as in the Dutch context euthanasia is one of the end-of-life options, our second exploration concerns communication about this topic:

> **“Do patients talk about euthanasia with their GP and if so, how do they communicate about this subject?”**

End-of-life care in general practice



Patient Education and Counseling

Patient Education and Counseling 66 (2007) 156–161

www.elsevier.com/locate/pateducou

Abstract

Objective: Public opinion and professional organisations dominate the euthanasia debate, and there is a need to understand the opinions of people confronted with euthanasia. The aim of this study was to investigate whether patients and their GPs talk about euthanasia, and if so, how they communicate about this.

Methods: Qualitative, semi-structured interviews were held with 20 GPs and 30 of their patients in primary care in the Netherlands, where euthanasia is legalised. The patients had a life expectancy of less than 6 months, and cancer, heart failure or chronic obstructive pulmonary disease as underlying disease.

Results: Many patients did not communicate about euthanasia with their GP. Neither the patient nor the GP were clear in formulating their expectations concerning future decision making.

Conclusion: The initial patient–GP communication consisted of an exchange of opinions about situations in which euthanasia would be desirable. GPs had different opinions about who should initiate communication, and found it difficult to judge the right moment to talk.

Practice implications: It is essential to pay attention to education in communication about dying and euthanasia and to train the GPs to gain insight in the patient's end-of-life preferences, and to direct care at the best possible quality of life.

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Spiritual care in Dutch nursing homes (NHs)

Background:

- In the near future, in the Netherlands, NHs will increasingly be the site of terminal care
- NHs are increasingly the place of end of life care for people with dementia
- Most NH patients will enter a terminal phase and eventually will die in the NH
- Also for these NH patients good end of life care should be given, including spiritual care at the end of life
- However, very little is known about spiritual care in the terminal phase of NH patients in the Netherlands

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Spiritual care in Dutch nursing homes

Background:

- It is unknown :
  - what spiritual care means
  - what spiritual needs terminally ill NH patients express
  - whether NH physicians assess these spiritual needs
  - whether NH physicians provide spiritual care for their terminally ill patients, incl for NH patients in the different stages of dementia (and their relatives)
  - whether NH physicians collaborate with, or refer to other care givers to provide spiritual care

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Spiritual care in Dutch nursing homes

Mixed Methods approach:

- Literature Review
- Focus Group Discussions
- Survey research with postal questionnaire
- Prospective Participant Observation

Spiritual care in Dutch nursing homes

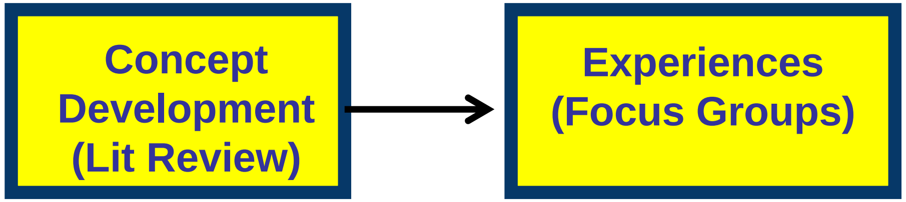
Concept Development (Lit Review)

Spiritual care in Dutch nursing homes

Aim of Literature Review :

- To review the content of spirituality at the end of life
- To review the meaning of spiritual care at the end of life in NHs

Spiritual care in Dutch nursing homes


Concept Development (Lit Review)

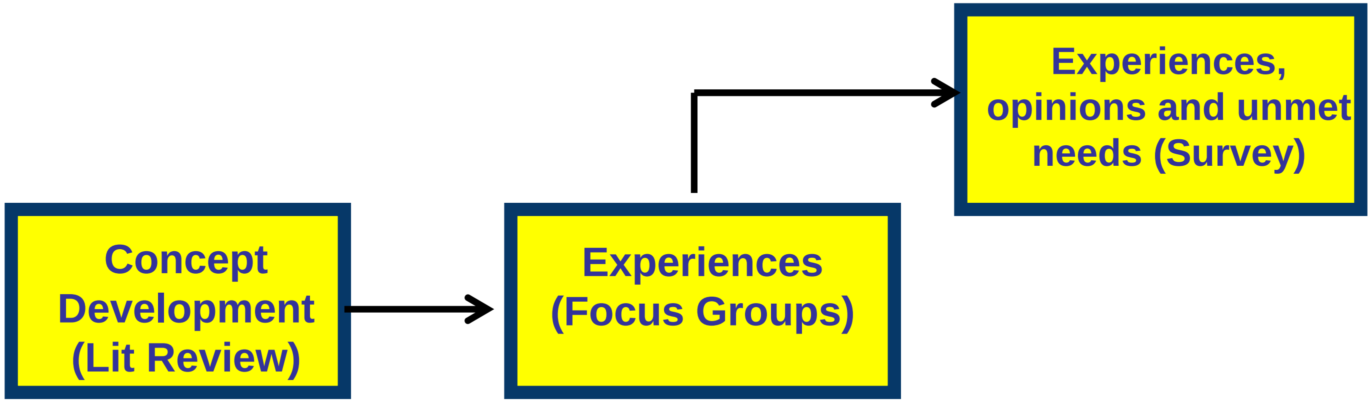
Experiences (Focus Groups)

