

Organisation of palliative care in Belgium - Supplement

KCE reports 1155

Federaal Kenniscentrum voor de Gezondheidszorg
Centre fédéral d'expertise des soins de santé
Belgian Health Care Knowledge Centre
2009



The Belgian Health Care Knowledge Centre

Introduction : The Belgian Health Care Knowledge Centre (KCE) is an organization of public interest, created on the 24th of December 2002 under the supervision of the Minister of Public Health and Social Affairs. KCE is in charge of conducting studies that support the political decision making on health care and health insurance.

Administrative Council

Actual Members : Pierre Gillet (President), Dirk Cuypers (Vice-president), Jo De Cock (Vice-president), Frank Van Massenhove (Vice-president), Yolande Avondtroodt, Jean-Pierre Baeyens, Ri de Ridder, Olivier De Stexhe, Peter Degadt, Daniel Devos, Jean-Noël Godin, Floris Goyens, Jef Maes, Pascal Mertens, Raf Mertens, Marc Moens, François Perl, Marco Schetgen, Yves Smeets, Patrick Verertbruggen, Michel Foulon, Myriam Hubinon

Substitute Members : Rita Cuypers, Christiaan De Coster, Benoît Collin, Lambert Stamatakis, Karel Vermeyen, Katrien Kesteloot, Bart Ooghe, Frederic Lernoux, Anne Vanderstappen, Paul Palsterman, Geert Messiaen, Anne Remacle, Roland Lemeye, Annick Poncé, Pierre Smiets, Jan Bertels, Catherine Lucet, Ludo Meyers, Olivier Thonon.

Government commissioner : Roger Yves

Management

Chief Executive Officer a.i. : Jean-Pierre Closon

Information

Federaal Kenniscentrum voor de gezondheidszorg - Centre fédéral d'expertise des soins de santé –
Belgian Health Care Knowledge Centre.
Centre Administratif Botanique, Doorbuilding (10th floor)
Boulevard du Jardin Botanique 55
B-1000 Brussels
Belgium
Tel: +32 [0]2 287 33 88
Fax: +32 [0]2 287 33 85
Email : info@kce.fgov.be
Web : <http://www.kce.fgov.be>

Organisation of palliative care in Belgium - Supplement

KCE reports 115S

EMMANUEL KEIRSE, CLAIRE BEGUIN, MARIANNE DESMEDT, MYRIAM DEVEUGELE, JOHAN MENTEN
STEVEN SIMOENS, JOHAN WENS, LIESBETH BORGERMANS, LAURENCE KOHN
BRAM SPINNEWIJN, ANN CARDINAEI, BETTY KUTTEN,
PAUL VANDEN BERGHE, DOMINIQUE PAULUS

KCE reports I I5S

- Title:** Organisation of palliative care in Belgium - Supplement
- Authors :** E. Keirse (Federatie Palliatieve Zorg Vlaanderen), C. Beguin (UCL), M. Desmedt (UCL), M. Deveugele (UGent), J. Menten (KULeuven), S. Simoens (KULeuven), J. Wens (UA), L. Borgermans (KULeuven), L. Kohn (KCE), B. Spinnewijn (UA), A. Cardinael (UGent), B. Kutten (KULeuven), P. Vanden Berghe (Federatie Palliatieve Zorg Vlaanderen), D. Paulus (KCE).
- Acknowledgements :** C. Léonard (KCE), B. Van den Eynde (UA), K. Dirven (UA), L. Vos (UA), A. Drowart (ULB), C. Doyen (Fédération Wallonne des Soins Palliatifs), L. Fontaine (Fédération Wallonne des Soins palliatifs), J. Lobbestael (UGent), S. Roels (UCL), P. Fontaine (UCL), Y. de la Kethulle (UCL)
- External experts :** N. Barthelemy (CHU Sart Tilman), Cécile Bolly (médecin généraliste, Neufchâteau), N. Bossuyt (ISSP – WIV), J. De Lepeleire (KULeuven), D. Demuynck (Dijlehof, Leuven), M. Desmet (Virga Jesse Ziekenhuis, Hasselt), B. Gielen (LCM, Brussel), R. Goetschalckx (INAMI-RIZIV), P. Pype (Palliatief Netwerk De mantel, Roeselare), T. Thibo (Ministry of Public Health), M. Pirson (ESP, ULB), M. Vanhalewyn (Société Scientifique de Médecine Générale), A. Veris (UZ, KULeuven)
- External validators:** Y. Bourgueil (IRDES, Paris), F. Buntinx (KULeuven), N. Van Den Noortgate (UGent)
- Conflict of interest:** J. De Lepeleire declared to be member of the FPZV working group “Palliatieve Zorg en Geriatrie”
- Disclaimer:** The external experts were consulted about a (preliminary) version of the scientific report. Subsequently, a (final) version was submitted to the validators. The validation of the report results from a consensus or a voting process between the validators. Only the KCE is responsible for errors or omissions that could persist. The policy recommendations are also under the full responsibility of the KCE.

Layout : Ine Verhulst

Brussels, 22 October 2009

Study nr 2007-18

Domain: Health Services Research (HSR)

Mesh: Palliative care ; Health Services needs and demands ; Health Care surveys ; Economics, medical ; Review [Publication Type]

NLM classification: WB 310

Language: English

Format: Adobe® PDF™ (A4)

Legal depot: D/2009/10.273/43

Any partial reproduction of this document is allowed if the source is indicated. This document is available on the website of the Belgian Health Care Knowledge Centre.

How to refer to this document?

Keirse E, Beguin C, Desmedt M, Deveugele M, Menten J, Simoens S, Wens J, Borgermans L, Kohn L, Spinnewijn B, Cardinael A, Kutten B, Vandenberghe P, Paulus D. Organisation of palliative care in Belgium – Supplement. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Centre (KCE). 2009. KCE reports I I5S (D/2009/10.273/43)



Organisation of palliative care in Belgium

Appendices

Table of contents

I	APPENDICES PART ONE LITERATURE - DEFINITIONS	3
1.1	DEFINITIONS BY ASSOCIATIONS.....	3
1.1.1	Inventory of organisations.....	3
1.1.2	WHO definition - 2002.....	6
1.1.3	EAPC definition	6
1.1.4	Summary tables of definitions from organisations.....	7
1.1.5	Synthesis of definitions from organisations.....	22
1.2	LITERATURE SEARCH –DEFINITIONS	29
1.2.1	Search strategies.....	29
1.2.2	Summary tables - Theoretical definitions selected in the indexed literature	32
1.2.3	Synthesis of the theoretical definitions selected in the indexed literature	34
1.2.4	Summary tables - Definitions used in surveys.....	36
2	APPENDIX PART TWO: LITERATURE - NEEDS.....	47
2.1	PART NEEDS - SEARCH TERMS AND KEYWORDS.....	47
2.2	PART NEEDS - DETAILED SEARCH STRATEGIES	48
2.3	PART NEEDS - SELECTION OF THE ARTICLES.....	52
2.4	PART NEEDS - SELECTED ARTICLES.....	53
2.5	PART NEEDS - DESCRIPTION OF THE PAPERS	54
2.5.1	Description of papers about spiritual needs of palliative patients	54
2.5.2	Description of papers about needs of palliative patients with cancer	55
2.5.3	Description of papers about needs of palliative patients with heart failure	56
2.5.4	Description of papers about needs of palliative patients with respiratory diseases	57
2.5.5	Description of papers about needs of palliative patients with muscular- and neurodegenerative diseases	57
2.5.6	Description of papers about needs of palliative patients with neurological diseases	58
2.5.7	Description of papers about needs of children and their carers	58
2.5.8	Description of papers about needs of palliative patients in miscellaneous settings	59
2.5.9	Table of literature identified per needs and per type of pathology	61
3	APPENDIX PART THREE: LITERATURE – ORGANISATION MODELS.....	65
3.1	ORGANISATIONS MODELS: SEARCH TERMS AND SEARCH STRATEGIES.....	65
3.1.1	Search in Medline	65
3.1.2	Search in CINHALL	66
3.1.3	Search in EMBASE.....	67
3.1.4	COCHRANE DATABASE	68
3.2	QUALITY ASSESSMENT OF THE SYSTEMATIC REVIEWS INCLUDED IN THE CHAPTER ON PALLIATIVE CARE MODELS	68
3.3	FRAMEWORK FOR THE ANALYSIS OF ORGANISATION MODELS.....	81
3.4	OVERVIEW OF EVIDENCE FROM 59 STUDIES ON PALLIATIVE CARE MODELS.....	83
3.5	REFERENCES.....	95
3.6	DESCRIPTION OF THE SELECTED STUDIES.....	98
4	APPENDIX EPIDEMIOLOGICAL SURVEYS.....	176
4.1	APPENDICES WEB SURVEY	176

4.1.1	Web based questionnaire in Dutch.....	176
4.1.2	Results of the principal components analysis on the web-based questionnaire, part 3.....	180
4.2	APPENDICES SURVEY HOME SETTING.....	182
4.2.1	Sample size calculation: GPs and nursing homes.....	182
4.2.2	General questionnaire for GPs HA 2 (in Dutch).....	184
4.2.3	Initial questionnaire GP HA3a (in Dutch).....	185
4.2.4	Questionnaire GP HA3b at follow-up (in Dutch).....	189
4.3	APPENDICES SURVEY NURSING HOMES.....	193
4.3.1	General questionnaire ROB/RVT 1 (in Dutch).....	193
4.3.2	Initial Questionnaire ROB/RVT 2a (in Dutch).....	195
4.3.3	Follow-up questionnaire ROB/RVT2b (in Dutch).....	200
4.4	APPENDICES HOSPITALS.....	205
4.4.1	Patients selection in hospitals.....	205
4.4.2	Questionnaires on patients.....	209
4.4.3	Sample Size in hospitals.....	235
4.4.4	Hospitals' Sample and characteristics.....	236
5	DESCRIPTION OF STUDIES MEASURING PALLIATIVE CARE COSTS.....	238
6	REFERENCES.....	244

I APPENDICES PART ONE LITERATURE - DEFINITIONS

I.1 DEFINITIONS BY ASSOCIATIONS

I.1.1 Inventory of organisations

Country of Origin	# / C*	Developer	Definition
International	1	WHO	WHO definition 2002
	2	EACP	EACP definition
	3	International Association for Hospice and Palliative Care	WHO definition 2002 + additional info from IAHPC Manual
Belgium	1	Federatie Palliatieve Zorg Vlaanderen	WHO definition 2002
	2	Fédération Wallonne des Soins Palliatifs	own
	3	Fédération Bruxelloise Pluraliste de Soins Palliatifs et Continus	own
	4	Rijksdienst voor Ziekte- en Invaliditeitsverzekering	No specific definition on website, but related info
	5	Ministère des affaires sociales, de la santé publique et de l'environnement	own
	6	Palliatief Netwerk De Mantel	WHO definition 2002
UK	1	The National Council for Palliative Care + National Council for Hospice and Specialist Palliative Care Services	according to NICE definition
	2	National Health Service	No specific definition on website, but related info, according to the NICE definition
	3	Department of Palliative Care and Policy, St.Christopher's Hospice, London	WHO definition 2002
	4	Great Britain "Hospice Information - Help the Hospices"	WHO definition 2002
	5	Sheffield Palliative Care Studies Group (SPCSG) - University of Sheffield	WHO definition 2002
	6	HELP – helpful links to palliative care, UK =>Referral to MacMillan Organisation	own
	7	National Institute for Clinical Excellence (NICE)	own

Country of Origin	# / C*	Developer	Definition
	8	Association for Palliative Medicine of Great Britain and Ireland	Website unavailable
	9	Association of Palliative Care Social Workers	No website detected
	10	Palliative Care Research Society UK	No specific definition on website
	11	Royal College of Nursing (RCN) – Palliative Nursing Group (PNG)	No specific definition on website
	12	Association of Hospice Chaplains	No specific definition on website
	13	Hospice on the Net in the UK and Ireland	No specific definition on website
	14	Marie Curie Cancer Care	No specific definition on website
	15	Palliative Medicine Wales, UK	No specific definition on website
The Netherlands	1	Netherlands Palliative Care Network for Terminally Ill Patients	WHO definition 2002
	2	Rijksinstituut voor Volksgezondheid en Milieu / Nationaal Kompas Volksgezondheid (Website over de Nederlandse volksgezondheid)	No specific definition on website
	3	Nederlands Instituut voor onderzoek en gezondheidszorg	WHO definition 2002 + additional info
	4	Nederlandse Overheid	WHO definition 2002 + additional info
	5	Ministerie volksgezondheid, welzijn en sport	No specific definition on website
France	1	Fédération JALMALV	WHO definition 2002
	2	Société Française d'Accompagnement et de Soins Palliatifs	Definition of palliative patient
	3	Association pour le développement des Soins Palliatifs	
	4	Haute Autorité Santé	own
	5	Ministère de la santé	WHO definition 2002
Germany	1	Deutsche Gesellschaft für Palliativmedizin	WHO definition 2002
	2	Hospiz bewegung Deutschland	WHO definition 2002 + EACP definition
	3	Bundesärztekammer (Arbeitsgemeinschaft der Deutschen Ärztekammern)	WHO definition 2002
	4	Bundesministerium für Gesundheit (BMG)	No specific definition on website
	5	Krebshilfe Deutschland	No specific definition on website
	6	German Hospice Foundation	No specific definition on website
	7	Wegweiser Hospiz und Palliativmedizin Deutschland	No specific definition on website
Sweden	1	Swedish Association for Palliative Care	WHO definition 2002 + EACP definition

Country of Origin	# / C*	Developer	Definition
	2	Swedish Council for Palliative Care - Nationella Rådet för Palliativ Vård	WHO definition 2002
	3	National Board of Health and Welfare	No specific definition on website, reference to e.g. WHO definition
Australia	1	Australia and New Zealand Society of Palliative Medicine	No specific definition on website
	2	Australian Government's Department of Health and Ageing.	WHO definition 2002 + own definition of palliative approach (in the aged)
	3	A Program of Experience in the Palliative Approach (PEPA)	WHO definition 2002
	4	Australian Government	No specific definition on website
	5	Australasian Chapter of Palliative Medicine	Website unavailable
	6	The Palliative Care Outcomes Collaborative	No specific definition on website
	7	Palliative Care Australia	WHO definition 2002 + additional Standards for Providing Quality Palliative Care for all Australians
Canada	1	Canadian Hospice Palliative Care Association	Own
	2	Health Canada (Federal department)	Own
	3	Edmonton Palliative Care Program	Website unavailable
USA	1	National Hospice and Palliative Care Organization	own
	2	American Academy of Hospice and Palliative Medicine	own
	3	The National Hospice and Palliative Care Organization	own
	4	Hospice Education Institute	WHO definition 2002
	5	Hospice Palliative Nurses Association	No specific definition on website
	6	Palliative Care Nursing Association	No specific definition on website
	7	Department of Health and Human Services' Health Resources and Services Administration	No specific definition on website

* # / C : amount of organisations found / country

I.1.2 WHO definition - 2002

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (<http://www.who.int/cancer/palliative/definition/en>).

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement
- Counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

<http://www.who.int/cancer/palliative/definition/en>

I.1.3 EAPC definition

Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.

I.1.4 Summary tables of definitions from organisations

EUROPEAN COUNTRIES

Belgium

WHO ?		Definition
Federation Palliative zorg Vlaanderen http://www.palliatief.be	FPCF	WHO definition 2002
Fédération Wallonne des Soins Palliatifs http://www.fwsp.be	FBSP	L'aide et l'assistance pluridisciplinaire qui sont dispensés à domicile, dans un hébergement collectif non hospitalier ou dans un hôpital, afin de rencontrer globalement les besoins physiques, psychiques et spirituels des patients durant la phase terminale de la maladie, et qui contribuent à la préservation d'une qualité de vie
Fédération Bruxelloise Pluraliste de Soins Palliatifs et Continus	FBSP	Les soins continus et palliatifs impliquent un suivi actif et global par une équipe pluridisciplinaire des personnes atteintes d'une maladie évolutive à issue fatale. Leur objectif est de maintenir une qualité de vie conforme au désir du patient, par le traitement de ses symptômes physiques et la prise en compte de sa souffrance psychique, sociale et spirituelle au sens large du terme.
Rijksdienst voor Ziekte- en Invaliditeitsverzekering www.riziv.be	RIZIV	No specific definition on website links to e.g. www.palliatifs.be + Palliatieve zorg garandeert aan de zieke op zijn levenseinde - en aan zijn familie - de beste levenskwaliteit en een zo groot mogelijke autonomie In palliatieve zorg wordt er met verschillende aspecten rekening gehouden : pijnbestrijding, comfortzorg, psychologische, sociale en spirituele steun... Dankzij het supportteam staat de zieke - en zijn naasten - centraal in de voortgang.
Ministère des affaires sociales, de la santé publique et de l'environnement http://www.ejustice.just.fgov.be		Loi relative aux soins palliatifs (14 juin 2002) : Par soins palliatifs, il y a lieu d'entendre : l'ensemble des soins apportés au patient atteint d'une maladie susceptible d'entraîner la mort une fois que cette maladie ne réagit plus aux thérapies curatives. Un ensemble multidisciplinaire de soins revêt une importance capitale pour assurer l'accompagnement de ces patients en fin de vie, et ce sur les plans physique, psychique, social et moral. Le but premier des soins palliatifs est d'offrir au malade et à ses proches la meilleure qualité de vie possible et une autonomie maximale. Les soins palliatifs tendent à garantir et à optimiser la qualité de vie pour le patient et pour sa famille, durant le temps qu'il lui reste à vivre.

UK

WHO ?		Definition
The National Council for Palliative Care www.ncpc.org.uk/		DEFINITION supportive care + palliative care; according to NICE Palliative care is part of supportive care. It embraces many elements of supportive care. It has been defined by NICE as follows: Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. Palliative care aims to: • Affirm life and regard dying as a normal process • Provide relief from pain and other distressing symptoms • Integrate the psychological and spiritual aspects of patient care • Offer a support system to help patients live as actively as possible until death • Offer a support system to help the family cope during the patient's illness and in their own bereavement
National Council for Hospice and Specialist Palliative Care Services http://www.hospice-spc-council.org.uk		= same website as above
National Health Service http://www.nhs.uk/Pages/homepage.aspx		No specific definition on website, but: Palliative care is 'treatment of symptoms where cure is no longer considered an option'; in other words, the patient is dying. It focuses on controlling pain and other symptoms, improving quality of life for the patient and their family, and social, emotional and spiritual needs. Hospices, good medical and nursing care, company, therapy and counselling can all help terminally ill patients. It is argued that if the patient is comfortable, has company, and is not experiencing suffering or pain, they are less likely to consider the route of euthanasia. Links to other resources (electronic databases etc) Info on advance care planning: http://www.endoflifecare.nhs.uk/eolc
Department of Health http://www.dh.gov.uk/en/index.htm www.dh.gov.uk/en/Policyandguidance/H		Definition according/related to NICE Palliative care is holistic care by multi-professional teams for people, their families and carers whose illness may no longer be curable. It enables them to achieve the best possible quality of life during the final stages of their

ealthandsocialcaretopics/Cancer/DH_4001753		illness. The care may be provided in a number of settings; at home (with support from specially trained staff), in a hospice or palliative care unit, the hospital or at a hospice day centre. Services provided include family support and bereavement services. Palliative care was first developed in the UK by the voluntary hospice movement but is increasingly being provided within NHS hospitals and palliative care centres in the community. It is now a recognised and integral part of health service provision and the principles and practice of palliative care apply equally across all conditions and in all settings.
Great Britain “Hospice Information - Help the Hospices” http://www.hospiceinformation.info/		= same website as above
Department of Palliative Care and Policy St.Christopher's Hospice, London http://www.kcl.ac.uk/kis/schools/kcsmd/palliative/top.htm Hospice information Service St. Christopher Hospice http://www.hospiceinformation.info/		referral to WHO → 2 documents (definition and needs): * Palliative care: the solid facts (WHO Report) * Better palliative care for older people (WHO Report)
Sheffield Palliative Care Studies Group (SPCSG) - University of Sheffield http://www.sheffield-palliative.org.uk/		WHO definition 2002
HELP – helpful links to palliative care, UK http://www.dundee.ac.uk/meded/help/index.htm		Referral to MacMillan → definition: Palliative care focuses on controlling pain and other symptoms connected with cancer, and meeting your social, emotional and spiritual needs. You may come across a palliative care team at any stage of your cancer experience. Palliative care concentrates on your quality of life and that of people who are close to you. Palliative care should be offered to everyone who has cancer, but it is especially important for people whose cancer cannot be cured. Some people need specialist palliative care support, which may be provided by teams of health professionals working from hospitals or in the community. http://www.macmillan.org.uk/Get_Support/What_to_expect/The_medical_journey/Palliative_care.aspx
National Institute for Clinical Excellence http://www.nice.org.uk/nicemedia/pdf/csgpmanual.pdf		Palliative care is the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. Palliative care is based on a number of principles, and aims to: • provide relief from pain and other distressing symptoms • integrate the psychological and spiritual aspects of patient care • offer a support system to help patients to live as actively as possible until death and to help the family to cope during the patient's illness and in their own bereavement

		• be applied early in the course of illness in conjunction with other therapies intended to prolong life (such as chemotherapy or radiation therapy), including investigations to better understand and manage distressing clinical complications It is now widely recognised that palliative care has a crucial role in the care received by patients and carers throughout the course of the disease and should be delivered in conjunction with anticancer and other treatments. In the minds of patients, carers and some health and social care professionals, however, it tends to be associated with care for dying people. This has significant implications for acceptability and access. Although palliative care encompasses many of the elements identified as ‘supportive care’, there are well-defined areas of expertise within specialist palliative care to which patients and carers may need access, such as interventions to respond to: • unresolved symptoms and complex psychosocial issues for patients with advanced disease • complex end-of-life issues • complex bereavement issues. Importantly, both palliative and supportive care are often provided by patients’ family and other carers, and not exclusively by professionals.
--	--	---

The Netherlands

WHO ?		Definition
Netherlands Palliative Care Network for Terminally Ill Patients - http://www.palliatief.nl		WHO definition 2002
Nederlands Instituut voor onderzoek en gezondheidszorg - http://www.nivel.nl/		WHO definition 2002 In aansluiting bij de definitie van de World Health Organization uit 2002 verstaan we onder palliatieve zorg: een benadering die de kwaliteit van het leven verbetert van patiënten en hun naasten die te maken hebben met een levensbedreigende aandoening, door het voorkomen en verlichten van lijden, door middel van vroegtijdige signalering en zorgvuldige beoordeling en behandeling van pijn en andere problemen van lichamelijke, psychosociale en spirituele aard
Nederlandse Overheid - http://www.overheid.nl/		WHO definition 2002 De definitie van de WHO is ruim en kan ook toegepast worden op de zorgverlening aan chronisch zieken. Daarom wordt voor dit programma aan de definitie toegevoegd dat het gaat om de zorg rondom het levenseinde van patiënten die een levensverwachting hebben van maximaal drie tot zes maanden.
Netwerk Palliatieve Zorg - http://www.netwerkpalliatievezorg.nl/		Palliatieve zorg is de zorg in de laatste levensfase, als een levensbedreigende ziekte niet meer te genezen is. Deze zorg wordt ook wel terminale zorg of stervensbegeleiding genoemd, maar is veel breder. Het doel van palliatieve zorg is om een zo hoog mogelijke kwaliteit van leven voor patiënten en hun familie te realiseren. Palliatieve zorg is de zorg aan stervenden, aan mensen in de laatste fase van hun leven. Het richt zich niet meer op genezing van de ziekte, maar wel op het voorkomen of verlichten van klachten en ongemakken. Er is aandacht voor verschillende moeilijkheden in deze fase, zoals lichamelijke klachten, gevoelens van angst, verdriet en verwerking van de ziekte en allerlei praktische zaken. De aandacht gaat daarbij uit naar de patiënt en naar de naasten. In de palliatieve zorg wordt de patiënt ondersteund om zo actief mogelijk te kunnen leven en worden de naasten geholpen bij het omgaan met de patiënt en bij de rouwverwerking na het overlijden. De belangrijkste doelen zijn: * het verlichten van lichamelijk, psychosociaal en spiritueel lijden * het ondersteunen bij de afronding van het bestaan. Uitgangspunt zijn de klachten en vragen van de patiënt en naaste(n). De laatste fase van het leven wordt ook wel terminale fase genoemd.