Spiritual care in Dutch nursing homes

Aim of Focus Groups:

- discussing the meaning of spiritual care according to NH physicians and NH nurses
- discussing experiences of NH physicians and NH nurses with spiritual care for the terminally ill NH patients

Spiritual care in Dutch nursing homes



Concept Development (Lit Review)

Experiences (Focus Groups)

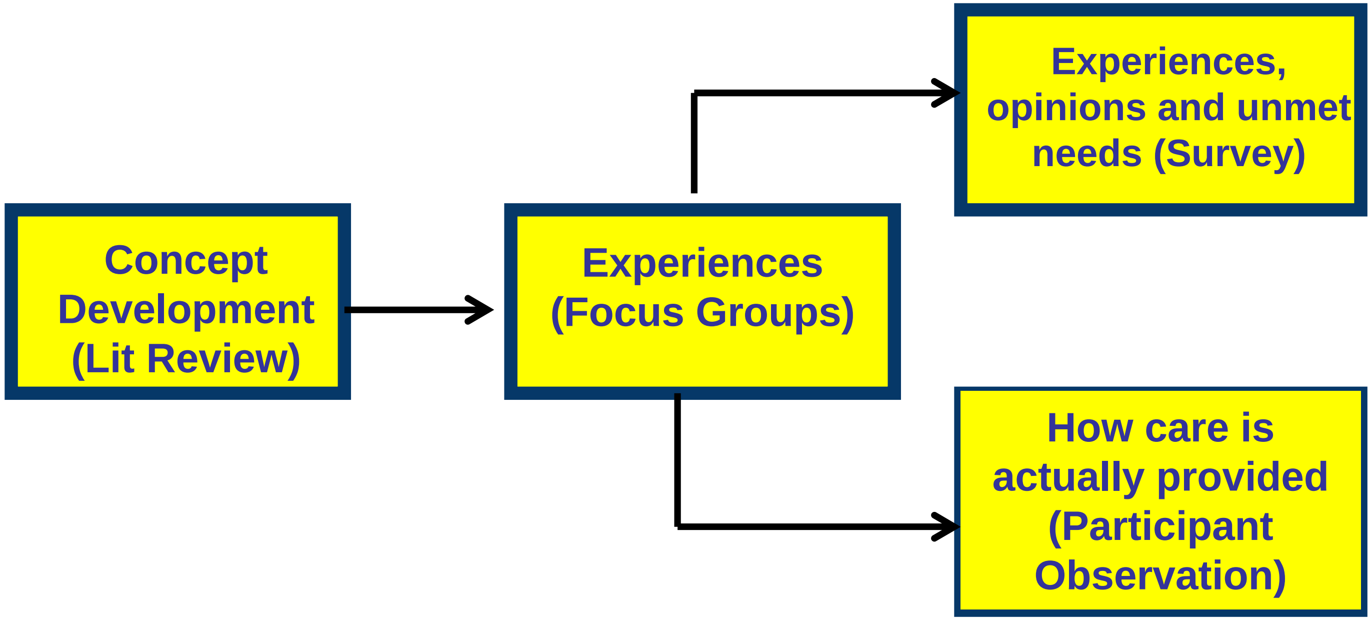
Experiences, opinions and unmet needs (Survey)

Spiritual care in Dutch nursing homes

Survey research :

1. Postal survey to a representative sample of NH physicians
2. Aims at quantitative analyses of:
    1. Whether and how spiritual care is provided
    2. Characteristics of NHs, physicians and patients
3. Standardised questionnaire, based on results of review and focus groups
4. Including validated instruments, e.g. End of Life with dementia (EOLD)
5. Demographics and characteristics of NH physicians