France

WHO ?		Definition
Fédération JALMALV http://www.jalmalv.org		WHO definition 2002: L'Organisation mondiale de la santé définit les soins palliatifs comme des « soins actifs et complets donnés aux malades dont l'affection ne répond plus au traitement curatif. La lutte contre la douleur et les autres symptômes, ainsi que la prise en considération des problèmes psychologiques, sociaux et spirituels sont primordiaux. Ils ne hâtent ni ne retardent le décès. Leur but est de préserver la meilleure qualité de vie possible jusqu'à la mort.
Société Française d'Accompagnement et de Soins Palliatifs - http://www.sfap.org Le répertoire des soins palliatifs de la SFAP - http://www.sfap.org/content/view/38/76 http://www.sfap.org/component?option=com_w_rapper&Itemid,106/		La définition sur laquelle le ministère s'est accordé est la suivante, sur proposition de la SFAP : Les personnes relevant des soins palliatifs sont atteintes d'une pathologie grave, évolutive, mettant en jeu le pronostic vital en phase avancée ou terminale et quel que soit l'âge.
Union Nationale des Associations pour le développement des Soins Palliatifs - ASP (Association pour le développement des Soins Palliatifs) Les implantations des ASP en France http://www.aspfondatrice.org/gsn/map.asp		Les soins palliatifs sont des soins actifs dans une approche globale de la personne atteinte d'une maladie grave évolutive ou terminale : prendre en compte et viser à soulager les douleurs physiques ainsi que la souffrance psychologique, sociale et spirituelle devient alors primordial.
Haute Autorité Santé http://www.has-sante.fr/portail/display.jsp?id=j_5		La définition de la Haute Autorité (ANAES à l'époque) dans son rapport de Décembre 2002 : « Modalités de prise en charge de l'adulte nécessitant des soins palliatifs » est la suivante : « Les soins palliatifs sont des soins actifs, continus, évolutifs, coordonnés et pratiqués par une équipe pluriprofessionnelle. Ils ont pour objectif, dans une approche globale et individualisée, de prévenir ou de soulager les symptômes physiques, dont la douleur, mais aussi les autres symptômes, d'anticiper les risques de complications et de prendre en compte les besoins psychologiques, sociaux et spirituels, dans le respect de la dignité de la personne soignée. Les soins palliatifs cherchent à éviter les investigations et les traitements déraisonnables et se refusent à provoquer intentionnellement la mort. Selon cette approche, le patient est considéré comme un être vivant et la mort comme un processus naturel. Les soins palliatifs s'adressent aux personnes atteintes de maladies graves évolutives ou mettant en jeu le pronostic vital ou en phase avancée et terminale, ainsi qu'à leur famille et à leurs proches. Des bénévoles, formés à l'accompagnement et appartenant à des associations qui les sélectionnent peuvent compléter, avec l'accord du malade ou de ses proches, l'action des équipes soignantes ».
Ministère de la santé http://www.sante.gouv.fr/		WHO definition 2002 Une approche qui améliore la qualité de vie des patients et de leurs familles, lorsqu'ils sont confrontés aux problèmes inhérents à une maladie menaçant leur vie, grâce à la mise en place de mesures permettant la prévention, et, le soulagement des douleurs et des symptômes susceptibles d'apparaître en les identifiant précocement, les évaluant de façon méthodique et précise et en les faisant bénéficier des traitements adaptés aux douleurs ou autres symptômes physiques, psychosociaux et spirituels.

Germany

WHO ?		Definition
Deutsche Gesellschaft für Palliativmedizin http://www.dgpalliativmedizin.de		WHO definition 2002 Palliative Care ist ein „Ansatz zur Verbesserung der Lebensqualität von Patienten und ihren Familien, die mit Problemen konfrontiert sind, die mit einer lebensbedrohlichen Erkrankung einhergehen, und zwar durch Vorbeugen und Lindern von Leiden, durch frühzeitiges Erkennen, untadelige Einschätzung und Behandlung von Schmerzen sowie anderen belastenden Beschwerden körperlicher, psychosozialer und spiritueller Art“ (WHO 2002). Palliative Care ist der international übliche Fachausdruck. Als deutsche Übertragungen werden verwendet: Palliativmedizin, Palliativbetreuung oder Palliativversorgung. Die Begriffe Palliativpflege und Hospizarbeit beinhalten wichtige Teilaspekte von Palliative Care + other related definitions
Hospiz bewegung Deutschland http://www.hospiz.net/pal/was.html		WHO definition 2002: Nach der Definition der Weltgesundheitsorganisation (WHO) ist palliative Therapie die umfassende und aktive Behandlung von Patienten, deren Erkrankung einer kurativen Therapie nicht mehr zugänglich ist, und für die das Behandlungsziel die bestmögliche Lebensqualität für sie selbst und ihre Angehörigen ist. EACP definition: Die Definition der European Association for Palliative Care lautet ähnlich: Palliativmedizin ist die angemessene medizinische Versorgung von Patienten mit fortgeschrittenen und progredienten Erkrankungen, bei denen die Behandlung auf die Lebensqualität zentriert ist und die eine begrenzte Lebenserwartung haben. Palliativmedizin schließt die Berücksichtigung der Bedürfnisse der Familie vor und nach dem Tod des Patienten mit ein. Diese umfassende Betreuung der Patienten und deren Angehörigen erfordert ein multidisziplinäres Team, zu dem neben Pflegepersonal und Ärzten auch Sozialarbeiter, Psychologen, Seelsorger, Psychotherapeuten und Krankengymnasten gehören können. Die Palliativmedizin beschränkt sich dabei nicht auf die letzte Lebensphase. Viele Grundsätze der Palliativmedizin werden auch in frühen Krankheitsstadien zusammen mit der kausalen Therapie wirkungsvoll eingesetzt.
Bundesärztekammer (Arbeitsgemeinschaft der Deutschen Ärztekammern) http://www.bundesaerztekammer.de/downloads/kurspalliativ.pdf		WHO definition 2002

Sweden

WHO ?		Definition
Swedish Association for Palliative Care - http://www.sfpmp.org		WHO definition 2002 + EACP definition En specialistutbildad läkare, oavsett specialitet (Nivå B) som arbetar med palliativ vård, skall förstå och besluta i enlighet med WHO:s och EACP's definition av palliativ vård. Denne läkare ska utifrån en etisk plattform kunna arbeta i ett multidisciplinärt team och erbjuda basal palliativ vård till patienter med avancerad, progressiv och ej längre botbar sjukdom. Läkaren skall ha god kunskap/förståelse om: • kommunikation. • symtomkontrollens fyra dimensioner. • patienter och närståendes behov. • veta när man skall konsultera/remittera patienten till andra specialister inklusive specialisten i palliativ medicin. För den döende människan med komplexa symtom i livets slut samt för handledning, utbildning och forskning inom ämnesområdet bör en ny specialitet, palliativ medicin, tillskapas.
Swedish Council for Palliative Care - Nationella Rådet för Palliativ Vård http://www.nrpv.se		Definition av palliativ vård enligt WHO, 2002 Palliativ vård bygger på ett förhållningssätt som syftar till att förbättra livskvaliteten för patienter och familjer som drabbas av problem som kan uppstå vid livshotande sjukdom. Palliativ vård förebygger och lindrar lidande genom tidig upptäckt, noggrann analys och behandling av smärta och andra fysiska, psykosociala och existentiella problem. * Lindrar smärta och andra plågsamma symtom. * Bekräftar livet och betraktar döendet som en normal process. * Syftar inte till att påskynda eller fördröja döden. * Integrerar psykologiska och existentiella aspekter i patientens vård. * Erbjuder organiserat stöd till hjälp för patienter att leva så aktivt som möjligt fram till döden. * Erbjuder organiserat stöd till hjälp för familjen att hantera sin situation under patientens sjukdom och efter dödsfallet. * Tillämpar ett teambaserat förhållningssätt för att möta patienters och familjers behov samt tillhandahåller, om det behövs, även stödjande och rådgivande samtal. * Befrämjar livskvalitet och kan även påverka sjukdomens förlopp i positiv bemärkelse. * Är tillämpbar tidigt i sjukdomsskedet tillsammans med terapier som syftar till att förlänga livets såsom cytostatika och strålbehandling. Palliativ vård omfattar även sådana undersökningar som är övriga för att bättre förstå och ta hand om plågsamma symtom och komplikationer.

WHO ?		Definition
Société Suisse de Médecine et de Soins Palliatifs http://www.palliative.ch	Palliative.ch	La médecine et les soins palliatifs comprennent tous les traitements médicaux, les soins physiques, le soutien psychologique, social et spirituel, destinés aux malades souffrant d'une affection évolutive non guérissable. Son but est de soulager la souffrance, les symptômes et d'assurer le confort et la qualité de vie du malade et de ses proches. La pratique de la médecine et des soins palliatifs implique : a) le soulagement des symptômes majeurs ; b) la recherche des moyens les plus appropriés pour aider le malade et ses proches, et leur constante réévaluation ; c) l'intégration des aspects sociaux, psychologiques et spirituels dans les soins aux malades ; d) le soutien de l'entourage pendant la maladie du patient et après sa mort ; e) la prise en considération des aspects éthiques liés à la particularité de chaque situation ; f) le respect de la vie et de son terme naturel ; g) la mise en commun des compétences et des objectifs dans un esprit respectant l'interdisciplinarité ; h) une attention particulière portée au soutien, à la formation continue des soignants et à la prévention de l'épuisement professionnel.
AGMSP Association Genevoise de Médecine et de Soins Palliatifs http://www.agmsp.ch		Idem + WHO

NON - EUROPEAN COUNTRIES

Australia

WHO ?		Definition
Australian Government's Department of Health and Ageing. www.health.gov.au/palliativecare - http://www.health.gov.au/		Approved by the National Health and Medical Research Council: WHO definition 2002 + Definition of palliative approach A palliative approach aims to improve the quality of life for individuals with a life-limiting illness and their families, by reducing their suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social, and spiritual needs.[*] All these facets of a palliative approach are considered in their relevant chapters in this document; however, the reader should also consider cultural issues as integral to care provision, particularly when implementing any part of these guidelines. Underlying the philosophy of a palliative approach is a positive and open attitude towards death and dying. The promotion of a more open approach to discussions of death and dying between the aged care team, residents and their families facilitates identification of their wishes regarding end-of-life care. A palliative approach is not confined to the end stages of an illness. Instead, a palliative approach provides a focus on active comfort care and a positive approach to reducing an individual's symptoms and distress, which facilitates residents' and their families' understanding that they are being actively supported through this process. [* Kristjanson, L. J., Toye, C. T. & Dawson, S. (2003). New dimensions in palliative care: a palliative approach to neurodegenerative diseases and final illness in older people. <i>Medical Journal of Australia</i>, 179, (Suppl. 6), S42–44.] Definition aged people in nursing homes (developed by the Australian Palliative Residential Aged Care (APRAC) project team) : In considering palliative care for residents in RACFs, it is important to distinguish between a palliative approach, specialised palliative care service provision and end-of-life (terminal) care. The distinction among these forms of palliative care is important in care planning and clarifying the goals for treatment for residents. (see PDF) Link to CARESEARCH & PEPA Links to NEEDS programs and other relevant info: http://www.health.gov.au/internet/wcms/publishing.nsf/Content/palliativecare-publicat.htm http://www.health.gov.au/internet/wcms/publishing.nsf/Content/palliativecare-needs-assess-guide-l
A Program of Experience in the Palliative Approach http://www.pepaeducation.com/		WHO definition 2002 Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
Palliative Care Australia		WHO definition 2002

http://www.pallcare.org.au/		Standards for Providing Quality Palliative Care for all Australians: Palliative care is care provided for people of all ages who have a life limiting illness, with little or no prospect of cure, and for whom the treatment goal is quality of life.
---	--	---

Canada

WHO ?		Definition
Canadian Hospice Palliative Care Association http://www.chpca.net/ http://www.chpca.net/canadian_directory_of_services.htm		Palliative care is a special kind of health care for individuals and families who are living with a life-threatening illness that is usually at an advanced stage. The goal of palliative care is comfort and dignity for the person living with the illness as well as the best quality of life for both this person and his or her family. A "family" is whoever the person says his or her family is. It may include relatives, partners and friends. An important objective of palliative care is relief of pain and other symptoms. Palliative care is planned to meet not only physical needs but also the psychological, social, cultural, emotional and spiritual needs of each person and family. Palliative care may be the main focus of care when a cure for the illness is no longer possible. Palliative care services help people in later life who are ill to live out their remaining time in comfort and dignity. Palliative care services are helpful not only when a person is approaching death but also at earlier stages in the illness. Palliative care may be combined with treatments aimed at reducing or curing the illness, such as chemotherapy. Families also benefit from support when their loved one is dying and after his or her death. What is involved in palliative care? 1. Pain management - People living with life-threatening illness may experience pain. Families are concerned about pain and how to relieve it. Health care providers work with patients and their families to find out what is causing the pain and the best ways to relieve it. Pain may be managed with narcotics and other drugs and by other means such as massage therapy and relaxation exercises. 2. Symptom management - Often people have to deal with a variety of other symptoms. These can include loss of appetite, nausea, weakness, difficulty breathing, bowel and bladder problems and confusion. Palliative care can help relieve these symptoms that may be very distressing. 3. Social, psychological, emotional and spiritual support - The health of the whole person is important in palliative care. Because of this, palliative care services provide many different kinds of support to both the individual and family. 4. Caregiver support - People may be concerned about whether they will be able to look after their ill family member, especially when the person is being cared for at home. Palliative care services that help the family cope include: * advice and assistance from health care providers such as nurses and doctors who are skilled in providing palliative care. * instruction on how to care for the person. For example, how to give medication, how to

		prevent skin problems, how to recognize when the person is close to death and what to do at that time. * home support services that provide assistance with household tasks such as meal preparation, shopping and transportation. * relief for the caregiver. Sometimes a volunteer stays with the person so the family caregiver can go out. In other situations, the person who is ill may go to a day program or enter a hospital or long-term care facility for a short period of time. Hospice Palliative Care aims to relieve suffering and improve the quality of living and dying. Hospice Palliative Care is appropriate for any patient and/or family living with, or at risk of developing a life-threatening illness due to any diagnosis, with any prognosis, regardless of age and at any time that they have unmet expectations and/or needs, and are prepared to accept care. Hospice Palliative Care aims to address: - physical, psychological, social, spiritual and practical expectations and needs - loss, grief and bereavement - preparation for, and management of, self-determined life closure and the dying process It may complement and enhance disease-modifying therapy or it may become the total focus of care. It is most effectively delivered by an interdisciplinary team. The Pan-Canadian Gold Standard for Palliative Home Care: Palliative home care is provided by a number of different professionals, volunteers and family members who work together as a team to meet the client's physical, psychological, emotional, social, spiritual, practical, end-of-life care and grief needs as well as the family's needs. Team members collaborate to provide comprehensive, coordinated, compassionate care that can enhance the client's/patient's and family's quality of life throughout the advanced illness, the process of dying, the last days of living, the event of death, and bereavement.
Health Canada (Federal department) www.hc-sc.gc.ca/hcs-sss/palliat/index_e.html		Palliative care addresses the physical and psychological aspects of end of life. It involves: • Pain and other symptom management; • Social, psychological, cultural, emotional and spiritual support; • Caregiver support; and, • bereavement support. Whether palliative care is offered through a formal palliative care program or through a variety of other avenues, the focus of the care is on achieving comfort and respect for the person nearing death and maximizing quality of life for the patient, family and loved ones. Palliative care is appropriate for any patient at any stage of a life threatening illness, regardless of age. Palliative and end-of-life care touches all parts of the health care system, from hospital to hospice to community to home and usually involves an interdisciplinary team of caregivers that deal with the medical and psycho-social, spiritual and economic needs of the patient and the family.

USA

WHO ?		Definition
National Hospice and Palliative Care Organization http://www.nhpco.org/		Palliative care focuses on relieving suffering and achieving the best possible quality of life for patients and their family caregivers. It involves symptom assessment and treatment; aid with decision making and establishing goals of care; practical support for patients and their family caregivers; mobilization of community support and resources to assure a secure and safe living environment; and collaborative and seamless models of care (hospital, home, nursing homes, and hospice). It is offered simultaneously with life prolonging and curative therapies for persons living with serious, complex, and eventually terminal illness. Palliative care is a healthcare specialty that is both a philosophy of care and an organized, highly structured system for delivering care. Multiple studies have demonstrated that palliative care improves health care quality in three domains: the relief of physical and emotional suffering; improvement and strengthening of the process of patient-physician communication and decision-making; and assurance of coordinated continuity of care across multiple healthcare settings – hospital, home, hospice and long-term care.
American Academy of Hospice and Palliative Medicine http://www.aahpm.org/		The goal of palliative care is to prevent and relieve suffering, and to support the best possible quality of life for patients and their families, regardless of their stage of disease or the need for other therapies, in accordance with their values and preferences. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care. Palliative Care's Place in the Course of Illness Palliative care is operationalized through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs and culture(s). Evaluation and treatment should be comprehensive and patient-centered, with a focus on the central role of the family in decision-making. Palliative care affirms life by supporting the patient and family's goals for the future, including their hopes for cure or life prolongation, as well as their hopes for peace and dignity throughout the

		course of illness, including the dying process and death. Palliative care aims to guide and assist the patient and family in making decisions that enable them to work toward their goals during whatever time they have remaining.
The National Hospice and Palliative Care Organization - http://www.nhpco.org/i4a/pages/index.cfm?pageid=4646		NHPCO's Standards of Practice for Hospice Programs describes palliative care as: Treatment that enhances comfort and improves the quality of an individual's life during the last phase of life. No specific therapy is excluded from consideration. The test of palliative care lies in the agreement between the individual, physician(s), primary caregiver, and the hospice team that the expected outcome is relief from distressing symptoms, the easing of pain, and/or enhancing the quality of life. The decision to intervene with active palliative care is based on an ability to meet stated goals rather than affect the underlying disease. An individual's needs must continue to be assessed and all treatment options explored and evaluated in the context of the individual's values and symptoms. The individual's choices and decisions regarding care are paramount and must be followed.
Hospice Education Institute http://www.hospiceworld.org		WHO definition 2002 Palliative Care: • provides relief from pain and other distressing symptoms • affirms life and regards dying as a normal process • intends neither to hasten or postpone death • integrates the psychological and spiritual aspects of care • offers a support system to help patients live as actively as possible until death • offers a support system to help the family cope during the patient's illness and in their own bereavement • uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated • will enhance the quality of life, and may also positively influence the course of the illness • is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

International

WHO ?		Definition
International Association for Hospice and Palliative Care - http://www.hospicecare.com		WHO definition 2002 + IAHPC Manual: Palliative care is the care of patients with active, progressive, far-advanced disease, for whom the focus of care is the relief and prevention of suffering and the quality of life. The following should be noted - o active disease: this activity can be confirmed and measured objectively by clinical examination and investigations - o progressive disease: this too can be assessed clinically - o far-advanced disease: more difficult to define but examples are ▪ extensive metastatic disease in cancer ▪ refractory cardiac failure ▪ total dependency in neurodegenerative conditions or A - o focus on the quality of life is the key feature of the definition - o it is person-oriented, not disease-oriented - o it is not primarily concerned with life prolongation (nor with life shortening) - o it is not primarily concerned with producing long term disease remission - o it is holistic in approach and aims to address all the patient's problems, both physical and psychosocial - o it uses a multidisciplinary or interprofessional approach involving doctors, nurses and allied health personnel to cover all aspects of care - o it is dedicated to the quality of whatever life remains for the patient - o palliative care is appropriate for all patients with active, progressive, far-advanced disease and not just patients with cancer - o palliative care is appropriate for patients receiving continuing therapy for their underlying disease palliative care should never be withheld until such time that all treatment alternatives for the underlying disease have been exhausted. The message of palliative care is that whatever the disease, however advanced it is, whatever treatments have already been given, there is always something which can be done to improve the quality of the life remaining to the patient.

I.1.5 Synthesis of definitions from organisations

Table I: Definitions of palliative care in different countries: type of care, setting, main goal and target population

Country of origin	Source of the definition	characteristics of the definition													
		type of care			place					main goal			target population		
		Holistic / global	interdisciplinary	in conjunction with other therapies	Home	hospital	nursing homes	PCU	hospice	improve quality of life	hasten nor postpone death	dying as normal process	patients	family	community
International	WHO	X	X	X						X	X	X	X	X	
	EACP	X	X		X	X				X	X	X	X	X	X
	International Association for Hospice and Palliative Care	X	X	X						X	X	X	X	X	
Belgium	Federatie Palliative Zorg Vlaanderen	X	X	X						X	X	X	X	X	
	Fédération Wallonne des Soins Palliatifs	X	X		X	X	X	X	X	X					
	Fédération Bruxelloise Pluraliste de Soins Palliatifs et Continus	X	X							X					
	Rijksdienst voor Ziekte- en Invaliditeitsverzekering	X	X							X	X		X	X	
	Ministère des affaires sociales, de la santé publique et de l'environnement		X							X			X	X	
UK	The National Council for Palliative Care + National Council for Hospice and Specialist Palliative Care Services	X	X	X						X		X	X	X	
	National Health Service	X	X	X				X	X	X			X	X	
	Department of Health	X	X		X	X	X	X	X	X			X	X	X

[illegible]

Country of origin	Source of the definition	characteristics of the definition													
		type of care			place					main goal			target population		
		Holistic / global	interdisciplinary	in conjunction with other therapies	Home	hospital	nursing homes	PCU	hospice	improve quality of life	hasten nor postpone death	dying as normal process	patients	family	community
	Haute Autorité Santé	X	X	X ^a						X	X	X	X	X	X
	Ministère de la santé	X	X	X						X	X	X	X	X	
Germany	Hospiz bewegung Deutschland	X	X	X						X	X	X	X	X	
	Deutsche Gesellschaft für Palliativmedizin	X	X	X	X	X				X	X	X	X	X	X
	Bundesärztekammer (Arbeitsgemeinschaft der Deutschen Ärztekammern)	X	X	X						X	X	X	X	X	
Sweden	Swedish Association for Palliative Care	X	X	X	X	X				X	X	X	X	X	X
	Swedish Council for Palliative Care - Nationella Rådet för Palliativ Vård	X	X	X						X	X	X	X	X	
	National Board of Health and Welfare	X	X	X						X	X	X	X	X	
Switzerland	Société Suisse de Médecine et de Soins Palliatifs	X	X	X						X		X	X	X	X
	Association genevoise de médecine et de soins palliatifs	X	X	X						X	X	X	X	X	X
Australia	Australian Government's Department of Health and Ageing.	X	X	X						X	X	X	X	X	X

^a Excepted investigations and unreasonable treatments

Country of origin	Source of the definition	characteristics of the definition													
		type of care			place					main goal			target population		
		Holistic / global	interdisciplinary	in conjunction with other therapies	Home	hospital	nursing homes	PCU	hospice	improve quality of life	hasten nor postpone death	dying as normal process	patients	family	community
	A Program of Experience in the Palliative Approach (PEPA)	X	X	X						X	X	X	X	X	
	Palliative Care Australia	X	X	X						X	X	X	X	X	
Canada	Canadian Hospice Palliative Care Association	X	X	X	X	X		X	X	X	X		X	X	X
	Health Canada (Federal department)	X	X	X	X	X		X	X	X		X	X	X	X
USA	National Hospice and Palliative Care Organization		X	X	X	X	X	X	X	X			X	X	X
	American Academy of Hospice and Palliative Medicine	X		X						X			X	X	
	The National Hospice and Palliative Care Organization		X	X			X	X	X	X			X	X	
	Hospice Education Institute	X	X	X						X	X	X	X	X	

☐ Green = WHO 2002 definition

☐ Blue= EAPC definition

☐ purple= NICE definition

☐ yellow= WHO+EAPC definition

Table 2: Definitions of palliative care in different countries: diagnosis, start of palliative care, duration and means

Country of origin	Source of the definition	characteristics of the definition								
		Diagnosis		start		duration		means		
		specific disease	life threatening illness	course of illness	terminal phase	until death	bereavement after death	symptom control	control of other problems	bereavement
International	WHO		X	X		X	X	X	X	X
	EACP		X			X		X	X	
	International Association for Hospice and Palliative Care		X	X		X	X	X	X	X
Belgium	Federatie Palliative Zorg Vlaanderen		X	X		X	X	X	X	X
	Fédération Wallonne des Soins Palliatifs		X		X	X		X	X	
	Fédération Bruxelloise Pluraliste de Soins Palliatifs et Continus		X					X	X	
	National Institute for Health and Disability Insurance		X		X			X	X	
	Ministère des affaires sociales, de la santé publique et de l'environnement		X		X	X				
UK	The National Council for Palliative Care + National Council for Hospice and Specialist Palliative Care Services		X	X		X	X	X	X	X
	National Health Service		X		X			X	X	
	Department of Health		X		X					X
	HELP (MacMillan Organisation)	X (CANCER)						X	X	
	National Institute for Clinical Excellence		X	X		X	X	X	X	X
	Department of Palliative Care and Policy St Christopher's hospice, London		X	X		X	X	X	X	X
	Sheffield Palliative Care studies group		X	X		X	X	X	X	X
The Netherlands	Netherlands Palliative Care Network for Terminally Ill Patients		X	X		X	X	X	X	X
	Nederlands Instituut voor onderzoek en gezondheidszorg		X	X		X	X	X	X	X

Country of origin	Source of the definition	characteristics of the definition								
		Diagnosis		start		duration		means		
		specific disease	life threatening illness	course of illness	terminal phase	until death	bereavement after death	symptom control	control of other problems	bereavement
	Nederlandse Overheid		X	X	X	X	X	X	X	X
	Netwerk Palliatieve Zorg		X		X			X	X	X
France	Fédération JALMALV		X	X		X	X	X	X	X
	Société Française d'Accompagnement et de Soins Palliatifs - SFPA		X		X					
	Union nationale des associations pour le développement des Soins Palliatifs		X	X	X			X	X	
	Haute Autorité Santé		X	X	X			X	X	
	Ministère de la santé		X	X		X	X	X	X	X
Germany	Deutsche Gesellschaft für Palliativmedizin Hospiz bewegung Deutschland		X	X	X	X	X	X	X	
	Bundesärztekammer (Arbeitsgemeinschaft der Deutschen Ärztekammern)		X	X		X	X	X	X	X
Sweden	Swedish Association for Palliative Care		X	X		X	X	X	X	
	Swedish Council for Palliative Care - Nationella Rådet för Palliativ Vård		X	X		X	X	X	X	X
	National Board of Health and Welfare		X	X				X	X	
Switzerland	Société Suisse de Médecine et de Soins Palliatifs		X	X		x	x	x	x	x
	Association genevoise de médecine et de soins palliatifs		X	X		x	x	x	x	x
Australia	Australian Government's Department of Health and Ageing		X	X		x	x	x	x	x
	A Program of Experience in the Palliative Approach (PEPA)		X	X		x	x	x	x	x
	Palliative Care Australia		X	X		x	x	x	x	x

Country of origin	Source of the definition	characteristics of the definition								
		Diagnosis		start		duration		means		
		specific disease	life threatening illness	course of illness	terminal phase	until death	bereavement after death	symptom control	control of other problems	bereavement
Canada	Canadian Hospice Palliative Care Association		X	X	x	x	x	x	x	x
	Health Canada (Federal department)		X	X	x		x	x	x	x
USA	National Hospice and Palliative Care Organization		X					x	x	x
	American Academy of Hospice and Palliative Medicine		X	X	x	x		x	x	
	The National Hospice and Palliative Care Organization		X		x			x	x	
	Hospice Education Institute		X	X		x		x	x	x

1.2 LITERATURE SEARCH –DEFINITIONS

1.2.1 Search strategies

Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1950 to Present

#	Searches	Results
1	exp *Terminally Ill/	1989
2	exp *Hospice Care/	2325
3	exp *Palliative Care/	13797
4	exp *Critical Illness/	4592
5	*Attitude to Death/	5890
6	incurabl*.mp. [mp=title, original title, abstract, name of substance word, subject heading word]	3622
7	patient\$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]	3437277
8	6 and 7	2501
9	1 or 2 or 3 or 4 or 5 or 8	29340
10	defin\$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]	564768
11	9 and 10	1525
12	palliative.mp. [mp=title, original title, abstract, name of substance word, subject heading word]	41600
13	11 and 12	784
14	limit 13 to (yr="2002 - 2008" and (dutch or english or flemish or french) and humans and (classical article or clinical trial or controlled clinical trial or evaluation studies or government publications or guideline or journal article or meta analysis or multicenter study or practice guideline or randomized controlled trial or "review" or technical report or validation studies))	361

CINAHL - Cumulative Index to Nursing & Allied Health Literature 1982 to May Week 2 2008

#	Searches	Results
1	exp *Terminally Ill/	2772
2	exp *Hospice Care/	2773
3	exp *Palliative Care/	6122
4	exp *Critical Illness/	1214
5	*Attitude to Death/	1914
6	incurabl*.mp. [mp=title, subject heading word, abstract, instrumentation]	391
7	patient\$.mp. [mp=title, subject heading word, abstract, instrumentation]	397042
8	6 and 7	283
9	1 or 2 or 3 or 4 or 5 or 8	13470
10	defin\$.mp. [mp=title, subject heading word, abstract, instrumentation]	41429
11	9 and 10	505

12	palliative.mp. [mp=title, subject heading word, abstract, instrumentation]	12001
13	11 and 12	259
14	limit 13 to (yr="2002 - 2008" and (dutch or english or flemish or french) and humans and (classical article or clinical trial or controlled clinical trial or evaluation studies or government publications or guideline or journal article or meta analysis or multicenter study or practice guideline or randomized controlled trial or "review" or technical report or validation studies)) [Limit not valid in: CINAHL; records were retained]	176

PsycINFO 1806 to May Week 1 2008

#	Searches	Results
1	exp *Terminally Ill Patients/	2404
2	exp *hospice/	1220
3	exp *palliative care/	2962
4	exp *TERMINAL CANCER/	666
5	exp *"death and dying"/	12062
6	1 or 2 or 3 or 4 or 5	16666
7	incurabl\$.mp. [mp=title, abstract, heading word, table of contents, key concepts]	497
8	patient\$.mp. [mp=title, abstract, heading word, table of contents, key concepts]	376158
9	7 and 8	272
10	6 or 9	16851
11	defin\$.mp. [mp=title, abstract, heading word, table of contents, key concepts]	144901
12	10 and 11	922
13	palliative.mp. [mp=title, abstract, heading word, table of contents, key concepts]	4205
14	12 and 13	263
15	limit 14 to (human and (chapter or journal article or reprint or reviews) and (dutch or english or french) and human)	210
16	limit 15 to yr="2002 - 2008"	158

EMBASE.com

No.	Query	Results
#3.	'terminal disease'/exp	3,395
#4.	'palliative therapy'/exp/mj	10,132
#5.	'palliative nursing'/exp/mj	3
#6.	'hospice care'/exp/mj	630
#7.	'terminally ill patient'/exp/mj	1,211
#8.	'dying'/exp/mj	1,977
#9.	'critically ill patient'/exp/mj	391
#10.	#3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9	16,718
#11.	defin*	596,260
#12.	#10 AND #11	813
#13.	palliative	51,879
#14.	#12 AND #13	607
#15.	#12 AND #13 AND ([dutch]/lim OR [english]/lim OR [french]/lim)	203

AND [humans]/lim AND [embase]/lim AND [2002 - 2008]/py	
--	--

354 duplicates

→ 544 articles reviewed on base of title and abstract

50

→ 44 articles selected for further lecture

2 additional references

Definition for the survey

Medline

#	Search History	Results
1	exp Palliative Care/	15896
2	exp Patients/	21171
3	1 and 2	172
4	exp Data Collection/	621299
5	3 and 4	66
6	from 5 keep 3, 8, 12-14, 16, 20, 40...	13
7	palliative patient.mp.	19
8	survey.mp.	106332
9	7 and 8	0
10	3 and 8	14
11	from 10 keep 11-12, 14	3
12	identif\$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]	693756
13	3 and 12	28
14	from 13 keep 2, 6, 24-25	4

Embase

((('dying'/exp AND [embase]/lim AND [2002-2008]/py) OR ('terminally ill patient'/exp AND [embase]/lim AND [2002-2008]/py)) AND ((identif* AND [embase]/lim AND [2002-2008]/py) OR ('epidemiology'/exp AND [embase]/lim AND [2002-2008]/py))) AND (palliati* AND [embase]/lim AND [2002-2008]/py) 30 Jan 2008 303

2 références intéressantes

Econlit

« Palliati\$ » results 0 pertinents

Sociological abstract

palliati* and (identif* or census* or defin*)

126 results found in Multiple Databases

126 Sociological Abstracts

0 Recent References Related to the Social Sciences

172 results found in COS Scholar Universe: Social Science

0 results found in Web Resources Related to the Social Sciences/Humanities

Date Range: Earliest to 2008

I.2.2 Summary tables - Theoretical definitions selected in the indexed literature

WHO ?	Country	Definition
Ahmedzai et al, 2004 ¹		<i>We recommend that palliative care should be defined as follows:</i> • <i>Palliative care</i> is the person-centred attention to symptoms, psychological, social and existential distress in patients with limited prognosis, in order to optimise the quality of life of patients and their families or close friends. Based on this definition, we propose two further types of palliative care which reflect the reality of how palliative care is actually delivered: • <i>Basic palliative care</i> is the standard of palliative care which should be provided by all healthcare professionals, in primary or secondary care, within their normal duties to patients with life-limiting disease. • <i>Specialised palliative care</i> is a higher standard of palliative care provided at the expert level, by a trained multi-professional team, who must continually update their skills and knowledge, in order to manage persisting and more complex problems and to provide specialised educational and practical resources to other non-specialised members of the primary or secondary care teams. If a patient has difficult symptoms which cannot be controlled by his/her current healthcare team, he/she has a <i>right to be referred</i>, and the current healthcare provider has an <i>obligation to refer</i>, to the local palliative care team. Important priorities to ensure the standardisation of, and uniform access to, palliative care for all cancer patients include: • Integration of palliative care services with the primary care and oncology teams. • Establishment of a specialised palliative care service in each major cancer centre. • Establishment of educational programmes covering palliative care for undergraduates, oncologists, primary care team members and specialists training in palliative care. • Support for research using appropriate methodologies to underpin the scientific basis of palliative care. • Establishment of quality assurance programmes. • Recognition of palliative medicine as a medical specialty. • Establishment of academic centres of excellence with chairs of palliative medicine and palliative care nursing. • Removal of unnecessary restrictions on all drugs which are proven to be of benefit in symptom control, especially improving access to strong opioids. • Improved information for patients and family carers to allow them to make choices and exercise autonomy.
Hanratty et al, 2006 ²	UK	Palliative care refers to a 'mode', concept', 'situation' that is an ideal and a holistic approach (patient, family) including psychosocial issues and spiritual aspects as well as communication. Goals change and death is recognized.
Mathew et al ³	UK	Palliative care approach 'The palliative approach to care aims to promote both physical and psychological well-being and should be an 'integral part of all clinical practice' (NHS) Palliative interventions are Non curative treatments such as palliative radiotherapy or chemotherapy, anaesthetic interventions or surgical procedures aimed at improving quality of life. (NCHSPCS) Palliative care services encompass O A broad range of services in both community and inpatient settings.

^b Ahmedzai et al¹, 2004 pp 2192-93

		0 Funded and/or organized through either voluntary or statutory sources. 0 Multiprofessional or uniprofessional services. 0 Specialist training in palliative care and or wide experience in the area. (NCHSPCS) Specialist palliative care is provided 0 Where an individual has progressive, advanced disease with a limited prognosis. 0 Where individuals have complex or acute needs and require the care of a multiprofessional team with a broad mix of skills such as medical, nursing, social, pastoral or therapy services. (NCHSPCS) Specialist palliative care services are 'those services which have specialist palliative care as their core speciality and provide services directly to patients or indirectly through advice to a patient's existing professional carers'. (NCHSPCS) Terminal care is Is viewed as an important part of palliative care. Normally it refers to the care of an individual in the last few days, weeks or months of life.
Van Kleffens et al ⁴	The Netherlands	Palliative Care (referring to WHO) Care directed to: 1. Persons with noncurable life threatening disease 2. (Relief of) symptoms 3. Quality of life, recognized by patients 4. Neither hastening nor postponing death Palliative Treatments in Clinical Oncology Treatments directed to: 1. Incurable patients (in all stages of the disease) 2. Tumour and symptoms 3. Quality of life, not always recognized by patients 4. Life-prolonging
Zwerdling et al ⁵	USA	Fundamental concepts of palliative care include a theme of prevention that is often under-emphasized. Best palliative care anticipates complicated or ineffective grief and bereavement, addresses grief and loss prior to death, and, through formal programs, identifies individuals at high-risk and intervenes earlier to prevent or minimize complications.

I.2.3 Synthesis of the theoretical definitions selected in the indexed literature

Table 3: Characteristics of the specific definitions of palliative care/patient found in the medical literature: diagnosis, start of palliative care, duration and means used

Country of origin	Source of the definition	characteristics of the definition													
		type of care			Place					main goal			target population		
		Holistic / global	interdisciplinary	in conjunction with other therapies	home	hospital	nursing homes	PCU	Hospice	improve quality of life	hasten nor postpone death	dying as normal process	patients	family	community
The Netherlands	Van Kleffens et al, 2004 ⁴									x ^d	(x) ^e		x		
UK	Ahmedzai et al, 2004 ¹	x	x	X	x	x	x	x	X	x			x	x	x
	Hanratty et al, 2006 ²	x	x										x	x	
	Mathew et al ³	x	x	X	x	x	x	x	X	x					
USA	Zwerdling et al, 2005 ⁵														

^d not always recognized by patients in case of cancer

^e in case of cancer, the treatment could aim at life-prolonging

Table 4: Characteristics of the specific definitions of palliative care/patient found in the medical literature: type of care, setting, mains goals and target population

Country of origin	Source of the definition	characteristics of the definition								
		diagnosis		start		Duration		means		
		specific disease	life threatening illness	course of illness	terminal phase	until death	bereavement after death	symptom control	control of other problems	bereavement
The Netherlands	Van Kleffens et al, 2004 ⁴		x	x ^f				x	x ^g	
UK	Mathew et al ³		x	x	x			x	x	
	Hanratty et al, 2006 ²									
	Ahmedzai et al, 2004 ¹	X (cancer)	x	x	x		X	x	x	x
USA	Zwerdling et al, 2005 ⁵						X			

f for cancer patients
g tumour

I.2.4 Summary tables - Definitions used in surveys

Author, date	Country	Design / type of study	Setting	Population	Definition	Comments
Aabom et al, 2005 ⁶	Denmark	Retrospective cohort study		3445 patients died as a result of cancer	The “ <u>terminal declaration</u> ” is a document that gives right to economic benefits and increased care for the dying when there is a prognosis of death within 6 months: increased reimbursement for medicine and to entitle an informal carer full time or part-time paid leave. This declaration could be used as a proxy for formal terminal diagnosis. Bias of such proxy are discussed in the article	Useful for the definition of patient having right to financial support Useful for research definition
Addington-Hall, 2002 ⁷	UK	Methodological and ethical reflection		Terminally ill cancer patients	<u>Terminally ill patients</u> : patients who are in the last days, weeks or months of life, who may still be receiving radiotherapy or chemotherapy to control their symptoms but for whom it is reasonably clear that death will occur in the not too distant future	Useful for the operational definition + ethical reflection
Ahmedzai et al, 2004 ¹	UK	Position paper		Cancer patients	Definition of <u>palliative care</u> refined from the WHO 2002 definition. Distinction of the level of care: <u>basic palliative care</u> and <u>specialized palliative care</u> based on ESO distinction. Specific definition for <u>end-of life care</u> : when curative or life-prolonging treatments are decided to be not pursued	Useful for theoretical definition
Auret et al, 2003 ⁸	Australia	Cross-sectional study: questionnaires on 3 case-histories	Congress	51 haematologists	<u>Referral time for palliative care</u> : 80% for symptom control, 20% in the terminal phase. Problem: prognostication difficulties specific to non solid tumours. Variation on the identification of <u>terminal illness</u> : for myeloma=at diagnosis but for others, at the final stage of life.	Useful for discussion on identification of patients on prognosis basis Reference to Christakis and Lamont: referral the 3 last months – USA 6 month for hospice care

Author, date	Country	Design / type of study	Setting	Population	Definition	Comments
Baka et al, 2004 ⁹	UK			Small cell lung cancer patients	<u>Palliative treatment</u> aims to control symptoms, improve QoL and increase duration of survival. Balance between minimizing toxicity of treatment and maximizing clinical response. Utilization of prognostic factors to identify group of poor-prognosis patient candidate for palliative interventions: - tumor stage - performance status - serum sodium - alkaline phosphatase - serum lactate dehydrogenase → >4 = prognosis < 1 year	Identification of poor-prognosis cancer patients
Billings et al, 2002 ¹⁰	USA	Prospective survey (1 month follow up)	1 hospital	Medical and surgical beds	<u>Terminally ill patients</u>: patients whom case managers believed were likely to die in the next 6 months (Category A) or whom might be considered terminally ill but with a longer prognosis (Category B) This method use common senses or clinical by case managers criteria	Useful to discuss identification of <u>dying</u> patients in the survey and for operational definition
Borgsteede et al, 2006 ¹¹	The Netherlands	Prospective data collection 1 year registration	Dutch national survey of general practice	Identification of palliative patients among patients who died at least 3 months after the start of the study : 96 GP = 2194/375 899 patients	<u>Palliative patient</u> if 1 out of the 3 criteria: (1) No treatment directed at cure or life prolongation received (2) palliative care provided (3) No sudden or unexpected death	Useful for operational definition

Author, date	Country	Design / type of study	Setting	Population	Definition	Comments
Bouté et al, 1999 ¹²	France	Cross-sectional instant descriptive survey	All short-stay (private and public) institutions	Short-stay patients	<u>Patients eligible for palliative care:</u> - serious pathology - evolutive pathology - non acute pathology + <u>terminal stage:</u> max 3 months prognostic <u>3 categories of palliative care</u> based on prognostic and treatment: - active palliative care (with curative treatment) - symptomatic palliative care - terminal care with less than 3 month whatever the treatment	Useful to discuss identification of palliative patients in the survey and for operational definition
Casarett et al, 2004 ¹³	USA	Cross-sectional survey	Community-based hospice programs	Patients and their family	Possibility to screen patient at entrance to know if they are ready to participate in research	No info on definition – methodological article on recruitment
Casarett, 2005 ¹⁴	USA	Ethical discussion		End-of-life	Ethical discussion on research on end-of-life patients	Not useful for definitions
Christakis et al, 2000 ¹⁵	USA	Prospective cohort study	Outpatient hospice programmes in Chicago	468 terminally ill patients admitted to 5 outpatient hospice programmes	20% of prognoses were accurate: most were overestimated – less correct prediction in non-oncological medical subspecialties Cancer patients are overoptimistically estimated	In comments associated – allusion to 2 indices of prognosis (Morita's palliative prognosis Index and Maltoni palliative prognostic score)
Claxton-Oldfield et al, 2004 ¹⁶	Canada	2 surveys	General population – no precision on recruitment	Adults	WHO definition of <u>palliative care</u> Understanding of the term palliative care in general population	Poor methodological paper – utilisation of the WHO definition – not interesting
Currow et al, 2003 ¹⁷	Australia	Planning guide			Composition of the palliative care team: patient, caregivers (family and friends) primary health professionals	No definition, no added value for our objectives

Author, date	Country	Design / type of study	Setting	Population	Definition	Comments
Dinat et al, 2000 ¹⁸	South Africa			Adults with HIV/AIDS	Palliative care: WHO 2002 definition. Discussion on specific aspects of palliative care for HIV/AIDS patients	WHO definition – no added value
Edmonds et al, 2000 ¹⁹	UK	Cross-sectional epidemiological study (3 days) based on case-notes	Hospital	Patient in needs of palliative care	<u>Advanced disease</u> : disease that is no longer amenable to curative treatment, where the aim of any therapeutic intervention is to prove quality of life <u>Criteria</u> : prognosis < 3 months – patients receiving maximal medical therapy – symptoms from disease severely limiting activity and/or needing help with personal care – evidence of recent clinical deterioration	Definition and criteria used for research
El Osta, 2008 ²⁰	USA	Retrospective study	One comprehensive cancer center	Cancer patients who had palliative consultation and have died during a 30 month period	Median time between first consultation and death=42 days. This time has decreased over time	Study in only 1 centre – no definition used – specific population – not interesting
Farquhar et al, 2002 ²¹	UK	Longitudinal study	One district general hospital	241 Patients with a palliative diagnosis of lung or colorectal cancer	<u>Palliative patients</u> : eligible via their outpatient letter or discharge summary if there is an explicit reference to the need of for palliation in the hospital notes or status obvious in the notes Discrepancy: GP appear to show a greater reluctance to define patient as palliative than hospital doctors but it could be because they accede to different datasets on the information on the patient and basic knowledge Maybe a difference between 'palliative' and 'palliative care'	Definition not very accurate 'patient for palliative care' Useful for the discussion on operational definition