Spiritual care in Dutch nursing homes



Concept Development (Lit Review)

Experiences (Focus Groups)

Experiences, opinions and unmet needs (Survey)

How care is actually provided (Participant Observation)

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Spiritual care in Dutch nursing homes

Participant Observation :

- Aim: to observe the real practice of spiritual care at the end of life in NHs in the Netherlands
- Prospective design
- Participant = 1 NH physician
- Observations in a limited number of NHs

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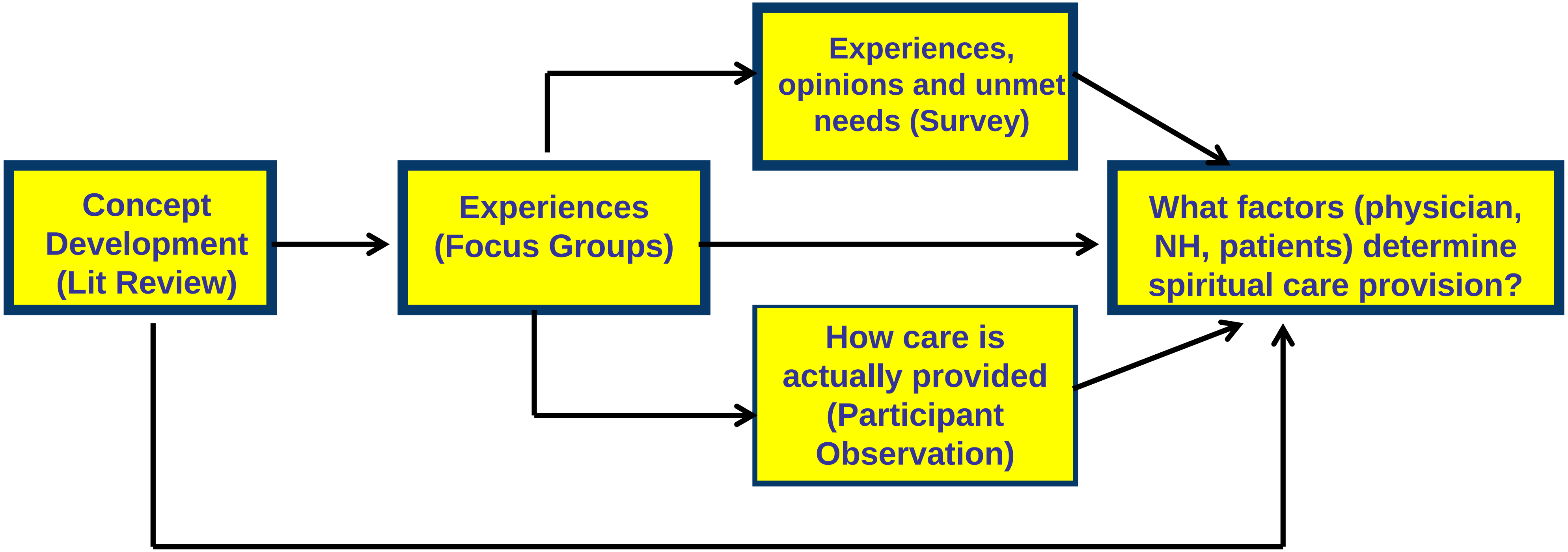
Spiritual care in Dutch nursing homes



Concept Development (Lit Review)

Experiences (Focus Groups)

Experiences, opinions and unmet needs (Survey)

How care is actually provided (Participant Observation)

What factors (physician, NH, patients) determine spiritual care provision?

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Conclusions 1: Opportunities

- MMR creates an opportunity for research skills enhancements, through learning and new research experiences
- MMR brings researchers together from different fields and disciplines
- MMR develops the researcher’s repertoire of methodologies, and fits into a researcher’s need of lifelong learning
- MMR deflects attention away from daily activities; hence, it is an encouragement for creative thinking

Conclusions 2: Risks

- As most scholarly journals are discipline based; writing up MMR and the choice of a journal may be a problem
- MMR is popular among policy makers and those who inform practice, while scientific research and journals may require more justification of methods
- Lack of time and resources for data analyses and reporting

Conclusions 3

- MMR offers opportunities and risks
- It may offer creative possibilities for addressing research questions with a range of methods
- MMR gets more prominent at a time in which research required to be practically relevant and applicable to policy
- The opportunity to learn new research skills is to be welcomed
- MMR facilitates multi-disciplinary research

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Thank you

Best regards from
Brussels and Amsterdam