Author, date	Country	Design / type of study	Setting	Population	Definition	Comments
Fox et al, 1999 ²²	USA	Validation study	5 US medical Centre	2607 seriously ill patients with chronic obstructive pulmonary disease, congestive heart failure end-stage liver diseases who survive to hospital discharge	Prognosis with 5 general and 2 disease-specific criteria for identifying patients with a prognosis ≤ 6 months and 3 sets of combination based on NHO guidelines. Recommended clinical prediction criteria are not effective in identifying a population with a survival prognosis ≤ 6 months	Discussion on prognosis accuracy for operational definitions
Gillick, 2005 ²³	USA	Editorial			<u>Palliative care</u>: based on the national Consensus project for Palliative Care: interdisciplinary team + focus on psychological issues, spiritual matters and medical decision-making + it can be delivered concurrently with life prolonging care → false dichotomy curative VS palliative, comfort oriented VS cure oriented: → < cancer – not adequate for the majority of chronic diseases where there is no cure. → change of the priorities of the patient in terms of goals of care during the progression of the illness. The role of the physician is to help patients figure out how they prioritize their goals and after that to develop an plan of care to implement those goals. → dichotomy derives from the oncology models → complementarities arose from the desire to distinguish hospice care from palliative medicine → dichotomy reflect a cultural construct: medicine aim to eradicate the disease, palliation aims to ameliorate suffering that arise on the path to cure, coming from the disease or the cure	Palliative and curative care could be concurrent Editorial but useful for theoretical discussion + definition of the CAPC
Glazer et al, 2006 ²⁴	USA	Preface			<u>Paediatric palliative medicine</u> : based on the 1990 WHO definition	Opinion article - No added value

Author, date	Country	Design / type of study	Setting	Population	Definition	Comments
Gott et al, 2001 ²⁵	UK	Prospective prevalence study (5 days) – identification by nurse + medical staff	Hospital	Patients in need of palliative care and suitable for referral to specialized palliative care beds	<u>Patients in needs of palliative care</u>:, need of a combination of active and compassionate therapies intended to comfort and support individuals and families who are living with or dying from a progressive life-threatening illness, or are bereaved. <u>Terminally ill patients</u>: prognostic < 3 months Suitability for specialised palliative care bed estimated by nursing + medical staff Little concurrence between nurses and doctors on identification of patients in need of palliative care (kappa=0.42) and for referral (kappa=0.35) – increased with proximity of death Reason for referral are listed in a table	Definitions used for research
Haddad et al, 2003 ²⁶	Canada	Prospective study 4 week follow-up	Outpatient clinic	Outpatients with brain metastases followed up by telephone or at the clinic	Quality and completeness of data were similar in both groups followed up: by phone or at the clinic. These could be complementary	Useful for methodology: design of the study but no information on the definition(s)
Hanratty et al, 2006 ²	UK	Qualitative study		7 focus groups: Doctors in GP, palliative medicine, cardiology, geriatrics and general medicine Interviews about patients dying with heart failure	<u>Palliative care</u> refers to a ‘mode’, concept’, ‘situation’ that is an ideal and an holistic approach (patient, family) including psychosocial issues and spiritual aspects as well as communication. Goals change and death is recognized. Challenge: identify the right time to switch to palliative care Palliative care are considered not to be very medical and largely nursing-ased in the terminal phase – they are time consuming GP and geriatricans seem to be more receptive to the concepts of palliative care than cardiologists and physicians	Theoretical definition based on perceptions of doctors on palliative care

Author, date	Country	Design / type of study	Setting	Population	Definition	Comments
Higginson et al, 2002 ²⁷	UK	Prospective cohort study	4 multi-professional palliative care teams	n=275 consecutive cancer referral	Comparison of <u>prognostic at referral (minimum – maximum)</u> with actual survival: 42% accurate, 36% over optimistic, 22% over pessimistic	Discussion on prognosis accuracy for operational definitions
Jaulin et al, 2006 ²⁸	France	Cross-sectional instant prevalence survey	Hospitals from the region Provence-Alpes-Côte d'Azur	Inpatients in medicine, surgery, gynaecology, reanimation middle and long-term care.	<u>Patients are susceptible to be admitted in the Palliative Care unit</u> are those : - being in a advanced stage (evolution radically unfavourable) of a disease - with a prognosis less than 3 months - for who staying at home is not (anymore) feasible (because they need a hospital treatment, familial difficulties or exhaustion,, lack of psychosocial support or isolation of the patient)	Useful to discuss identification of palliative patients in the survey and for operational definition
Kim, 2005 ²⁹ updated by Desai et al, 2007 ³⁰	USA			Cancer patients	Definition of <u>palliative care</u> = WHO 2002 + definitions of <u>palliative medicine, palliative chemotherapy, palliative rehabilitation, palliative radiation therapy, palliative surgery, interventional palliative procedures</u>	= Some 'practical modalities' of palliative care
Kuebler et al, 2005 ³¹	USA	Review			<u>Palliative care is not</u> characterized by the explanation of a specific disease state or therapeutic intervention but = distinction in the identification and management of the symptoms associated with an underlying disease for which ether is no cure. → aim to change how the patient aims lives the disease until death and to live better with it. It drives the practice of end-of-life care and is not reserved for the last weeks, days and hours of life	For theoretical definition. Also difference between supportive care / end-of-life care and palliative care

Author, date	Country	Design / type of study	Setting	Population	Definition	Comments
Lamers, 2002 ³²	USA	Commentary			Definitions of <u>hospice</u> – <u>palliative care</u> and palliative medicine	Commentary focusing on the pejorative view on hospice care and the confusion in the use of hospice care and palliative care – the 1 st being a sub part of the 2 nd one.
Lamers, 2007 ³³	USA	Queries/responses			Confusion between <u>hospice care</u> and <u>palliative care</u>	Opinion article - No added value
Lorenz et al, 2004 ³⁴	USA	Review		End-of-life	<u>Definition of 'end-of-life'</u>: 3 basic concepts: (1) death is imminent=active dying (2) patient eligible for hospice care, i.e. prognosis of less than 6 months + treatment focused upon palliative efforts (3) when the person is seriously afflicted with an eventually fatal condition <u>different approach to define end-of-life</u>: - patient 'readiness' : prognosis + giving up effort at curative = end-of-life BUT see paper - by severity of illness 'is this patient sick enough that is would not be a surprise if he or she die within 6 months (or 3 or 12 months)?'but performance??? - by prognosis: multiviable model as well as clinical judgment are not accurate.	Useful for the discussion on the operational definitions, mainly about prognosis
Martin, 2006 ³⁵	USA	Review			<u>Palliative care</u> : Utilisation of the 2002 WHO definition	Poor quality – review but no methodology and only a few references- no added value
Mathew et al, 2003 ³	UK	Review of policy documents Snowball sampling	Sectors of specialized palliative care, social services and primary care		Definitions of <u>palliative care</u> used from 1987 to 2000: Many references to the WHO definition + extension with developing the term 'palliative approach to care' (1996) that can be practise in all disciplines regardless of whether or not death is expected. 1987 terminal care= death expected within 12 months then evolution	Definitions in the table

Author, date	Country	Design / type of study	Setting	Population	Definition	Comments
Meier, 2006 ³⁶	USA	Clinical guideline			Definition of <u>palliative care</u> and domains in the new guideline of the National Consensus Project for Quality Palliative Care	Definition of the NHPCO (see in the table of definitions)
Milicevic, 2002 ³⁷	UK	Historical review	Hospice		WHO definition of palliative care + description of the UK system and the situation in other countries	WHO definition No added value
Morize et al, 2002 ³⁸	France	Cross-sectional instant descriptive survey	I hospital	454 inpatients in 31 departments hospitalised patients in advanced or terminal phase of a life-threatening disease	17% of the patients are identified as being in an advanced or terminal stage of a severe, progressive and life-threatening disease Utilisation of the definition of the <u>patients requiring palliative care</u> from the SFAP Kappa coefficient= 0.86 (CI 95%:0.80-0.92) in the terminal care support team (TCST) (nurse / physician) and 0.63,0.65 and 0.70 between TCST and the physician, the nurse and consensus respectively (CI 95%: 0.62-0.79) → the SFAP definition can be used by providers to identify patients who might require the support of the TCST	Useful to discuss identification of palliative patients in the survey and for operational definition Remark: this survey was repeated in 2004 using the same definition ³⁹
Nguyen et al, 2001 ⁴⁰	France	Cross-sectional epidemiological study (one given day)	Hospital	Patients in need of palliative care	<u>Patients in need of palliative care</u> : with an serious progressive life-threatening illness in advance or terminal stage. It is assessed by a physician and a nurse.	Useful for the definition for research
Payne et al, 2002 ⁴¹	UK	Qualitative study semi-structured interviews	Area of the Marie Curie Cancer Care	Providers and commissioners from statutory and voluntary health and social care services	Lack of consensus on definitions of <u>palliative care</u> : - Definitions based on WHO definition - Recognition of the importance of physical, social, psychological and spiritual aspects of the care 2 conceptual categories: - the remit of services (purpose and clientele) - the disease trajectory Belief that palliative care and terminal care are synonymous.	Useful to discuss identification of palliative patients in the survey

Author, date	Country	Design / type of study	Setting	Population	Definition	Comments
Steinhauser et al, 2006 ⁴²	USA	Longitudinal study		Seriously-ill patients and their caregiver	<u>Seriously-ill patients</u> : patients with chronic life-limiting illness. For the study patients with on average 50% 1-year survival. Identification of stage IV cancer, stage IIIb lung cancer, NYHA stage III or IV congestive heart failure (LVEF <40%), COPD with hypercapnea (pCO ₂ >46) + 1 ER visit or hospitalisation within the previous year. Identification through registry or hospital databases	Useful for definition for research. Methodological paper. Discussion on barriers for recruiting patients on clinical judgment of the GP or the physician
Todd et al, 2006 ⁴³	Hawaii	Review			WHO 2006 definition of <u>palliative care</u> Focus on the importance of culture → need to increase cultural competence in palliative care	For the theoretical definition, inclusion of the cultural dimension
Van Kleffens et al, 2004 ⁴	The Netherlands	Qualitative study In-depth interviews		30 cancer patients that have life expectancy of more than 3 months and have refused a recommended oncological treatment and 16 physicians	Difference between WHO definition of <u>palliative care</u> and 'palliative oncological treatment'	Definitions in the table
Vejlgaard et al, 2005 ⁴⁴	Denmark	Cross-sectional survey mailed, self-administrated questionnaire on attitude to palliative care		347 respondents: Nurses and doctors hospital and primary care in one Danish county with no palliative beds	WHO definition of <u>palliative care</u> + ' <u>terminal</u> '= less than 1 year	Useful for operational definition
Villard et al, 2003 ⁴⁵	France	Cross-sectional prevalence instant survey by questionnaire (administered by a physician and a nurse)	1 hospital	Hospitalised patients in advanced or terminal phase of a life-threatening disease	Inclusion of patients 'with a serious life-threatening disease in an advanced or terminal stage' – definitions of curative, palliative and terminal stages were foreseen at medical responsible (but not detailed in the article)	Useful to discuss identification of palliative patients in the survey but lack of the criteria and the definitions used

Author, date	Country	Design / type of study	Setting	Population	Definition	Comments
Widder et al, 2002 ⁴⁶	Austria	Scientific contribution			Palliative treatment versus symptomatic treatment of a disease Palliative intention versus curative intention Objectives of palliative treatment: symptoms, self-image (bodily dimension, symbolic dimension, social dimension) and proximity of death	Several elements for the theoretical definition of palliative care but restricted to the context of disease treatment
Zwerdling et al, 2005 ⁵	USA	Brief report			<u>Palliative care</u>: Includes prevention: There is an opportunity for palliative care and hospice programs to take advantage of the relationship between patient, family and caregiver to make prevention by the way of at risk family, genetic counselling or educational programs.	Definition in the table

2 APPENDIX PART TWO: LITERATURE - NEEDS

2.1 PART NEEDS - SEARCH TERMS AND KEYWORDS

Different methodological terms as Mesh terms, Emtree terms (Embase) or Major Index terms (PsycInfo), were combined with the different parts of the research question (ECLIPS). To explore the different databases (MedLine, PsychInfo, Cihnaht and British Nursing Index) we used the CEBAM portal. Here, mesh terms were used in OVID, besides free text searches. Searching PsycInfo we used similar Major Index terms. The resulting database of publications was build up, based on a primarily search oriented towards only two parts of the research question: expectations (needs) and client groups (patients). The others parts of the research questions were searched within this main database.

The search used next methodological terms:

Expectations: ability to benefit from health care.

Mesh terms:

- “Needs Assessment”: Systematic identification of a population's needs or the assessment of individuals to determine the proper level of services needed. Year introduced: 1999.
- “Health Services Needs and Demands”: Health services required by a population or community as well as the health services that the population or community is able and willing to pay for. Year introduced: 1991 (Aug 1977).

Emtree terms:

- “Needs assessment”
- “Health care need”

Free text terms:

Here we also searched for “patient*” within 2 words from “need*”, “patient*” within 2 words from “require*”, “patient*” within 2 words from “demand*”, and “patient*” within 2 words from “necess*” as free text in title and abstract.

Client group: people in palliative care, “end-of-life”

Mesh terms:

- “Palliative Care”: Care alleviating symptoms without curing the underlying disease. (Stedman, 25th ed). Year introduced: 1996.
- “Terminal Care”: Medical and nursing care of patients in the terminal stage of an illness. Year introduced: 1968(1964). (Includes “Hospice care”, “euthanasia”,)

Emtree terms

- “terminal ill patient”
- “palliative therapy”
- “dying”

Free text terms

combination of “patient” AND “incurabl*”

2.2 PART NEEDS - DETAILED SEARCH STRATEGIES

The different methodological terms (Mesh or Emtree) were combined resulting in next summarizing search tables:

Medline + Medline daily update + oldMedline Searches		1950 to present	Display
	Term		
1	exp *Terminally Ill/		1.933
2	exp *Palliative Care/		13.633
3	incurabl\$.mp.		3.543
4	patient\$.mp.		3.371.471
5	3 and 4		2.424
6	exp Needs Assessment/		14.613
7	exp "Health Services Needs and Demand"/		32.229
8	(patient\$ adj2 need\$).mp.		20.663
9	(patient\$ adj2 requir\$).mp.		44.988
10	(patient\$ adj2 demand\$).mp.		1.715
11	(patient\$ adj2 necess\$).mp.		3.629
23	exp *Hospices/		2.791
13	1 or 2 or 5 or 12		19.926
14	6 or 7 or 8 or 9 or 10 or 11		114.600
15	exp Critical Illness/		8.500
16	Chronic Disease/		176.843
17	15 and 16		174
18	13 or 17		20.097
19	13 and 14		1.178
20	14 and 18		1.194
21	limit 20 to (abstracts and humans and yr="1998 - 2008" and (dutch or english or flemish or french))		716

term = Mesh terms - display = number of hits

**CINAHL - Cumulative Index to Nursing & Allied Health Literature
1982 – 2008 (week 2)**

Searches		Display
	Term	
1	exp *Terminally Ill/	2.725
2	exp *Palliative Care/	6.012
3	incurabl\$.mp.	385
4	patient\$.mp.	386.822
5	3 and 4	277
6	exp Needs Assessment/	4.935
7	exp "Health Services Needs and Demand"/	5.977
8	(patient\$ adj2 need\$).mp.	9.060
9	(patient\$ adj2 requir\$).mp.	4.667
10	(patient\$ adj2 demand\$).mp.	1.542
11	(patient\$ adj2 necess\$).mp.	311
23	exp *Hospices/	635
13	1 or 2 or 5 or 12	9.006
14	6 or 7 or 8 or 9 or 10 or 11	22.368
15	exp Critical Illness/	1.729
16	Chronic Disease/	14.029
17	15 and 16	43
18	13 or 17	9.047
19	13 and 14	461
20	14 and 18	468
21	limit 20 to (abstracts and humans and yr="1998 - 2008" and (dutch or english or flemish or french))	303

term = Mesh terms - display = number of hits

British Nursing Index and Archive 1985 – 2008 (March)

Searches		Display
	Term	
1	exp *Terminally Ill/	0
2	exp *Palliative Care/	0
3	incurabl\$.mp.	34
4	patient\$.mp.	50.247
5	3 and 4	17
6	exp Needs Assessment/	3.985
7	exp "Health Services Needs and Demand"/	0
8	(patient\$ adj2 need\$).mp.	690
9	(patient\$ adj2 requir\$).mp.	129
10	(patient\$ adj2 demand\$).mp.	26
11	(patient\$ adj2 necess\$).mp.	7
23	exp *Hospices/	0
13	1 or 2 or 5 or 12	17
14	6 or 7 or 8 or 9 or 10 or 11	4.764
15	exp Critical Illness/	0
16	Chronic Disease/	22
17	15 and 16	0
18	13 or 17	17
19	13 and 14	2
20	14 and 18	2
21	limit 20 to (abstracts and humans and yr="1998 - 2008" and (dutch or english or flemish or french))	2

term = Mesh terms - display = number of hits

PsychInfo 1985 – 2008 (March)		
Searches	Term	Display
1	explode “Terminally-Ill-Patients” in MJ,MN	3159
2	explode “Terminal-Cancer” in MJ,MN	788
3	explode “Palliative-Care” in MJ,MN	3259
4	1 or 2 or 3	5948
5	explode “Critical-Period” in MJ,MN	221
6	explode “Chronic-Illness” in MJ,MN	12404
7	5 and 6	0
8	critical illness	97
9	(critical illness) and (explode “Chronic-Illness” in MJ,MN)	7
10	incurabl*	495
11	patient*	373055
12	10 and 11	271
13	4 or 7 or 9 or 12	6135
14	explode “Needs-Assessment” in MJ,MN	2419
15	explode “Health-Service-Needs” in MJ,MN	2320
16	explode “Needs-“ in MJ,MN	8564
17	explode “Psychological-Needs” in MJ,MN	787
18	explode “Special-Needs” in MJ,MN	1721
19	((patient* need*) in KC)or((patient* need*) in AB)or((patient* need*) in TI)	1828
20	14 OR 15 OR 16 OR 17 OR 18	12295
21	19 OR 20	13933
22	12 AND 21	186
23	Limit 22 to (PO:PSYI = HUMAN) and (PY:PSYI = 1998-2008)	138
24	Limit 23 to (LA:PSYI = DUTCH) or (LA:PSYI = ENGLISH) or (LA:PSYI = FRENCH)	137

term = Major Index term - display = number of hits

Embase

Searches	Term	Display
1	Terminal ill patient	600
2	Palliative therapy	11.261
3	Dying	1.616
4	Patient	576.433
5	Incurable*	2.429
6	4 AND 5	621
7	Health care needs	2.861
8	Health service	589.235
9	'patient *I needs'	1.441
10	1 OR 2 OR 3 OR 6	
11	7 OR 8 OR 9	
23	10 AND 11	188

term = Emtree terms - display = number of hits

Embase was searched with limits to “human”, “abstract available”, and “published 1998 – 2008”.

2.3 PART NEEDS - SELECTION OF THE ARTICLES

The results of these consecutive searches were brought together in one main database. Starting from the Medline search, Embase added 148 publications (188 minus 40 duplicates), then Cinahl added 302 publications (303 minus 1 duplicate), British Nursing Index added 2 publications and PsycInfo added 129 publications (137 minus 8 duplicates). Afterwards another 246 publications could be removed from the database by manually searching for duplicates. This resulted in a main EndNote database of 1.051 publications to be searched for specific needs in palliative care.

Systematic Reviews, Meta-analyses, Randomised Controlled Trials (RCT), Cohort Studies, Control Clinical Trials (CCT), Case Series and Case Reports got the first priority.

All potentially relevant studies were screened independently upon title and abstract by two reviewers. The most important criterion for selection was a main focus on the patient's perspective of "palliative needs". As such, literature focussing on families' needs, (home) carers' needs, different health care services' needs or even pure medical topics as treatment options was rejected. Qualitative and quantitative studies were considered.

After reading the first 70 titles and abstracts, results were compared and kappa calculated ($\kappa = 0.436 \pm 0.113$) as a pilot exercise. Then, more definitive criteria were agreed upon between both reviewers for selection of the remaining articles.

		BS		Total
		No		
JW	No	40	12	52
	yes	5	13	18
Total		45	25	70

Following criteria for selection were agreed on between the researchers (JW and BS):

The studies included are those that relate to the personal care giving towards people in need for palliative care in a patient perspective:

- articles describing information from patients themselves irrespective the originating disease (cancer and no cancer related diseases as heart failure, chronic obstructive lung disease, neurodegenerative diseases, ...) context (home care, hospice care, hospital care, even needs towards people in prison were considered) or age (children and adolescents as well as adults and elderly people),
- articles describing information from professionals and home carers if the objective of the particular research is the improvement of the care towards people in any palliative setting,
- articles describing information from relatives in the case of research on palliative care towards children and people with impossibilities to participate the research project (e.g. dementia)

the following papers were excluded:

- articles focusing on the needs for professionals, home carers, relatives etc.,
- articles focusing on the needs of the health care system (epidemiological data, provision of care, ...),
- articles focusing on any kind of medical treatment options in palliative setting, where the initiative is taken strictly medically (palliative surgery, stent options, drug treatments, ...)
- articles focusing on palliative management options, if the perspective of the study is the care setting rather than the patient's perspective,

After agreeing on these criteria, the resulting database was then searched for definitive inclusion. Individual selecting results were compared and remaining discrepancies between reviewers were resolved by discussion. An improved kappa value of 0.621, $\pm$ 0.27 was calculated. Full text copies were obtained from those studies which might contribute in answering the research question for further analysis.

		BS		Total
		yes	no	
JW	Yes	185	53	238
	no	103	861	964
Total		288	914	1202

The resulting 1202 papers in the table above correspond with the number of papers in the EndNote database before manual removal of duplicates, resulting in the final EndNote database of 1051 selected papers.

After screening for title and abstract the 1051 selected papers, 193 of them were included for data extraction. These papers were searched for in (mainly) electronically databases where 12 papers (1.14%) could not be retrieved. Of the remaining 181 papers 49 were excluded mainly because palliative care needs were not explicitly described in the main text, though mentioned or suggested in title or abstract. Some papers were excluded because the research performed was not focused on western civilization.

Finally 132 papers were used for this study.

2.4 PART NEEDS - SELECTED ARTICLES

Some papers (n=10) were used for the introduction about palliative care needs and 46 other ones were used in different parts of the report.

The body of this review is derived from 76 individual papers that relate to:

- Five specific pathology groups: cancer, heart failure, respiratory diseases, muscular- and neurodegenerative diseases, neurological diseases;
- Palliative needs in children and their carers;
- Spiritual needs in palliative care.

Aiming to list all palliative care needs for different diseases and different settings, we used a holistic model of palliative care, as supported by WHO that adds the cultural, spiritual and health care context related axes to the bio-psycho-social axes.

The classification of some needs was sometimes problematic and implied some compromises. For example patients' broad needs for information were split up in disease specific information (and then classified by the biological needs) while other aspects of communication more related to patient's illness perception (as the way of information provision) were classified under psychological needs.

This exhaustive literature review included papers from quantitative and qualitative research. No quality appraisal was performed on the selected studies since most papers had a descriptive (qualitative or quantitative) design.

2.5 PART NEEDS - DESCRIPTION OF THE PAPERS

The content analysis relied on a classification of the articles as follows:

- General points, including spiritual needs,
- Five specific pathology groups: cancer, heart failure, respiratory diseases, muscular- and neurodegenerative diseases, neurological diseases;
- Palliative needs in children and their carers;
- Spiritual needs in palliative care,
- Needs of palliative patients in miscellaneous settings.

The paragraphs below describe the papers found for each of these topics

2.5.1 Description of papers about spiritual needs of palliative patients

The section on spiritual needs in palliative care first included 17 papers. Five of them were excluded.

Papers excluded

Five papers of which one review⁴⁷, two questionnaire studies^{48, 49}, and two qualitative studies^{50, 51} were excluded in this stage, mainly because specific palliative care needs were not assessed in these papers though title or abstract were suggesting doing so.

Davies et al.⁴⁷ reviewed issues to spirituality in general and spirituality of children in particular aiming to present guidelines for addressing spiritual issues in children and families in paediatric hospice and palliative care. However, no clear palliative care needs of children or their families were explicitly described. The Finish questionnaire survey by M Kuuppelomäki⁴⁸ was excluded because the paper searched for different ways of spiritual support provision by nurses, rather than describing spiritual needs of patients at the end of their lives. EJ Taylor⁴⁹ used self-report questionnaires to measure the prevalence of spiritual needs and to identify factors associated with spiritual needs among patients with cancer and family caregiver. This study was excluded since performed in a cancer care setting, but not in a palliative care setting.

The qualitative study by Sand⁵⁰, based on in-depth interviews exploring existential loneliness in Swedish palliative home care was also excluded for the above mentioned reason that no palliative care needs were mentioned. For the same reason, the paper of PL Stephenson⁵¹ using an interpretative phenomenology methodology after semi-structured in-depth interviews to explore the experience of spirituality in the lives of hospice patients, was excluded.

Papers included

Results were based on twelve papers covering different research methods and leading to a broad spectrum of spiritual palliative care needs. We included two reviews^{52, 53}, one controlled intervention⁵⁴, five quantitative surveys⁵⁵⁻⁵⁹, three qualitative studies⁶⁰⁻⁶² and one case study⁶³.

Reviews

Byrne⁵² reviewed different methods of spiritual assessment and made an appraisal of the various beliefs regarding the concept of spirituality and spiritual needs of terminal ill patients. A. Kellehear⁵³ reviewed and discussed the concept of spirituality in palliative care.

Controlled interventions

DK Miller et al⁵⁴ developed a group intervention entitled “life-Threatening Illness Supportive-Affective Group Experience” (LTI-SAGE) for reducing patient spiritual, emotional, and death-related distress in patients with life-threatening illness at the end of life. The underlying purpose of the project was for each participant to develop a greater sense of hope, courage, and connection. The process relied heavily on

discussing experiences, expressing feelings, and sharing support. The most important aspect of the group dynamic was that process is more important than content.

Quantitative surveys

Hampton et al.⁵⁶ assessed by the Spiritual Needs Inventory the spiritual needs of 90 patients with advanced cancer who were newly admitted to hospice home care, shortly after hospice admission. Using the same Spiritual Needs Inventory, CP Hermann⁵⁹ described the degree to which spiritual needs of 100 hospice patients near the end of life are met. Besides she rated life satisfaction via the Cantril ladder, a single-item scale measure providing a global rating of the quality of life from the patients' perspective. Holmes et al.⁵⁸ explored physician-patient communication around spiritual concerns via questionnaires from 65 outpatients with end-stage illness and 67 primary care physicians. Kernohan⁵⁵ reviewed pastoral care notes as part of the nursing record in a search for an evidence based chaplaincy in palliative care. Besides, to assess personal needs and to understand their needs, patients admitted to the inpatient unit or attending day hospice sessions were invited to complete a semi-structured questionnaire. A. Kuin et al.⁵⁷ analysed the Dutch national register of palliative care consultations aiming to understand which spiritual issues were discussed in those consultation teams and to determine which factors influence whether they are raised or not.

Qualitative studies

To identify and compare changes in the psychological, social, and spiritual needs of people with end-stage disease during their last year of life data from two longitudinal, qualitative, in depth interview studies were analysed by Murray⁶⁰. In another Swedish qualitative survey by S. Strang⁶¹ open-ended questionnaire and content analysis techniques were used to categorize the three most important questions patients pose to hospital chaplains at the end of life and to assess the degree to which hospital staff should be able to handle them. CP Hermann⁶² performed also a qualitative study where semi-structured interviews were conducted to identify dying patients' definitions of spirituality and their spiritual needs.

Case study

In a case study D. Sulmasy⁶³ described the story of a patient suffering from metastatic pancreatic cancer and with a strong religious belief in a miraculous cure, to explore how better understanding of this belief and more explicitly spiritual conversation with the patient by his treatment team might have provided opportunities for an improved plan of care.

Galek's⁶⁴ 29 item, multi-dimension instrument on spiritual needs assessment was used as a steppingstone for presenting the results.

2.5.2 Description of papers about needs of palliative patients with cancer

This section is based on 23 papers, each of which reporting on specific palliative (supporting) needs for patients suffering from an incurable cancer diseases, their informal carers and/or professionals. Results were based on:

- Two reviews^{65, 66}.
- 15 papers with quantitative data of which 14 surveys and 1 paper based on computerized clinical records⁶⁷,
- 6 papers with qualitative design⁶⁸⁻⁷³.

Reviews

McDermot⁶⁵ reviewed the contribution of reflective narratives of palliative care professionals in order to provide an "other source" of evidence on patients' needs. Grocott reviewed the palliative care needs and made an assessment of patients' suffering from malignant wounds⁶⁶.

Quantitative surveys

Data on symptoms and needs were identified quantitatively in 15 papers. Most studies were survey with patients in different health care settings as hospitals^{74, 75}, out-patient hospital services⁷⁶⁻⁷⁸, home care⁷⁹⁻⁸³, night respite care⁸⁴ or without any specification⁸⁵⁻⁸⁸.

Data from computerized clinical records of patients enrolled in a hospice or pre-hospice program were used for needs assessment in the remaining paper by Casarett⁶⁷.

Qualitative studies

Six studies had a qualitative design. One study performed by K. Pollock⁶⁸ had a mixed qualitative design, incorporating face to face interviews and focus groups with healthcare professionals, patients and carers. This study investigates if pre-emptive support can identify and provide for palliative care needs.

The results of the 5 remaining qualitative papers all derived from in-depth interviews. H. Carter⁶⁹ explored priority areas while M. Goldstein⁷⁰ offered an insight in different ways how terminally ill patients talk about death and dying besides what is a good death. S. Murray⁷¹ described in her study experiences of illness and needs besides the use of services. The most salient needs at home and the extent to which home health services meet these needs were explored by Proot et al⁷² while Jarrett⁷³ identified the expectations and perceptions of patients with advanced cancer and their relatives.

Of all these selected papers, 6 were written in Australia/ New Zealand^{69, 76, 81, 84-86}, 7 in the UK^{65, 68, 71, 73, 82, 83, 88, 89}, 5 in The Netherlands^{70, 72, 75, 80, 87}, 2 in the USA/ Canada^{67, 77}, 2 in Sweden^{74, 79} and 1 in Portugal⁷⁸.

2.5.3 Description of papers about needs of palliative patients with heart failure

Initially seven papers were selected but two of them were excluded after reading.

Papers excluded

Lopez-Candalas⁹⁰ studied the use of intermittent infusion of inotropes in patients with end-stage heart failure in hospice and palliative care services but did not describe patients' needs in these settings. Aldred⁹¹ studied the impact of advanced heart failure on older patients and informal carers; however the focus of this paper was not on the palliative care setting.

Papers included

Results were based on the remaining 5 documents: 1 review⁹², 1 prospective survey⁹³ and 3 qualitative interview studies^{60, 94, 95}. All research from these 5 papers was performed in the U.K.

review

Lyle Oates⁹² provided a review on spiritual care in end-stage cardiac failure.

Quantitative survey

In Anderson's prospective survey⁹³, 66 patients with end-stage cardiac failure were asked to determine their main concerns which were compared to those of patients with terminal illness.

Quantitative studies

Cortis⁹⁴ explored by semi-structured interviews the experiences of older adults with chronic heart failure to gain a deeper understanding of their palliative and supportive needs and the value of possible interventions. Also Horne⁹⁵ used semi-structured interviews to explore the experiences of patients with severe heart failure in their homes and identify their needs for palliative care. Three-monthly interviews were used prospectively for up to one year by Scott A. Murray⁶⁰ with end-stage heart failure patients and their informal carers to explore whether they experience significant spiritual needs.

2.5.4 Description of papers about needs of palliative patients with respiratory diseases

In this section 9 papers were selected of which at the end two papers were excluded:

Papers excluded

Rushby ⁹⁶ describes in his CME article different treatment options for people with end-stage COPD, looking particularly at the management of dyspnoea, however without mentioning any (care) needs of this population though stressing this point in the abstract. Finset ⁹⁷ introduced in this editorial Habraken's literature review ⁹⁸ without adding new palliative care needs into the ongoing discussion.

Papers included

Results of this section were based on the remaining 7 documents: 2 reviews ^{98 99}, 1 survey ¹⁰⁰ and 4 qualitative interview studies ¹⁰¹⁻¹⁰⁴.

These 7 papers all report on specific palliative needs for patients suffering from end stage respiratory diseases (not lung cancer), mainly chronic obstructive pulmonary disease (COPD). One article explored the needs of patients with cystic fibrosis who are in the palliative phase of the illness ⁹⁹.

Reviews

Habraken et al. ⁹⁸ conducted a structured literature review to give an overview of relevant literature regarding health care needs in end-stage COPD. She used Bradshaw's classification of needs distinguishing four types of need that are all valid components of the concept of need. Jefferson ⁹⁹ highlighted in her review some of the difficulties that might be encountered in treating patients with end-stage cystic fibrosis and how they may be managed.

Quantitative survey

Besides these 2 reviews, a survey was performed by Elkington ¹⁰⁰. She quantified retrospectively by means of a questionnaire survey (n=209) the healthcare needs of COPD patients in the last year by the informants of 399 deaths from COPD.

Qualitative studies

In the remaining 4 papers a quantitative research methodology was used, sometimes in a multi-method design ^{101 103}. Jones et al. ¹⁰⁴ performed semi-structured interviews to determine prospectively the needs of patients dying in primary care from COPD, while Edmonds et al. ¹⁰² conducted post bereaved structured interviews for her collection of information provided by relatives, friends and carers of the deceased.

Gore ¹⁰¹ used a multi-method design involving standardised quality of life tools, semi-structured interviews and review of documents and Skilbeck ¹⁰³ also used a combination of qualitative (in depth interviews with open-ended questions) and quantitative (questionnaires and validated quality of life scales) research methods to identify palliative care needs of those dying from COPD and assess the level of service use among these people.

2.5.5 Description of papers about needs of palliative patients with muscular- and neurodegenerative diseases

This section is based on 11 papers that describe needs of palliative patients with specific diseases:

- Amyotrophic Lateral Sclerosis 105 106
- Huntington's disease 107, 108
- Multiple Sclerosis 109
- Muscular dystrophy 110, 111
- Parkinson's disease 112

- Systemic sclerosis 113
- a combination of pathologies 114, 115

Results are based on these 11 selected papers of which: 1 clinical reviews¹⁰⁸, 3 surveys^{105, 114, 115}, 6 qualitative studies^{106, 107, 109-112} and 1 case study¹¹³.

2.5.6 Description of papers about needs of palliative patients with neurological diseases

Initially, 7 papers were selected in this section, of which 6 from the UK/Ireland¹¹⁶⁻¹²¹ and 1¹²² in Australia; 5 out of 7 papers were reviews of literature. Tuffrey-Wyne¹²⁰ and Ryan¹²¹ performed a literature review on the palliative care needs of people with intellectual disabilities. Lorraine Burgess¹¹⁶ and Dylan Harris¹¹⁸ reviewed literature on palliative care needs for people with dementia while T. Stevens et al¹¹⁹ performed a critical review of the literature on palliative care after stroke.

An inductive qualitative study through grounded theory methodology of one case of variant Creutzfeldt-Jacob disease was carried out by de Vries et al.¹¹⁷ to explore issues that were raised in providing care for a young person with the disease who had died in a hospice unit. Beth Bailey¹²² audited the care of six patients suffering from Creutzfeldt-Jacob disease (CJD) using a retrospective chart review besides a focus group of nurses involved in the care. The families of the patients were not involved in this study.

2.5.7 Description of papers about needs of children and their carers

Initially, 14 papers were selected in this section, of which 3 reviews^{47, 123, 124} were excluded after reading.

Papers excluded

Browning's paper¹²³ is excluded since it describes the values, goals, educational philosophy, development process, general content, and resulting pedagogy of a new comprehensive and interdisciplinary curriculum that addresses knowledge, attitudes and skills that healthcare professionals need to better serve seriously ill children and their families. Besides some core values as maintaining a family-centred focus, recognizing that a child's well-being is inextricably linked to the strengths and resources of the family, respecting diversity, enhancing attention to symptom management, and the meaning that illness and the threat of death pose for children, families and professional caregivers, the needs themselves of dying children and their carers are not described in this paper. The curriculum is downloadable for free at www.ippcweb.org. Davies et al.⁴⁷ reviewed issues related to spirituality in general and spirituality of children in particular aiming to present guidelines for addressing spiritual issues in children and families in paediatric hospice and palliative care. However, no clear palliative care needs of children or their families were explicitly described. The review by Stillion¹²⁴ is also rejected because no specific paediatric palliative care needs were listed in the study.

Papers included

Results were based on eleven papers covering different research methods and leading to a broad spectrum of palliative care needs for children and their carers. We included three reviews¹²⁵⁻¹²⁷, three surveys¹²⁸⁻¹³⁰, two qualitative studies^{130, 131} and three studies with mixed design techniques¹³²⁻¹³⁴.

Reviews

Three reviews¹²⁵⁻¹²⁷ could be selected for data extraction. Schrijvers¹²⁵ performed a literature review on palliative care in different phases of adolescence. George¹²⁶ explored some underlying principles and the model of care that has emerged at a specialist's centre for adolescent care. Psychosocial and spiritual needs of children living with a life-limiting illness were reviewed by McSherry¹²⁷. In her paper she tried to integrate the limited available data with relevant theoretic conceptualizations aiming to provide a general outline of how medical teams can understand, assess, and respond to the psychosocial needs of children and families receiving palliative care.

Quantitative surveys

Data were also extracted from three surveys¹²⁸⁻¹³⁰. Kinsella¹²⁸ analyzed information from a large program that welcomes children from different countries with various diagnoses, albeit the majority has a history of cancer. DeCinque¹²⁹ performed a survey of all major tertiary paediatric oncology units in Australia and New Zealand to determine current practice relating to hospital-based bereavement support programmes while Nancy Contro¹³⁰ performed a written staff survey regarding comfort and expertise in delivering end-of-life care in a paediatric palliative care service.

Qualitative studies

Besides the above-mentioned survey, Contro¹³⁵ also interviewed 68 family members of 44 deceased children regarding treatment, transition to palliative care, and bereavement follow-up as a prelude to establishing a Pediatric Palliative Care Program, triangulating these results with the staff survey¹³⁰. A cross-sectional descriptive study using an interpretative phenomenological analysis technique was performed by Hannan¹³¹ to explore retrospectively the decisions made by parents regarding their choices of place of care at time of death for their child with advanced cancer.

Mixed design interventions

Three authors used mixed methodology techniques. Donnelly¹³² used qualitative and quantitative data to develop an empirically based conceptual model of the needs of children with life-limiting conditions. Also Jones¹³³ used in his study quantitative and qualitative methods to identify the social workers' perspective regarding the psychosocial needs of children with cancer at the end of life and their families. Monterosso¹³⁴ performed in a first phase a survey to obtain feedback from families of children receiving palliative and supportive care about their care needs in hospital and in community settings. Later, in a second phase of the study, face-to-face semi-structured telephone interviews were undertaken and qualitatively analysed.

2.5.8 Description of papers about needs of palliative patients in miscellaneous settings

In this section 23 papers were selected of which 7 were reporting on specific palliative (supporting) needs for patients suffering from an incurable non-cancer disease, their informal carers and / or professionals. Here, 3 reviews¹³⁶⁻¹³⁸ were selected, all listing biological and psychosocial needs besides 4 studies with a mixed qualitative and quantitative design. Fitzsimons et al.¹³⁹ used questionnaires, unstructured interviews and focus groups to explore the palliative care needs from the perspectives of the patient suffering from end-stage heart failure, renal failure or respiratory disease. Nelsson^{140, 141} included only patients with chronic critical illness in intensive care units and inventoried communicational needs. Parker et al.¹⁴² analysed prospectively data from case notes and interviews and included only residents of aged care facilities.

The remaining 16 articles did not specify patient groups. Within these, there were 5 review articles. Tan et al.¹⁴³ described the interpersonal processes in palliative care, Baker¹⁴⁴ overviewed the literature of the informational needs, Janet Abraham¹⁴⁵ focused on the management, Gibson¹⁴⁶ reported on sleep disturbances and assessment of pain needs while Coulter¹⁴⁷ overviewed the need for dental care. Five studies had a quantitative design of which 3 questionnaires: Emmanuel¹⁴⁸ focussing on assistance needs, Heyland¹⁴⁹ focussing on the needs to improve the quality of end-of-life care while Nguyen⁴⁰ inventoried the palliative needs of patients in university hospitals. Casserett¹⁵⁰ identified the needs of patients in nursing homes and patients living at home (762) and Evers¹⁵¹ identified the care needs of geriatric patients.

Four studies had a mixed qualitative and quantitative design: McIlfatrick¹⁵² used semi-structured qualitative interviews, focus groups, and face to face interviews to assess palliative care needs. Emmanuel¹⁵³ also used semi-structured interviews to identify economic and non economic burdens. Kutner¹⁵⁴ identified information needs, using interviews and structured instruments. Shah¹⁵⁵ compared patients' and professionals' perceptions of the needs for supportive care.

Two studies used a purely qualitative approach: Wenrich¹⁵⁶ used focus groups to identify the needs for emotional support and personalized care while Pervey¹⁵⁷ interviewed patients to know more about comfort provided during hospice care.

Of all these selected papers, 2 report on studies from Australia^{146 142}, 7 from the UK / Northern Ireland^{136-139, 147, 152, 155}, 13 from the USA / Canada^{140, 141, 143-145, 148-151, 153, 154, 156, 157} and 1 from France⁴⁰.

2.5.9 Table of literature identified per needs and per type of pathology

BIOLOGICAL NEEDS	Cancer	Heart Failure	respiratory diseases	muscular- and neurodegenerative diseases	neurological diseases	children	miscellaneous settings
Management of physical challenges	74, 79, 87, 158, 159			105		132, 134	40, 136, 137, 139, 160, 136
Pain	77, 159, 67, 71, 87, 88, 161	93, 95	99, 102, 100, 103	105	116-119, 122	125, 127, 130, 132, 133, 135	151, 136, 142, 162, 137, 145, 148, 150, 153, 163
Fatigue	87	94, 95	100, 103			125	137, 142, 162, 163
Dyspnoea	67, 88	93-95	102, 98, 100, 103		122	125	163, 136, 137, 142, 148, 150, 151, 153, 162
Cough			100, 102, 103				
angina /palpitations		93, 94					
Appetite/anorexia/dysphagia	67, 88	94, 95	100, 102, 103		116, 117, 122	125	163, 137, 163, 142, 150, 162, 150
pyrexia					122		
thirst			103				
vomiting	67, 88						137, 142, 150, 162
mouth problems			102, 103		122		
Edema	67	94, 95					150
sweating					122		
dehydration					116		
urinary tract infections							163
Incontinence	67				116, 117, 119		162, 148, 150, 153
Constipation	67	93, 95	102, 103		122		142, 150, 162, 163
headaches		94					
Seizures/myoclonic jerking	67				117, 122		
Spasticity and hyperreflexia					117, 122		
Tremor					116		
falls		94					
Ostomy/wound care	66, 67						

BIOLOGICAL NEEDS	Cancer	Heart Failure	respiratory diseases	muscular- and neurodegenera tive diseases	neurological diseases	children	miscellaneous settings
Impaired mobility / apraxia	67	93			116	125	148, 153
Consciousness	67						
Memory	87						
Sleep	158	93-95	100, 102 103	105	116, 117		142, 146, 162
Sexuality	87					125,133	
Speech and communicating				105, 112	118, 121		
deafness					117		
blindness					117		
Ventilatory support				105, 111			
Knowledge	75-78, 81, 83, 87, 158, 159	93-95			117, 122	127, 132-134	140, 141, 144, 152, 154.140, 141, 154
Taking care for co-morbidity		60					
Multiple medications		95			118		
Psychological needs							162
Emotional support					122		164
fear	158,87	60, 92, 94, 95	104			125-127, 134	
anxiety		92, 94, 95	98, 101	105, 114, 115	26, 27	125-127, 134	137 142, 151, 163
frustration	87	60, 94, 95			116		
depression	88, 159	92-95	98, 101, 102 100	105, 114, 115	116, 117, 119	127, 134	137, 148 40, 139, 142, 153, 163
guilt						127, 133	139
avoidance responses as denial, distraction or suppression or sensitizing responses			99				139
confused							
delirium hallucinations			102		116, 117		
Coping	68, 70, 71, 87, 88		102	109		125, 127, 129, 132-135	163, 165
Safety feelings		94				132	

BIOLOGICAL NEEDS	Cancer	Heart Failure	respiratory diseases	muscular- and neurodegenera tive diseases	neurological diseases	children	miscellaneous settings
Preservation of autonomy and self esteem		60, 94, 95	103			126, 130, 132, 133, 135	151, 152, 154
Psychological support	76, 67, 74, 80, 87, 158, 161		101				136, 137, 139, 152
Psychological support for family	67, 71				116, 117, 119, 122	132, 125, 127, 129, 130, 134, 135	136, 150
Information provision and Communication	78, 80, 83, 86	94, 95	101, 98, 104	106-109, 112	116-119, 121, 122	126, 127, 130, 131, 133- 135, 126, 132, 135	83, 144, 152, 140, 143, 144, 149, 154, 160
Social needs				166			
Management of daily living	68, 79, 80, 83, 87, 158	95	98, 101, 103	105	116		137, 139, 148, 152, 163, 164, 167
heavy housework	67, 87, 158	93	102, 100	105, 114, 115	116		148, 153, 167
personal transport	87		104	114, 115			148, 153, 167
shopping	87		102, 100	105	116		
personal care			101, 98, 103	105	116		162, 148, 153
Need to remain as independent as possible		60, 93-95					148, 154, 139
Normal live						131, 134, 132, 125, 126, 128, 132, 133	
Prevention of social isolation		60, 95	103	112	118		137, 139
Financial support	87, 81, 85, 158		101, 103	105, 107, 112, 114, 115	116, 118, 119	134	139, 152, 153, 139- 141, 153, 154, 167
Administrativ e support	83, 87						167
Ethno-specific needs	81, 159					132	168
Spiritual needs	74		99			125, 127, 132, 133	154, 162, 169
Dignity	69				116, 117	132	
Love/ belonging		60, 92, 94, 95		106, 109		132, 135	
Divine	71, 82	60			116, 118	127, 132	
Hope	86	60, 92, 94, 95				132, 135	

BIOLOGICAL NEEDS	Cancer	Heart Failure	respiratory diseases	muscular- and neurodegenera tive diseases	neurological diseases	children	miscellaneous settings
Meaning and purpose	79, 87, 158	60, 92, 95		106, 107		132	
Appreciation of beauty						132	
Resolution/death					118	135	139
Help with one's final responsibilities	70					133	170
Awareness and acceptance of one's imminent death	70, 87						
Preparation	89			105, 111			
Services needs / Health care related needs		60					
Primary care		93, 94, 95	98, 100, 102	111	122	129, 134	40, 83
Home care	83-85, 159			107, 111	116, 118, 119	131, 132, 134	40, 83, 152
Respite care/ hospice/ palliative care		95	101, 102	107, 109, 111	118	132, 134	136, 142
Hospital care			100, 102			132, 134	40, 142, 151
Easy access to care	80					127, 134	167
Health care setting	78						
Coordination of care	80, 82, 83, 89			106, 108, 112	116-118, 122	125-127, 132, 135	
Place of death						133	136
Expertise, education and intervention of health care workers				111	117, 118, 121, 122	131	

3 APPENDIX PART THREE: LITERATURE – ORGANISATION MODELS

3.1 ORGANISATIONS MODELS: SEARCH TERMS AND SEARCH STRATEGIES

Four databases (i.e., MEDLINE, COCHRANE database of Systematic Reviews, the Cumulative Index to Nursing and Allied Health Database-CINAHL and EMBASE) were searched for papers published in English, Dutch and French between January 1990 and October 2008.

3.1.1 Search in Medline

Search terms

The following free text and (combinations of) Medical Subject Headings (MeSH) were used in Perspective: Palliative Care / Terminal care/Hospice care

- Intervention and Comparison:
 - o Patient care: patient care/ case management/ continuity of patient care/ disease management/ family centered care/holistic care/ multidisciplinary care team/nursing care/ patient centered care / primary health care
 - o Health facilities: health facilities/academic medical centers/ambulatory care facilities/community health centers/health facility departments / hospital units/ hospitals / housing for the elderly / rehabilitation centers
 - o Health personnel: health personnel / or allied health personnel/ or community health workers / expert clinicians / home health aides/medical staff, hospital / nurses / nursing home personnel/physicians
 - o Health care delivery: health care delivery / health care delivery, integrated / health services accessibility / managed care programs / national health programs / primary health care;
- - Evaluation: quality of health care/outcomes/nursing outcomes / outcome assessment / treatment outcomes / health services research/ outcomes research.
- - Type of publication: systematic review, meta analysis, controlled clinical trial, RCT

Search strategy

The following search strategy has been used in Medline:

- 1 *Palliative Care/ (10014)
- 2 *Terminal Care/ (6161)
- 3 *Hospice Care/ (1913)
- 4 1 or 3 or 2 (16332)
- 5 patient care/ or case management/ or "continuity of patient care"/ or disease management/ or family centered care/ or holistic care/ or multidisciplinary care team/ or nursing care/ or patient centered care/ or primary health care/ (51682)
- 6 4 and 5 (703)
- 7 health facilities/ or academic medical centers/ or ambulatory care facilities/ or community health centers/ or health facility departments/ or hospital units/ or *hospitals/ or housing for the elderly/ or rehabilitation centers/ (25112)

- 8 4 and 7 (224)
- 9 health personnel/ or allied health personnel/ or community health workers/ or expert clinicians/ or home health aides/ or medical staff, hospital/ or *nurses/ or nursing home personnel/ or *physicians/ (37309)
- 10 4 and 9 (522)
- 11 *"quality of health care"/ or *"outcomes (health care)"/ or exp nursing outcomes/ or exp outcome assessment/ or *treatment outcomes/ (11424)
- 12 11 and 4 (308)
- 13 *health care delivery/ or health care delivery, integrated/ or *health services accessibility/ or *managed care programs/ or *national health programs/ or *primary health care/ (54135)
- 14 4 and 13 (362)
- 15 health services research/ or outcomes research/ (40706)
- 16 4 and 15 (409)
- 17 8 or 6 or 16 or 10 or 12 or 14 (2233)
- 18 limit 17 to (yr="1990 - 2008" and (controlled clinical trial or meta analysis or randomized controlled trial or review) (366)

3.1.2 Search in CINAHL

The following search strategy used similar terms as the MESHs from Medline, with limits between 1990 and 2008:

- 1 *Palliative Care/ (6691)
- 2 *Terminal Care/ (5063)
- 3 *Hospice Care/ (2913)
- 4 1 or 3 or 2 (13285)
- 5 patient care/ or case management/ or "continuity of patient care"/ or disease management/ or family centered care/ or holistic care/ or multidisciplinary care team/ or nursing care/ or patient centered care/ or primary health care/ (59729)
- 6 4 and 5 (1123)
- 7 health facilities/ or academic medical centers/ or ambulatory care facilities/ or community health centers / or health facility departments/ or hospital units/ or *hospitals/ or housing for the elderly / or rehabilitation centers/ (31782)
- 8 4 and 7 (281)
- 9 health personnel/ or allied health personnel/ or community health workers/ or expert clinicians/ or home health aides/ or medical staff, hospital/ or *nurses/ or nursing home personnel/ or *physicians/ (38355)
- 10 4 and 9 (514)
- 11 *"quality of health care"/ or *"outcomes (health care)"/ or exp nursing outcomes/ or exp outcome assessment/ or *treatment outcomes/ (31058)
- 12 11 and 4 (396)
- 13 *health care delivery/ or health care delivery, integrated/ or *health services accessibility/ or *managed care programs/ or *national health programs/ or *primary health care/ (41513)
- 14 4 and 13 (320)
- 15 health services research/ or outcomes research/ (7736)
- 16 4 and 15 (84)

17 8 or 6 or 16 or 10 or 12 or 14 (2398)

18 limit 17 to (yr="1990 - 2008" and (clinical trial or "systematic review")) and (Dutch or English or French)) (71)

19 from 18 keep 1-71 (71)

20 from 19 keep 1-71 (71)

3.1.3 Search in EMBASE

Emtree and free terms

Emtree terms

- Palliative Care: use palliative treatment
- Terminal care: use terminal care (including Hospice care)
- Patient Care Management:: use patient care
- Health facilities: use health care facilities and services
- Ambulatory care facilities: incl health care delivery
- Health personnel: use health care personnel
- Health care quality, access, and evaluation: use delivery of health care
- Health services research: use health services research

Search strategy

#6	'palliative therapy'/mj AND [1990-2008]/py	7,295
#7	'terminal care'/mj AND [1990-2008]/py	4,803
#8	'hospice care'/mj AND [1990-2008]/py	685
#9	#6 OR #7 OR #8	11,932
#10	'patient care'/mj AND [1990-2008]/py	21,207
#11	'case management'/exp OR 'holistic care'/exp OR 'patient assessment'/exp OR 'patient care planning'/exp OR 'patient referral'/exp OR 'rehabilitation care'/exp AND [1990- 2008]/py	50,492
#12	#10 OR #11	70,737
#13	#9 AND #12	678
#14	'health center'/exp OR 'hospice'/exp OR 'hospital'/exp/mj OR 'nursing home'/exp/mj OR 'rehabilitation center'/exp OR 'residential home'/exp OR 'pain clinic'/exp AND [1990-2008]/py	67,542
#15	#9 AND #14	1,059
#16	'health auxiliary'/exp OR 'hospital physician'/exp OR 'medical staff'/exp/mj OR 'physician'/exp/mj OR 'medical specialist'/exp/mj AND [1990-2008]/py	20,773
#17	#9 AND #16	156
#19	'clinical effectiveness'/exp OR 'clinical indicator'/exp OR 'nursing outcome'/exp OR 'performance measurement system'/exp OR 'outcome assessment'/exp/mj OR 'outcomes research'/exp/mj AND [1990-2008]/py	11,529
#20	#9 AND #19	16
#21	'clinical effectiveness'/exp OR 'clinical indicator'/exp OR 'nursing outcome'/exp OR 'performance measurement system'/exp OR 'outcome assessment'/exp OR 'outcomes research'/exp AND [1990-2008]/py AND [1990-2008]/py	120,703
#22	#9 AND #21	219
#23	'aftercare'/exp/mj OR 'ambulatory care'/exp/mj OR 'community care'/exp/mj OR 'day care'/exp/mj OR 'home care'/exp/mj OR 'hospital care'/exp/mj OR 'long term care'/exp/mj OR 'nursing care'/exp/mj OR 'primary health care'/exp/mj OR 'residential care'/exp/mj AND [1990-2008]/py	119,344

#24	#9 AND #23	1,158
#25	'health services research'/exp AND [1990-2008]/py	23,862
#26	#9 AND #25	150
#27	#13 OR #15 OR #17 OR #20 OR #22 OR #24 OR #26	2,972
#28	#13 OR #15 OR #17 OR #20 OR #22 OR #24 OR #26 AND ([cochrane review]/lim OR [controlled clinical trial]/lim OR [meta analysis]/lim OR [randomized controlled trial]/lim OR [systematic review]/lim) AND ([dutch]/lim OR [english]/lim OR [french]/lim)	72

3.1.4 COCHRANE DATABASE

“Palliative care” has been used in the Cochrane database with limits between 1990 and 2008.

3.2 QUALITY ASSESSMENT OF THE SYSTEMATIC REVIEWS INCLUDED IN THE CHAPTER ON PALLIATIVE CARE MODELS

Methodological quality of the reviews was performed using the QUOROM (Quality Of Reporting Of Meta-analyses) statement checklist⁸. The checklist describes the preferred way to describe the abstract, introduction, methods, results and discussion sections of systematic reviews/meta-analysis. It is organized into 20 headings and subheadings regarding searches, selection, validity assessment, data abstraction, study characteristics, quantitative data synthesis and trial flow. The researchers opted for this list as it is more comprehensive than the Cochrane Collaboration grid for critical appraisal of systematic reviews; the drawback is the binary character of the answers (Yes/no). The researchers added therefore to this standardized checklist a personal critical appraisal of the paper.

The QUOROM checklist has been initially designed to evaluate meta-analyses/systematic reviews of RCT's only. However, it is a valuable instrument to assess the quality of systematic reviews that included RCTs and other types of studies.

Systematic reviews
I. Critchley P, Jadad AR, Taniguchi A, Woods A, Stevens R, Reyno L, et al. Are some palliative care delivery systems more effective and efficient than others: a systematic review of comparative studies. <i>Journal of Palliative Care</i> . 1999;15(4):40-7.
II. Davies E, Higginson IJ. Systematic review of specialist palliative day-care for adults with cancer. <i>Support Care Cancer</i> . 2005;13(8):607-27.
III. Douglas H-R, Halliday D, Normand C, Corner J, Bath P, Beech N, et al. Economic evaluation of specialist cancer and palliative nursing: a literature review. <i>Int J Palliat Nurs</i> . 2003;9(10):424-8.
IV. Hearn J, Higginson IJ. Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review. <i>Palliative Medicine</i> . 1998;12(5):317-32.
V. Harding R, Karus D, Easterbrook P, Raveis VH, Higginson IJ, Marconi K. Does palliative care improve outcomes for patients with HIV/AIDS: a systematic review of the evidence. <i>Sexually Transmitted Infections</i> . 2005;81(1):5-14.
VI. Salisbury C, Bosanquet N, Wilkinson EK, Franks PJ, Kite S, Lorentzon M, Naysmith A. The impact of different models of specialist palliative care on patients' quality of life: a systematic review. <i>Palliative Medicine</i> 1999; 13: 3-17.
VII. Sampson EL, Ritchie CW, Lai R, Raven PW, Blanchard MR. A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. <i>International Psychogeriatrics</i> . 2005;17(1):31-40.
VIII. Thomas RE, Wilson D, Sheps S. A literature review of randomized controlled trials of the

⁸ Moher D, Cook DJ, Eastwood S, Olkin I, Rennie D, Stroup DF. Improving the quality of reports of meta-analyses of randomised controlled trials: the QUOROM statement. *Quality of Reporting of Meta-analyses*. *Lancet* 1999; 354(9193):1896-1900.

organization of care at the end of life. Canadian Journal on aging 2006; 25 (3): 271-293.

IX. Wadhwa S, Lavizzo-Mourey R. Do innovative models of health care delivery improve quality of care for selected vulnerable populations? A systematic review. Joint Commission Journal on Quality Improvement. 1999;25(8):408-21.

X. Wilkinson EK, Salisbury C, Bosanquet N, Franks PJ, Kite S, Lorentzon M, Naysmith A. Patient and carer preference for, and satisfaction with, specialist models of palliative care: a systematic review. Palliative Medicine 1999; 13: 197-216.

XI. Zimmermann C, Riechelmann R, Krzyzanowska M, Rodin G, Tannock I. Effectiveness of specialized palliative care. JAMA. 2008; 299(14): 1698-1709.

CRITCHLEY ET AL, 1999	
TITLE: The title mentioned a systematic review	
The SR identifies the report as a systematic review of comparative studies (RCT's and non randomized comparative studies)	
ABSTRACT (NO abstract available)	
Objectives	----
Data sources	----
Review methods	----
Results	----
Conclusion	----
INTRODUCTION	
The explicit rationale for the interventions and rationale for the review is provided: YES	
Methods	
Searching	The information sources are provided in detail: YES Databases: YES Restrictions: years considered, language of publication: YES
Selection	The inclusion and exclusion criteria are clearly defined (population, intervention, principal outcomes and study design): YES
Validity assessment	The criteria and process used (quality assessment and their findings) are clearly presented: YES
Data abstraction	The process is clearly described (who did the abstraction): YES
Study characteristics	The type of study design, participants characteristics, details of the intervention, outcome definitions are described + how heterogeneity was assessed (if applicable): YES
Quantitative data synthesis	The principal measures of effect are clearly described: YES
RESULTS	
Trial flow	Provide a profile summarising trial flow: NO
Study characteristics	Present descriptive data for each trial (country, age, sample size, intervention, ...): YES
Quantitative data synthesis	Report agreement on the selection and validity assessment: present simple summary results: YES
DISCUSSION	
Summarise key findings, interpret the results in light of totality of available evidence: describe potential biases in the review process and suggest a future research agenda: YES	
CRITICAL APPRAISAL	
- With the exception of the abstract and a summarising trial flow, all items are represented as required by the QUOROM (Quality Of Reporting Of Meta-analyses) statement checklist. - Major databases consulted + manual search of eligible studies - Independent review of eligible studies by four investigators - Particular strength of the SR: the quality of randomized controlled studies was assessed using a validated tool (Jaddad et al., 1996). - Only four of the 41 studies that were initially selected provided information on all clinically relevant elements selected a priori. These studies were conducted in the US(2), England (1) and Australia (1) representing different health care systems compared to the Belgian health care system. Moreover, these studies were non randomized comparative studies, two with contemporaneous controls and two with historical controls. Studies represented a high number of subjects (from 276 to > 12.000) SR recognizes the difficulties in drawing conclusions as to the superiority of any particular palliative care setting or model of care. Focus on one modality of palliative care and the fact only 4 RCT's were included makes its value to practitioners or policy makers somewhat limited.	

DAVIES, 2005	
TITLE: The title mentioned a systematic review	
The SR identifies the report as a systematic review of quantitative and qualitative studies	
ABSTRACT: YES	
Objectives	The research question is explicitly described: YES
Data sources	The databases and other information sources are clearly described: YES
Review methods	The selection criteria (population, intervention, outcome and study design), methods for validity assessment, data abstraction, and study characteristics and qualitative data synthesis) is described in sufficient detail to permit replication: YES
Results	Characteristics of the studies included and excluded are reported as well as qualitative and quantitative findings and subgroup analysis: YES
Conclusion	The main results are clearly reported: YES
INTRODUCTION	
The explicit rationale for the interventions and rationale for the review is provided: YES	
Methods	
Searching	The information sources are provided in detail: Databases: YES Restrictions: years considered, language of publication: YES
Selection	The inclusion and exclusion criteria are clearly defined (population, intervention, principal outcomes and study design): YES
Validity assessment	The criteria and process used (quality assessment and their findings) are clearly presented: YES
Data abstraction	The process is clearly described (who did the abstraction): YES
Study characteristics	The type of study design, participants characteristics, details of the intervention, outcome definitions are described + how heterogeneity was assessed (if applicable): YES
Quantitative data synthesis	The principal measures of effect: YES, handling of missing data, how statistical heterogeneity was assessed (if applicable), a rationale for any a-priori sensitivity and subgroup analyses and any assessment of publication bias: NO
RESULTS	
Trial flow	Provide a profile summarising trial flow: NO
Study characteristics	Present descriptive data for each trial (country, age, sample size, intervention, ...): YES
Quantitative data synthesis	Report agreement on the selection and validity assessment: present simple summary results: YES
DISCUSSION	
Summarise key findings, interpret the results in light of totality of available evidence: describe potential biases in the review process and suggest a future research agenda: YES	
CRITICAL APPRAISAL	
- With the exception of a summarising trial flow and the assessment of statistical heterogeneity, all items are represented as required by the QUOROM statement checklist. - Major databases consulted but no grey literature reviewed. - Only studies published in English - Studies appraised and graded for the rigour of design and analysis. All studies were grade IIIC except on prospective study (grade IIIA). - SR attempted to integrate both qualitative and quantitative results. - With one exception all studies were carried out in the UK. - Fifteen studies included with only six from medical and nursing databases. These 15 papers report data from 12 observational studies of day-care. - Limited number of study subjects: from 33 to 131. - Limitation of this SR: data on service structure, health-related quality of life and symptom control were scarce. - CCL: Insufficient studies to provide conclusive evidence that symptom control or health-related quality of life improved in patients represented in the different studies, or that any model of day care was associated with better patient outcomes compared to other models.	

DOUGLAS, 2003	
TITEL: mentioned no systematic review	
The SR identifies the report as a literature review of economic studies of clinical nurse specialists	
ABSTRACT: YES	
Objectives	The research question is explicitly described: YES
Data sources	The databases and other information sources are clearly described: NO
Review methods	The selection criteria (population, intervention, outcome and study design), methods for validity assessment, data abstraction, and study characteristics and qualitative data synthesis) is described in sufficient detail to permit replication: NO
Results	Characteristics of the studies included and excluded are reported as well as qualitative and quantitative findings and subgroup analysis: YES
Conclusion	The main results are clearly reported: YES
INTRODUCTION	
The explicit rationale for the interventions and rationale for the review is provided	
Methods	
Searching	The information sources are provided in detail: Databases: YES Restrictions: years considered, language of publication: YES
Selection	The inclusion and exclusion criteria are clearly defined (population, intervention, principal outcomes and study design): YES
Validity assessment	The criteria and process used (quality assessment and their findings) are clearly presented: NO
Data abstraction	The process is clearly described (who did the abstraction): NO
Study characteristics	The type of study design, participants characteristics, details of the intervention, outcome definitions are described + how heterogeneity was assessed (if applicable): YES
Quantitative data synthesis	The principal measures of effect: YES, handling of missing data, how statistical heterogeneity was assessed (if applicable), a rationale for any a-priori sensitivity and subgroup analyses and any assessment of publication bias: NO
RESULTS	
Trial flow	Provide a profile summarising trial flow: NO
Study characteristics	Present descriptive data for each trial (country, age, sample size, intervention, ...): YES
Quantitative data synthesis	Report agreement on the selection and validity assessment: present simple summary results: YES
DISCUSSION	
Summarise key findings, interpret the results in light of totality of available evidence: describe potential biases in the review process and suggest a future research agenda: YES	
CRITICAL APPRAISAL	
- Some limitations when assessing the items of the QUOROM statement checklist since the inclusion and exclusion criteria are e.g. not clearly described. - Major databases consulted + manual search of eligible studies - Seventeen studies included including seven RCT's. Studies with various research designs were included, with even two case studies. - For many of the studies included the economic evaluation has not been undertaken with reference to economic evaluation theory or good methodological practice. - Wide range in the number of study subjects (from 1 to 821) with a mean recruitment of 200 patients per study. - CCL: the SR could not provide robust evidence to support decisions about how clinical nurse specialist nurses should be use their skills and knowledge to influence care to palliative patients in a cost-effective way.	

HEARN, 1998	
TITEL: mentioned a systematic review	
The SR identifies the report as a systematic review of RCT's and	
ABSTRACT: YES	
Objectives	The research question is explicitly described: YES
Data sources	The databases and other information sources are clearly described: YES
Review methods	The selection criteria (population, intervention, outcome and study design), methods for validity assessment, data abstraction, and study characteristics and qualitative data synthesis) is described in sufficient detail to permit replication: YES
Results	Characteristics of the studies included and excluded are reported as well as qualitative and quantitative findings and subgroup analysis: YES
Conclusion	The main results are clearly reported: YES
INTRODUCTION	
The explicit rationale for the interventions and rationale for the review is provided: YES	
Methods	
Searching	The information sources are provided in detail: Databases: YES Restrictions: years considered, language of publication: YES
Selection	The inclusion and exclusion criteria are clearly defined (population, intervention, principal outcomes and study design): YES
Validity assessment	The criteria and process used (quality assessment and their findings) are clearly presented: NO
Data abstraction	The process is clearly described (who did the abstraction): NO
Study characteristics	The type of study design, participants characteristics, details of the intervention, outcome definitions are described + how heterogeneity was assessed (if applicable): YES
Quantitative data synthesis	The principal measures of effect: YES, handling of missing data, how statistical heterogeneity was assessed (if applicable), a rationale for any a-priori sensitivity and subgroup analyses and any assessment of publication bias: NO
RESULTS	
Trial flow	Provide a profile summarising trial flow: NO
Study characteristics	Present descriptive data for each trial (country, age, sample size, intervention, ...): YES
Quantitative data synthesis	Report agreement on the selection and validity assessment: present simple summary results: YES
DISCUSSION	
Summarise key findings, interpret the results in light of totality of available evidence: describe potential biases in the review process and suggest a future research agenda: YES	
CRITICAL APPRAISAL	
- Some limitations when assessing the items of the QUOROM statement checklist since e.g. a profile summarising trial flow is not presented. - Major databases consulted + manual search of eligible studies - Eighteen studies identified, including RCT's, comparative and observational studies. - Available information graded according to the rigour of the study design and analysis - Number of study subjects ranged widely, from 65 to 1754, with a mean recruitment of +/- 150 patients per study. - Consistent problem with many studies is the use of outcome measures which are not responsive to change, not validated (satisfaction with care at one month) or not appropriate in patients who need palliative care (treatment effectiveness) - The review indicates that in hospital, hospice and community settings a multi-professional approach is beneficial.	

HARDING, 2005	
TITEL: mentioned a systematic review	
The SR identifies the report as a systematic review of RCT's, prospective studies with a comparison group, retrospective or observational studies and cross sectional studies	
ABSTRACT: YES	
Objectives	The research question is explicitly described: YES
Data sources	The databases and other information sources are clearly described: YES
Review methods	The selection criteria (population, intervention, outcome and study design), methods for validity assessment, data abstraction, and study characteristics and qualitative data synthesis) is described in sufficient detail to permit replication: YES
Results	Characteristics of the studies included and excluded are reported as well as qualitative and quantitative findings and subgroup analysis: YES
Conclusion	The main results are clearly reported: YES
INTRODUCTION	
The explicit rationale for the interventions and rationale for the review is provided: YES	
Methods	
Searching	The information sources are provided in detail: Databases: YES Restrictions: years considered, language of publication: YES
Selection	The inclusion and exclusion criteria are clearly defined (population, intervention, principal outcomes and study design): YES
Validity assessment	The criteria and process used (quality assessment and their findings) are clearly presented: YES
Data abstraction	The process is clearly described (who did the abstraction): YES
Study characteristics	The type of study design, participants characteristics, details of the intervention, outcome definitions are described + how heterogeneity was assessed (if applicable): YES
Quantitative data synthesis	The principal measures of effect: YES handling of missing data, how statistical heterogeneity was assessed (if applicable), a rationale for any a-priori sensitivity and subgroup analyses and any assessment of publication bias: NO
RESULTS	
Trial flow	Provide a profile summarising trial flow: NO
Study characteristics	Present descriptive data for each trial (country, age, sample size, intervention, ...): YES
Quantitative data synthesis	Report agreement on the selection and validity assessment: present simple summary results: YES
DISCUSSION	
Summarise key findings, interpret the results in light of totality of available evidence: describe potential biases in the review process and suggest a future research agenda: YES	
CRITICAL APPRAISAL	
- The SR presents some limitations when assessing the items of the QUOROM statement checklist since e.g. a profile summarising trial flow is not presented. - Major databases consulted + manual search of eligible studies - Thirty-two studies were identified, including only one RCT. - Available information was graded to the rigour of the study design and analysis - Only about half (18/32) studies stated explicitly that their patient management was palliative. - The qualitative studies identified in the SR generally had a poor methodology with sample sizes, data collection and analysis methods seldom reported. - The number of study subjects ranged widely from 3 to 265. - CCL of the SR: no care model for HIV patients superior to another care model.	

SALISBURY, 1999	
TITEL: mentioned a systematic review	
The SR identifies the report as a systematic review of descriptive and comparative studies	
ABSTRACT: YES	
Objectives	The research question is explicitly described: YES
Data sources	The databases and other information sources are clearly described: NO
Review methods	The selection criteria (population, intervention, outcome and study design), methods for validity assessment, data abstraction, and study characteristics and qualitative data synthesis) is described in sufficient detail to permit replication: NO
Results	Characteristics of the studies included and excluded are reported as well as qualitative and quantitative findings and subgroup analysis: NO
Conclusion	The main results are clearly reported: NO
INTRODUCTION	
The explicit rationale for the interventions and rationale for the review is provided: YES	
Methods	
Searching	The information sources are provided in detail: YES Databases: YES Restrictions: years considered, language of publication: YES
Selection	The inclusion and exclusion criteria are clearly defined (population, intervention, principal outcomes and study design): YES
Validity assessment	The criteria and process used (quality assessment and their findings) are clearly presented: NO
Data abstraction	The process is clearly described (who did the abstraction): NO
Study characteristics	The type of study design, participants characteristics, details of the intervention, outcome definitions are described + how heterogeneity was assessed (if applicable): YES
Quantitative data synthesis	The principal measures of effect: YES, handling of missing data, how statistical heterogeneity was assessed (if applicable), a rationale for any a-priori sensitivity and subgroup analyses and any assessment of publication bias: NO
RESULTS	
Trial flow	Provide a profile summarising trial flow: NO
Study characteristics	Present descriptive data for each trial (country, age, sample size, intervention, ...): YES
Quantitative data synthesis	Report agreement on the selection and validity assessment: present simple summary results: YES
DISCUSSION	
Summarise key findings, interpret the results in light of totality of available evidence: describe potential biases in the review process and suggest a future research agenda: YES	
CRITICAL APPRAISAL	
- With the exception of a summarising trial flow and the assessment of statistical heterogeneity, all items are represented as required by the QUOROM statement checklist. - Major databases consulted - Both experimental and descriptive studies were included if they evaluated a model of specialist palliative care. Non comparative studies were included and assessed but little weight is given to them in the conclusions. - Twenty-two comparative studies were included: the majority used matched rather than randomly allocated control groups. - The number of study subjects ranged widely from 41 to 1754. - SR recognizes the difficulties with selection bias with different forms of care attracting different types of patients. - Many studies based on very small patient numbers and suffered from attrition pb. - Most studies were too small and methodologically weak to detect any differences in outcomes between studies - SR point out that some evaluations have used inappropriate outcome measures which are insensitive to detect any benefits achieved by specialist palliative care	

SAMPSON, 2005	
TITEL: mentioned a systematic review	
The SR identifies the report as a systematic review of controlled trials	
ABSTRACT: YES	
Objectives	The research question is explicitly described: YES
Data sources	The databases and other information sources are clearly described: YES
Review methods	The selection criteria (population, intervention, outcome and study design), methods for validity assessment, data abstraction, and study characteristics and qualitative data synthesis) is described in sufficient detail to permit replication: YES
Results	Characteristics of the studies included and excluded are reported as well as qualitative and quantitative findings and subgroup analysis: YES
Conclusion	The main results are clearly reported: YES
INTRODUCTION	
The explicit rationale for the interventions and rationale for the review is provided: YES	
Methods	
Searching	The information sources are provided in detail: Databases: YES Restrictions: years considered, language of publication: YES
Selection	The inclusion and exclusion criteria are clearly defined (population, intervention, principal outcomes and study design): YES
Validity assessment	The criteria and process used (quality assessment and their findings) are clearly presented: NO
Data abstraction	The process is clearly described (who did the abstraction): NO
Study characteristics	The type of study design, participants characteristics, details of the intervention, outcome definitions are described + how heterogeneity was assessed (if applicable): YES
Quantitative data synthesis	The principal measures of effect: YES, handling of missing data, how statistical heterogeneity was assessed (if applicable), a rationale for any a-priori sensitivity and subgroup analyses and any assessment of publication bias: NO
RESULTS	
Trial flow	Provide a profile summarising trial flow: NO
Study characteristics	Present descriptive data for each trial (country, age, sample size, intervention, ...): YES
Quantitative data synthesis	Report agreement on the selection and validity assessment: present simple summary results: YES
DISCUSSION	
Summarise key findings, interpret the results in light of totality of available evidence: describe potential biases in the review process and suggest a future research agenda: YES	
APPRAISAL	
- The SR has some limitations when assessing the items of the QUOROM statement checklist e.g. a profile summarising trial flow is not presented. - Major databases consulted + manual search of eligible studies - Only four papers were eligible for full appraisal and only two met all criteria for inclusion (a prospective cohort study and one RCT, both conducted in the US). - Studies had small sample size (n= 50) - Available information was not graded according to the rigour of the study design and analysis. - CCL: few studies that measure the effectiveness of palliative care for patients with dementia.	

THOMAS, 2006	
TITEL: did not mention a systematic review	
The SR identifies the report as a review of randomized controlled trials	
ABSTRACT: YES	
Objectives	The research question is explicitly described: YES
Data sources	The databases and other information sources are clearly described: YES
Review methods	The selection criteria (population, intervention, outcome and study design), methods for validity assessment, data abstraction, and study characteristics and qualitative data synthesis) is described in sufficient detail to permit replication: NO
Results	Characteristics of the studies included and excluded are reported as well as qualitative and quantitative findings and subgroup analysis: YES
Conclusion	The main results are clearly reported: YES
INTRODUCTION	
The explicit rationale for the interventions and rationale for the review is provided: YES	
Methods	
Searching	The information sources are provided in detail: YES Databases: YES Restrictions: years considered, language of publication: YES
Selection	The inclusion and exclusion criteria are clearly defined (population, intervention, principal outcomes and study design): YES
Validity assessment	The criteria and process used (quality assessment and their findings) are clearly presented: YES
Data abstraction	The process is clearly described (who did the abstraction): YES
Study characteristics	The type of study design, participants characteristics, details of the intervention, outcome definitions are described + how heterogeneity was assessed (if applicable): YES
Quantitative data synthesis	The principal measures of effect: YES handling of missing data, how statistical heterogeneity was assessed (if applicable), a rationale for any a-priori sensitivity and subgroup analyses and any assessment of publication bias: YES
RESULTS	
Trial flow	Provide a profile summarising trial flow: YES
Study characteristics	Present descriptive data for each trial (country, age, sample size, intervention, ...): YES
Quantitative data synthesis	Report agreement on the selection and validity assessment: present simple summary results: YES
DISCUSSION	
Summarise key findings, interpret the results in light of totality of available evidence: describe potential biases in the review process and suggest a future research agenda: YES	
APPRAISAL	
- The SR has some limitations when assessing the items of the QUOROM statement checklist, e.g. no selection criteria in the abstract. - Major databases consulted + manual search of eligible studies - Twenty-three RCTs included. - Cochrane Collaboration criteria used to assess the methodological quality of the RCT. - Most RCTs were single-site studies with some studies with small sample sizes (from 14 to 707 subjects).	

WADHWA, 1999	
TITEL: mentioned a systematic review	
The SR identifies the report as a systematic review of studies including a comparison group receiving conventional care	
ABSTRACT: YES	
Objectives	The research question is explicitly described: YES
Data sources	The databases and other information sources are clearly described: NO
Review methods	The selection criteria (population, intervention, outcome and study design), methods for validity assessment, data abstraction, and study characteristics and qualitative data synthesis) is described in sufficient detail to permit replication: NO
Results	Characteristics of the studies included and excluded are reported as well as qualitative and quantitative findings and subgroup analysis: NO
Conclusion	The main results are clearly reported: YES
INTRODUCTION	
The explicit rationale for the interventions and rationale for the review is provided: YES	
Methods	
Searching	The information sources are provided in detail: YES - Databases: YES - Restrictions: years considered, language of publication YES
Selection	The inclusion and exclusion criteria are clearly defined (population, intervention, principal outcomes and study design): YES
Validity assessment	The criteria and process used (quality assessment and their findings) are clearly presented: NO
Data abstraction	The process is clearly described (who did the abstraction): NO
Study characteristics	The type of study design, participants characteristics, details of the intervention, outcome definitions are described + how heterogeneity was assessed: YES
Quantitative data synthesis	The principal measures of effect: YES, handling of missing data, how statistical heterogeneity was assessed (if applicable), a rationale for any a-priori sensitivity and subgroup analyses and any assessment of publication bias: NO
RESULTS	
Trial flow	Provide a profile summarising trial flow: NO
Study characteristics	Present descriptive data for each trial (country, age, sample size, intervention, ...): YES
Quantitative data synthesis	Report agreement on the selection and validity assessment: present simple summary results: YES
DISCUSSION	
Summarise key findings, interpret the results in light of totality of available evidence: describe potential biases in the review process and suggest a future research agenda: YES	
CRITICAL APPRAISAL	
- The SR presents limitations when assessing the items of the QUOROM statement checklist, e.g. the process of data abstraction is unclear. - Major databases consulted + manual search of eligible studies - Seven studies included, including 4 RCTs but these were not blinded and had small sample sizes (from 81 to 318) - There was evidence that there was widespread diffusion of one or more elements of the interventions into the control group, so that results had to be interpreted with caution. - Available information not graded according to the rigour of the study design and analysis.	

WILKINSON, 1999	
TITEL: mentioned a systematic review	
The SR identifies the report as a systematic review of RCT's, prospective studies with a comparison group, retrospective or observational studies and cross sectional studies	
ABSTRACT: YES	
Objectives	The research question is explicitly described: YES
Data sources	The databases and other information sources are clearly described: NO
Review methods	The selection criteria (population, intervention, outcome and study design), methods for validity assessment, data abstraction, and study characteristics and qualitative data synthesis) is described in sufficient detail to permit replication: NO
Results	Characteristics of the studies included and excluded are reported as well as qualitative and quantitative findings and subgroup analysis: NO
Conclusion	The main results are clearly reported: YES
INTRODUCTION	
The explicit rationale for the interventions and rationale for the review is provided: YES	
Methods	
Searching	The information sources are provided in detail: YES - Databases: YES - Restrictions: years considered, language of publication: Yes
Selection	The inclusion and exclusion criteria are clearly defined (population, intervention, principal outcomes and study design): YES
Validity assessment	The criteria and process used (quality assessment and their findings) are clearly presented: YES
Data abstraction	The process is clearly described (who did the abstraction): YES
Study characteristics	The type of study design, participants characteristics, details of the intervention, outcome definitions are described + how heterogeneity was assessed: YES
Quantitative data synthesis	The principal measures of effect: YES, handling of missing data, how statistical heterogeneity was assessed (if applicable), a rationale for any a-priori sensitivity and subgroup analyses and any assessment of publication bias: YES
RESULTS	
Trial flow	Provide a profile summarising trial flow: NO
Study characteristics	Present descriptive data for each trial (country, age, sample size, intervention, ...): YES
Quantitative data synthesis	Report agreement on the selection and validity assessment: present simple summary results: YES
DISCUSSION	
Summarise key findings, interpret the results in light of totality of available evidence: describe potential biases in the review process and suggest a future research agenda: YES	
CRITICAL APPRAISAL	
- The SR presents limitations when assessing the items of the QUOROM statement checklist, e.g. a profile summarising trial flow was not available. - Major databases consulted + manual search of eligible studies - 22 comparative studies included - Number of study subjects ranging from 8 to 1683. - Validity of the articles assessed using separate checklists for studies of different settings. The checklists ensured consideration of the study design, potential biases, the extent to which results are attributable to the intervention, and reliability of results. - CCL: no evidence to determine whether any care model has shown its superiority.	

ZIMMERMAN, 2008	
TITEL: mentioned systematic review	
The SR identifies the report as a systematic review of randomized controlled trials	
ABSTRACT	
Objectives	The research question is explicitly described: YES
Data sources	The databases and other information sources are clearly described: YES
Review methods	The selection criteria (population, intervention, outcome and study design), methods for validity assessment, data abstraction, and study characteristics and qualitative data synthesis) is described in sufficient detail to permit replication: YES
Results	Characteristics of the studies included and excluded are reported as well as qualitative and quantitative findings and subgroup analysis: YES
Conclusion	The main results are clearly reported: YES
INTRODUCTION	
The explicit rationale for the interventions and rationale for the review is provided: YES	
Methods	
Searching	The information sources are provided in detail: YES - Databases: YES - Restrictions: years considered, language of publication: YES
Selection	The inclusion and exclusion criteria are clearly defined (population, intervention, principal outcomes and study design): YES
Validity assessment	The criteria and process used (quality assessment and their findings) are clearly presented: YES
Data abstraction	The process is clearly described (who did the abstraction): YES
Study characteristics	The type of study design, participants characteristics, details of the intervention, outcome definitions are described + how heterogeneity was assessed: YES
Quantitative data synthesis	The principal measures of effect, handling of missing data, how statistical heterogeneity was assessed (if applicable), a rationale for any a-priori sensitivity and subgroup analyses and any assessment of publication bias: YES
RESULTS	
Trial flow	Provide a profile summarising trial flow: YES
Study characteristics	Present descriptive data for each trial (country, age, sample size, intervention, ...): YES
Quantitative data synthesis	Report agreement on the selection and validity assessment: present simple summary results: YES
DISCUSSION	
Summarise key findings, interpret the results in light of totality of available evidence: describe potential biases in the review process and suggest a future research agenda: YES	
CRITICAL APPRAISAL	
- The SR presents no limitation when assessing the items of the QUOROM statement checklist - Major databases consulted + manual search of eligible studies - 22 RCTs included with the number of study subjects ranging from 37 to 2652. - Validity of the articles assessed using 25 quality criteria, grouped into 7 categories. - RCT's of variable quality with 50% scoring 60 points or more out of 100. - This SR only provides consistent evidence for family satisfaction with specialized care. It concludes that evidence for other outcomes (quality of life, symptoms, cost savings) is sparse and limited by the methodology of the trials.	

3.3 FRAMEWORK FOR THE ANALYSIS OF ORGANISATION MODELS

The review of systematic reviews followed the guidelines outlined by Grimshaw et al.¹⁷¹ (2003) based on the Cochrane Effective Practice and Organization of Care Group (EPOC) Standards⁹.

A standardized form (12 items) has been created to assess the components and the effectiveness of palliative care models. The abstraction form was based on the form developed by the effective Practice and Organization of Care Group (EPOC)¹⁰. The items that will be studied in individual studies are:

- Country in which the study was conducted
- Presence of a conceptual background
- Type of research design
- Type of objectives
- Prognosis of the patient population
- Type of care models in different settings
- Type and number of populations targeted
- Type and number of caregivers
- Type and number of interventions
- Type and number of needs addressed
- Type of outcomes measures
- Results on (cost)effectiveness

The table below gives details on the definitions of these different elements.

⁹ **Effective Practice and Organization of Care Group (EPOC).** <http://www.epoc.uottawa.ca>. 2007
¹⁰ Cochrane Effective Practice and Organization of Care Group (EPOC). Data abstraction template. <http://www.epoc.cochrane.org/files/website/Reviewer%20Resources/data%20Abstraction20%Form>.

Definitions of elements used to assess diversity and effectiveness of palliative care models.

Item	Definition
1. Country	Place where the study was conducted including countries in Europe, U.S., Australia and Asia.
2. Presence of a conceptual background	Conceptual backgrounds refer to existing frameworks and models on high quality care or high quality palliative care.
3. Type of research design	The research design refers to RCT, before-after study,...
4. Type of objectives	Goals of palliative care models are defined as improvements in continuity, coordination, health or economic outcomes and improvements in efficiency and effectiveness of care.
5. Prognosis of the patient population	The prognosis refers to the life expectancy that is defined.
6. Setting	The setting refers to the type of health care setting (primary care, hospital, nursing home,...).
7. Type of population targeted	The type of population refers to patients with cancer, heart failure, neurodegenerative diseases, respiratory diseases and AIDS.
8. Type and number of caregivers	Caregivers refers to individual professional and care providers.
9. Type and number of interventions	Interventions refer to all actions that are provided by caregivers, either medical, psycho-social or spiritual.
10. Type and number of needs addressed	Needs refer to biological needs, psychological needs, social needs, spiritual needs, health related needs, Family caregivers/proxy's needs.
11. Type of outcome measures/indicators	Outcome measures refer to measurable items of care which focus upon some aspects of structure, process (clinical or inter-personal) or outcome and for which there is evidence or consensus that it can be used to assess the quality of care provided, and hence change it. These include biological outcomes, psycho-social outcomes and economic outcomes.
12. (Cost)effectiveness	Effectiveness is defined in this review as the degree to which the objectives of a program, care, service or system are achieved. The review did not specifically look for economic aspects as these are the topic of another part of the study.

3.4 OVERVIEW OF EVIDENCE FROM 59 STUDIES ON PALLIATIVE CARE MODELS

HOME CARE

	Author, year	Country ¹¹	CB	Design ¹²	Prognosis	Setting ¹³	Population ¹⁴	Caregivers	Interventions	Needs ¹⁵	Outcomes ¹⁶	Effectiveness
1.	Addington-Hall, 1992	EUR: + US: CA: AU: AS:	-	RCT: + CT: DD:	Less than one year	HC: + DC: HOC: NH: TM:	CA: + HF: ND: RD: AI:	Nurse	Co-ordination of care	BN: + PN: + SN: + SPN: HCN: + FPN:	BO: + PSO: + EO: +	BO: + PSO: + EO: +
2.	Aiken, 2006	EUR: US: + CA: AU: AS:	-	RCT: + CT: DD:	Two years	HC: + DC: HOC: NH: TM:	CA: HF: + ND: RD: + AI:	Nurse Case Manager	Case management	BN: + PN: + SN: + SPN: HCN: + FPN:	BO: + PSO: + EO: +	BO: + PSO: + EO: +
3.	Aristides, 1993	EUR: US: CA: AU: + AS:	-	RCT: CT: DD: +	Not specified	HC: + DC: HOC: NH: TM:	CA: + HF: ND: RD: AI:	Nurse	Nurse care after hours and week-end	BN: - PN: - SN: - SPN: - HCN: - FPN: -	BO: PSO: EO:	BO: PSO: EO: -
4.	Brumley, 2007	EUR: US: + CA: AU: AS:	-	RCT: + CT: DD:	One year or less	HC: + DC: HOC: NH: TM:	CA: + HF: + ND: RD: + AI:	Team	In-home palliative care	BN: - PN: - SN: - SPN: - HCN: - FPN: -	BO: PSO: + EO: +	PSO: + EO: +
5.	Bunch, 1998	EUR: +	-	RCT:	Not	HC: +	CA:	Nurse	Skilled nurse	BN: +	BO: +	EO: +

• ¹¹ EUR: Europe, US: United States of America, CA: Canada, AU: Australia, AS: Asia

• ¹² RCT: Randomised Controlled trial, CT: controlled trial, DD: descriptive design or observational study

• ¹³ HC: home care, DC: day care, HOC: hospital care, NH: nursing home, TM: transmural care

• ¹⁴ CA: Cancer, HF: Heart failure, ND: neurodegenerative diseases, RD: Respiratory diseases, AI: AIDS/HIV

• ¹⁵ BN: Biological needs, PN: psychological needs, SN: social needs, SPN: spiritual needs, HCN: healthcare related needs, FPN: family caregivers, proxy's needs.

• ¹⁶ BO: biological outcomes, PSO: psycho-social outcomes, EO: economic outcomes

		US: CA: AU: AS:		CT: DD: +	specified	DC: HOC: NH: TM:	HF: ND: RD: AI: +			PN: + SN: + SPN: HCN: + FPN:	PSO: + EO: +	
6.	Butters, 1992	EUR: + US: CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: + DC: HOC: NH: TM:	CA: HF: ND: RD: AI: +	Team	Community teams	BN: + PN: + SN: + SPN: - HCN: + FPN: +	BO: + PSO: + EO: +	BO: + PSO: + EO: +
7.	Butters, 1993	EUR: + US: CA: AU: AS:	+	RCT: CT: DD: +	Not specified	HC: + DC: HOC: NH: TM:	CA: HF: ND: RD: AI: +	Team	Community teams	BN: + PN: + SN: + SPN: + HCN: + FPN: +	BO: + PSO: + EO: +	PSO: +
8.	Engelhardt, 2006	EUR: US: + CA: AU: AS:	-	RCT: + CT: DD:	Not specified	HC: + DC: HOC: NH: TM:	CA: + HF: + ND: RD: + AI:	Team	Team coordination	BN: + PN: + SN: + SPN: + HCN: + FPN:	BO: + PSO: + EO: +	PSO: + No effect: +
9.	Field, 1992	EUR: + US: CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: + DC: HOC: NH: + TM:	CA: HF: ND: RD: AI: Not specified	Nurse Family doctor Hospice caregivers	Evaluation activities	BN: PN: SN: SPN: HCN: FPN: Not specified	BO: PSO: EO: Carers satisfaction	Other: Caregivers satisfaction
10.	Field, 1998	EUR: + US: CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: + DC: HOC: + NH: TM:	CA: + HF: ND: RD: AI:	Nurse Family doctor Specialist	Evaluation activities	BN: PN: SN: SPN: HCN: FPN: Not specified	BO: PSO: + EO:	PSO +
11.	Helgesen, 2000	EUR: + US: CA: AU:	-	RCT: + CT: DD:	More than 3 months	HC: + DC: HOC: NH:	CA: + HF: ND: RD:	Nurse	On-demand telephone follow-up	BN: PN: SN: SPN:	BO: + PSO: + EO: +	EO: + No + effect

		AS:				TM:	AI:			HCN: FPN: Not specified		
12.	Higginson, 1997	EUR: + US: CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: + DC: HOC: + NH: TM:	CA: + HF: ND: RD: AI:	Team	Support team	BN: PN: SN: SPN: HCN: FPN: Not specified	BO: + PSO: EO:	BO: +
13.	Koffman, 1996	EUR: + US: CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: + DC: HOC: NH: TM:	CA: HF: ND: RD: AI: +	Nurse and specialist	Hospice at home service	BN: PN: SN: SPN: HCN: FPN: Not specified	BO: + PSO: + EO:	BO: + PSO: +
14.	Lowenthal, 1996	EUR: US: CA: AU: + AS:	-	RCT: CT: DD: +	Not specified	HC: + DC: HOC: + NH: TM:	CA: + HF: ND: RD: AI:	Oncology nurse	Home oncology nursing service	BN: PN: SN: SPN: HCN: FPN: Not specified	BO: + PSO: EO: +	EO: +
15.	McCorkle, 1998	EUR: US: + CA: AU: AS:	+	RCT: + CT: DD:	More than 6 months	HC: + DC: HOC: NH: TM:	CA: + HF: ND: RD: AI:	Oncology nurse	Home nursing care	BN: + PN: + SN: + SPN: HCN: FPN: +	BO: + PSO: + EO:	BO: +
16.	McMillan, 2007	EUR: US: + CA: AU: AS:	+	RCT: CT: + DD:	Not specified	HC: + DC: HOC: NH: TM:	CA: + HF: ND: RD: AI:	Nurse	COPE intervention method	BN: + PN: + SN: + SPN: HCN: FPN:	BO: + PSO: + EO:	PSO: + No + effect
17.	Miller, 2005	EUR: US: + CA:	-	RCT: + CT: DD:	Limited life expectancy	HC: + DC: HOC:	CA: + HF: + ND:	Nurse	LTI-sage groups	BN: PN: + SN: +	BO: PSO: + EO:	PSO: +

		AU: AS:				NH: TM:	RD: + AI: +			SPN: + HCN: FPN:		
18.	Moons, 1994	EUR: + US: CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: + DC: HOC: NH: TM:	CA: HF: ND: RD: AI: +	Nurse	Nurse home visits	BN: + PN: + SN: + SPN: + HCN: + FPN:	BO: PSO: + EO:	PSO: +
19.	Nickel, 1996	EUR: US: + CA: AU: AS:	-	RCT: + CT: DD:	Not specified	HC: + DC: HOC: NH: TM:	CA: HF: ND: RD: AI: +	Nurse case manager	Case management	BN: + PN: + SN: + SPN: + HCN: + FPN:	BO: +	BO: +
20.	Raftery, 1996	EUR: + US: CA: AU: AS:	-	RCT: + CT: DD:	Less than 1 year	HC: + DC: HOC: NH: TM:	CA: + HF: ND: RD: AI:	Nurse coordinator	Coordination activities	BN: + PN: + SN: + SPN: + HCN: + FPN:	BO: PSO: EO: +	EO: +
21.	Ritz, 2000	EUR: US: + CA: AU: AS:	-	RCT: + CT: DD:	Not specified	HC: + DC: HOC: NH: TM:	CA: + HF: ND: RD: AI:	Advanced practice nurse	Advanced practice nurse services	BN: + PN: + SN: + SPN: HCN: + FPN:	BO: + PSO: + EO: +	PSO: + No + effect
22.	Schwartz, 2002	EUR: US: + CA: AU: AS:	-	RCT: + CT: DD:	Not specified	HC: + DC: HOC: NH: TM:	CA: HF: ND: RD: AI: Not specified	Nurse facilitator	Advanced care planning	BN: + PN: + SN: + SPN: + HCN: + FPN:	BO: PSO: + EO:	PSO: +
23.	Siegel, 1992	EUR: US: + CA: AU: AS:	-	RCT: + CT: DD:	Not specified	HC: + DC: HOC: NH: TM:	CA: + HF: ND: RD: AI:	Social worker	Automated telephone needs assessment	BN: + PN: + SN: + SPN: + HCN: + FPN:	BO: PSO: EO:	PSO: +

HOSPITAL CARE

	Author, year	Country ¹⁷	CB	Design ¹⁸	Prognosis	Setting ¹⁹	Population ²⁰	Caregivers	Interventions	Needs ²¹	Outcomes ²²	Effectiveness
24.	Ahronheim, 2000	EUR: US: + CA: AU: AS:	-	RCT: + CT: DD:	Less than 6 months	HC: DC: HOC: + NH: TM:	CA: HF: ND: + RD: AI:	Team	Palliative care team	BN: + PN: + SN: + SPN: HCN: + FPN: +	BO: + PSO: EO: +	BO: PSO: EO: +
25.	Baker, 2000	EUR: US: + CA: AU: AS:	+	RCT: CT: DD: +	Not specified	HC: DC: HOC: + NH: TM:	CA: + HF: + ND: RD: + AI:	Clinical nurse specialist	Clinical nurse specialist	BN: - PN: - SN: - SPN: - HCN: - FPN: -	BO: PSO: + EO:	PSO: +
26.	Hanks, 2002	EUR: + US: CA: AU: AS:	-	RCT: + CT: DD:	Not specified	HC: DC: HOC: + NH: TM:	CA: + HF: + ND: + RD: + AI:	Nurse and specialist	Needs assessment + individual treatment plan + liaison with community	BN: PN: SN: SPN: HCN: FPN: Not specified	BO: + PSO: + EO: +	BO: + PSO: + No + effect
27.	Lucas, 1997	EUR: US: CA: AU: + AS:	-	RCT: CT: DD: +	Not specified	HC: DC: HOC: + NH: TM:	CA: + HF: ND: RD: AI:	Liaison clinical Pharmacist	Liaison activities and recommendations	BN: PN: SN: SPN: HCN:	BO: - PSO: - EO: -	Compliance

• ¹⁷ EUR: Europe, US: United States of America, CA: Canada, AU: Australia, AS: Asia

• ¹⁸ RCT: Randomised Controlled trial, CT: controlled trial, DD: descriptive design or observational study

• ¹⁹ HC: home care, DC: day care, HOC: hospital care, NH: nursing home, TM: transmural care

• ²⁰ CA: Cancer, HF: Heart failure, ND: neurodegenerative diseases, RD: Respiratory diseases, AI: AIDS/HIV

• ²¹ BN: Biological needs, PN: psychological needs, SN: social needs, SPN: spiritual needs, HCN: healthcare related needs, FPN: family caregivers, proxy's needs.

• ²² BO: biological outcomes, PSO: psycho-social outcomes, EO: economic outcomes

28.	Lloyd-Williams, 2002	EUR: + US: CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: DC: HOC: + NH: TM:	CA: HF: ND: + RD: AI:	Nurse specialist	Multidiscipli- nary guideline implementation	FPN: Not specified BN: + PN: + SN: SPN: HCN: FPN:	BO: + PSO: + EO: +	EO: +
29.	McCarthy, 1996	EUR: + US: CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: DC: HOC: + NH: TM:	CA: HF: + ND: RD: AI:	Team	Hospital care team	BN: PN: + SN: SPN: HCN: FPN:	BO: PSO: + EO:	PSO: +
30.	McQuillan, 1996	EUR: + US: CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: DC: HOC: + NH: TM:	CA: + HF: ND: RD: AI: +	Specialist Pharmacist	Palliative care service	BN: + PN: + SN: SPN: HCN: FPN:	BO: + PSO: EO:	BO: + PSO: +
31.	Micheels, 1995	EUR: US: + CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: DC: HOC: + NH: TM:	CA: + HF: ND: RD: AI:	Nurse	Case management	BN: PN: SN: SPN: HCN: FPN: Not specified	BO: PSO: EO: +	No + effect
32.	Moore, 2002	EUR: + US: CA: AU: AS:	-	RCT: + CT: DD:	Not specified	HC: DC: HOC: + NH: TM:	CA: + HF: ND: RD: AI:	Nurse	Nurse home visits	BN: + PN: + SN: + SPN: HCN: + FPN:	BO: + PSO: + EO: +	BO: + No + effect
33.	Rummans, 2007	EUR: US: + CA: AU: AS:	-	RCT: + CT: DD:	Six months	HC: DC: HOC: + NH: TM:	CA: + HF: ND: RD: AI:	Team	Structured sessions	BN: + PN: + SN: + SPN: + HCN: + FPN:	BO: + PSO: + EO:	BO: + PSO: +
34.	Seale, 1997	EUR: +	-	RCT:	Not	HC:	CA: +	Hospice	Palliative care	BN:	BO:	PSO: +

		US: CA: AU: AS:		CT: DD: +	specified	DC: HOC: + NH: TM:	HF: ND: RD: AI:	care and hospital care	services	PN: SN: SPN: HCN: FPN: Not specified	PSO: + EO:	
35.	Toseland, 1995	EUR: US: + CA: AU: AS:	-	RCT: + CT: DD:	Not specified	HC: DC: HOC: + NH: TM:	CA: + HF: ND: RD: AI:	Social worker	Counselling sessions	BN: + PN: + SN: + SPN: HCN: FPN:	BO: + PSO: + EO: +	No + effect
36.	Viney, 1994	EUR: US: CA: AU: + AS:	-	RCT: CT: DD: +	Not specified	HC: DC: HOC: + NH: TM:	CA: + HF: ND: RD: AI:	Team	Support services	BN: PN: + SN: + SPN: HCN: FPN:	BO: PSO: + EO:	PSO: + No + effects
37.	Volicer, 1994	EUR: US: + CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: DC: HOC: + NH: TM:	CA: HF: ND: + RD: AI:	Team	Comfort services	BN: PN: SN: SPN: HCN: FPN: Not specified	BO: + PSO: + EO: +	BO: + EO: + No + effect

TRANSMURAL CARE SYSTEMS

Author, year	Country ²³	CB	Design ²⁴	Prognosis	Setting ²⁵	Population ²⁶	Caregivers	Interventions	Needs ²⁷	Outcomes ²⁸	Effectiveness
38. Butters, 1995	EUR: + US: CA: AU: AS:		RCT: CT: DD: +	Not specified	HC: DC: HOC: NH: TM: +	CA: HF: ND: RD: AI: +	Team	Home support team	BN: PN: SN: HCN: FPN: Not specified	BO: + PSO: + EO: +	Not specified
39. Cornbleet, 2002	EUR: + US: CA: AU: AS:	+ -	RCT: + CT: DD:	A least 6 months	HC: DC: HOC: NH: TM: +	CA: + HF: ND: RD: AI:	—————	Patient-held record	BN: PN: SN: HCN: FPN: Not specified	BO: PSO: + EO:	No effect: +
40. Cummings, 1990	EUR: US: + CA: AU: AS:	-	RCT: + CT: DD:	Six months or less	HC: DC: HOC: NH: TM: +	CA: HF: ND: RD: AI: Not specified	Team	Team home care	BN: PN: SN: HCN: FPN: Not specified	BO: + PSO: + EO: +	PSO: + EO: + No effect: +

• ²³ EUR: Europe, US: United States of America, CA: Canada, AU: Australia, AS: Asia

• ²⁴ RCT: Randomised Controlled trial, CT: controlled trial, DD: descriptive design or observational study

• ²⁵ HC: home care, DC: day care, HOC: hospital care, NH: nursing home, TM: transmural care

• ²⁶ CA: Cancer, HF: Heart failure, ND: neurodegenerative diseases, RD: Respiratory diseases, AI: AIDS/HIV

• ²⁷ BN: Biological needs, PN: psychological needs, SN: social needs, SPN: spiritual needs, HCN: healthcare related needs, FPN: family caregivers, proxy's needs.

• ²⁸ BO: biological outcomes, PSO: psycho-social outcomes, EO: economic outcomes

41.	Foley, 1995	EUR: US: + CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: DC: HOC: NH: TM: +	CA: HF: ND: RD: AI: +	Team	Case management	BN: + PN: + SN: + SPN: + HCN: + FPN:	BO: PSO: + EO:	PSO: +
42.	Grande, 1999	EUR: + US: CA: AU: AS:	-	RCT: + CT: DD:	Two weeks or less	HC: DC: HOC: NH: TM: +	CA: + HF: ND: + RD: AI: +	Nurses	Hospital at home	BN: PN: SN: SPN: HCN: + FPN:	BO: PSO: EO: Place of death	No + effect
43.	Grande, 2000	EUR: + US: CA: AU: AS:	-	RCT: + CT: DD:	Two weeks or less	HC: DC: HOC: NH: TM: +	CA: + HF: ND: + RD: AI: +	Nurses	24-h practical nursing care	BN: PN: SN: SPN: HCN: + FPN:	BO: + PSO: + EO: +	PSO: + No + effect
44.	Higginson, 1990	EUR: + US: CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: DC: HOC: NH: TM: +	CA: + HF: ND: RD: AI:	Team	Coordination of care + support	BN: PN: SN: SPN: HCN: + FPN:	BO: + PSO: + EO: +	PSO: +
45.	Higginson, 1992	EUR: + US: CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: DC: HOC: NH: TM: +	CA: + HF: ND: RD: AI:	Team	Support team	BN: + PN: + SN: SPN: + HCN: + FPN: +	BO: + PSO: + EO: +	BO: + PSO: + EO: +
46.	Hughes, 1992	EUR: US: + CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: DC: HOC: NH: TM: +	CA: + HF: + ND: + RD: + AI:	Team	Comprehens. team care	BN: PN: SN: SPN: HCN: FPN: Not specified	BO: + PSO: + EO: +	PSO: + EO: + No + effect
47.	Hughes, 2000	EUR: US: + CA: AU:	-	RCT: + CT: DD:	Not specified	HC: DC: HOC: NH:	CA: HF: + ND: RD: +	Team	Home-based primary care team	BN: PN: SN: SPN:	BO: + PSO: + EO: +	BO: + PSO: + EO: +

						TM: +	Al:			HCN: FPN: Not specified		No + effect
48.	Jordhoy, 2000	EUR: + US: CA: AU:	-	RCT: + CT: DD:	2 to 9 months	HC: DC: HOC: NH: TM: +		Team	Coordination of care, supervision and advice	BN: PN: SN: SPN: HCN: FPN: Not specified	BO: PSO: EO: +	Place of death: + No + effect
							CA: + HF: ND: RD: Al:					
49.	Jordhoy, 2001	EUR: + US: CA: AU:	-	RCT: + CT: DD:		HC: DC: HOC: NH: TM: +	CA: + HF: ND: RD: Al:	Team	Coordination of care, supervision and advice	BN: PN: SN: SPN: HCN: FPN: Not specified	BO: + PSO: + EO:	No + effect
					5 to 9 months							
50.	King, 2000	EUR: US: CA: AU: +	-	RCT: + CT: DD:	Not specified	HC: + DC: HOC: + NH: TM:	CA: + HF: ND: RD: Al:	Oncology nurse	Home visits	BN: PN: SN: SPN: HCN: FPN: Not specified	BO: PSO: + EO: +	No + effect
51.	McCann, 1991	EUR: + US: CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: DC: HOC: NH: TM: +	CA: HF: ND: RD: Al: +	Team	Home support team	BN: + PN: + SN: + SPN: HCN: + FPN:	BO: PSO: + EO:	PSO: +

52.	McWhinney, 1994	EUR: + US: CA: AU: AS:	-	RCT: + CT: DD:	Two months	HC: DC: HOC: NH: TM: +	CA: + HF: ND: RD: AI:	Team	Palliative home support team	BN: + PN: + SN: + SPN: + HCN: + FPN:	BO: + PSO: EO:	No + effect
53.	Rabow, 2004	EUR: US: + CA: AU: AS:	-	RCT: + CT: DD:	1 to 5 years	HC: DC: HOC: NH: TM: +	CA: + HF: + ND: RD: + AI:	Family doctor in liaison with team	Comprehen. Services	BN: + PN: + SN: + SPN: + HCN: + FPN:	BO: + PSO: + EO: +	
54.	Ringdal, 2002	EUR: + US: CA: AU: AS:	-	RCT: + CT: DD:	Not specified	HC: DC: HOC: NH: TM: +	CA: + HF: ND: RD: AI:	Team	Multidis. team services	BN: PN: SN: SPN: HCN: FPN: Not specified	BO: PSO: + EO:	PSO: +
55.	Smeenk, 1998	EUR: + US: CA: AU: AS:	-	RCT: CT: + DD:	Less than 6 months	HC: DC: HOC: NH: TM: +	CA: + HF: ND: RD: AI:	Team	Primary care team	BN: + PN: + SN: + SPN: + HCN: + FPN:	BO: PSO: EO: +	EO: +
56.	Topp, 1998	EUR: US: + CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: DC: HOC: NH: TM: +	CA: HF: + ND: RD: AI:	Clinical nurse specialist	Case management	BN: + PN: + SN: + SPN: HCN: + FPN:	BO: PSO: EO: +	EO: +
57.	Tramarin, 1992	EUR: + US: CA: AU: AS:	-	RCT: CT: DD: +	Not specified	HC: DC: HOC: NH: TM: +	CA: HF: ND: RD: AI: +	Team	Hospital-based team providing home services	BN: + PN: + SN: + SPN: HCN: + FPN:	BO: PSO: EO: +	EO: +

NURSING HOME

Author,year	Country ²⁹	CB	Design ³⁰	Prognosis	Setting ³¹	Population ³²	Caregivers	Interventions	Needs ³³	Outcomes ³⁴	Effectiveness
58. Casarett, 2005	EUR: US: + CA: AU: AS:	-	RCT: + CT: DD:	Not specified	HC: DC: HOC: NH: + TM:	CA: HF: ND: RD: AI: Not specified		Assessment of eligibility for hospice care	BN: Na PN: SN: SPN: HCN: FPN: Not specified	BO: PSO: + EO:	PSO: +

DAY CARE

59. Goodwin, 2003	EUR: + US: CA: AU: AS:	-	RCT: CT: + DD:	Not specified	HC: DC: + HOC: NH: TM:	CA: HF: ND: RD: AI: Not specified	Not specified	Palliative care services with and without day care	BN: + PN: + SN: + SPN: HCN: FPN:	BO: PSO: + EO:	No + effect
-------------------	---	---	-----------------------------	---------------	---	--	---------------	--	--	-----------------------------	-------------

²⁹ **EUR:** Europe, **US:** United States of America, **CA:** Canada, **AU:** Australia, **AS:** Asia

³⁰ **RCT:** Randomised Controlled trial, **CT:** controlled trial, **DD:** descriptive design or observational study

³¹ **HC:** home care, **DC:** day care, **HOC:** hospital care, **NH:** nursing home, **TM:** transmural care

³² **CA:** Cancer, **HF:** Heart failure, **ND:** neurodegenerative diseases, **RD:** Respiratory diseases, **AI:** AIDS/HIV

³³ **BN:** Biological needs, **PN:** psychological needs, **SN:** social needs, **SPN:** spiritual needs, **HCN:** healthcare related needs, **FPN:** family caregivers, proxy's needs.

³⁴ **BO:** biological outcomes, **PSO:** psycho-social outcomes, **EO:** economic outcomes

3.5 REFERENCES

1. Addington-Hall J, MacDonald L, Anderson H, Chamberlain J, Freeling P, Bland J, et al. Randomised controlled trial of effects of coordinating care for terminally ill cancer patients. *BMJ*. 1992;305(6865):1317-22.
2. Ahronheim JC, Morrison RS, Morris J, Baskin S, Meier DE. Palliative care in advanced dementia: a randomized controlled trial and descriptive analysis. *J Palliat Med*. 2000 Fall;3(3):265-73.
3. Aiken LS, Butner J, Lockhart CA, Volk-Craft BE, Hamilton G, Williams FG. Outcome evaluation of a randomized trial of the PhoenixCare intervention: program of case management and coordinated care for the seriously chronically ill. *J Palliat Med*. 2006 Feb;9(1):111-26.
4. Aristides M, Shiell A. The effects of hospital use and costs of a domiciliary palliative care nursing service. *Australian Health Review* 1993;16(4):405-13.
5. Baker R, Wu AW, Teno JM, Kreling B, Damiano AM, Rubin HR, et al. Family satisfaction with end-of-life care in seriously ill hospitalized adults. *J Am Geriatr Soc*. 2000 May;48(5 Suppl):S61-9.
6. Brumley R, Enguidanos S, Jamison P, Seitz R, Morgenstern N, Saito S, et al. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. *J Am Geriatr Soc*. 2007 Jul;55(7):993-1000.
7. Bunch E. AIDS in Norway: a post hoc evaluation of an AIDS home care project. *J Clin Nursing* 1998;7:183-7.
8. Butters E, Higginson I. Two HIV/AIDS community support teams: patient characteristics, problems at referral and during the last 6 weeks of life. *AIDS care*. 1995;7(5):593-603.
9. Butters E, Higginson I, George R, McCarthy M. Palliative care for people with HIV/AIDS: views of patients, carers and providers. *AIDS care*. 1993;5(1):105-16.
10. Butters E, Higginson I, George R, Smits A, McCarthy M. Assessing the symptoms, anxiety and practical needs of HIV/AIDS patients receiving palliative care. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*. 1992 Feb;1(1):47-51.
11. Casarett D, Karlawish J, Morales K, Crowley R, Mirsch T, Asch D. Improving the use of hospice services in nursing homes: a randomized controlled trial. *Jama*. 2005;294(2):211-7.
12. Cornbleet MA, Campbell P, Murray S, Stevenson M, Bond S, Joint Working Party of the Scottish Partnership Agency for Palliative and Cancer Care and National Council for Hospice and Specialist Palliative Care S. Patient-held records in cancer and palliative care: a randomized, prospective trial. *Palliat Med*. 2002 May;16(3):205-12.
13. Cummings JE, Hughes SL, Weaver FM, Manheim LM, Conrad KJ, Nash K, et al. Cost-effectiveness of Veterans Administration hospital-based home care. A randomized clinical trial. *Arch Intern Med*. 1990 Jun;150(6):1274-80.
14. Engelhardt JB, McClive-Reed KP, Toseland RW, Smith TL, Larson DG, Tobin DR. Effects of a program for coordinated care of advanced illness on patients, surrogates, and healthcare costs: a randomized trial. *The American journal of managed care*. 2006 Feb;12(2):93-100.
15. Field D, Dand P, Ahmedzai S, Biswas B. Care and information received by lay carers of terminally ill patients at the Leicestershire Hospice. *Palliat Med*. 1992;6:237-45.
16. Field D, McGaughey J. An evaluation of palliative care services for cancer patients in the Southern Health and Social Services Board of Northern Ireland. *Palliat Med*. 1998 Mar;12(2):83-97.
17. Foley ME, Fahs MC, Eisenhandler J, Hyer K. Satisfaction with home healthcare services for clients with HIV: preliminary findings. *The Journal of the Association of Nurses in AIDS Care : JANAC*. 1995 Sep-Oct;6(5):20-5.
18. Goodwin DM, Higginson IJ, Myers K, Douglas H-R, Normand CE. Effectiveness of palliative day care in improving pain, symptom control, and quality of life. *J Pain Symptom Manage*. 2003 Mar;25(3):202-12.
19. Grande G, Todd C, Barclay S, Farquhar M. Does hospital at home for palliative care facilitate death at home? Randomised controlled trial. *BMJ*. 1999;319(7223):1472-5.

20. Grande G, Todd C, Barclay S, Farquhar M. A randomized controlled trial of a hospital at home service for the terminally ill. *Palliat Med.* 2000;14:375-85.
21. Hanks GW, Robbins M, Sharp D, Forbes K, Done K, Peters TJ, et al. The imPaCT study: a randomised controlled trial to evaluate a hospital palliative care team. *British journal of cancer.* 2002 Sep 23;87(7):733-9.
22. Helgesen F, Andersson SO, Gustafsson O, Varenhorst E, Goben B, Carnock S, et al. Follow-up of prostate cancer patients by on-demand contacts with a specialist nurse: a randomized study. *Scandinavian journal of urology and nephrology.* 2000 Feb;34(1):55-61.
23. Higginson I, Wade A, McCarthy M. Palliative care: views of patients and their families. *BMJ.* 1990;301(6746):277-81.
24. Higginson IJ, Hearn J. A multicenter evaluation of cancer pain control by palliative care teams. *J Pain Symptom Manage.* 1997 Jul;14(1):29-35.
25. Higginson IJ, Wade AM, McCarthy M. Effectiveness of two palliative support teams. *Journal of public health medicine.* 1992 Mar;14(1):50-6.
26. Hughes SL, Cummings J, Weaver F, Manheim L, Braun B, Conrad K. A randomized trial of the cost effectiveness of VA hospital-based home care for the terminally ill. *Health services research.* 1992 Feb;26(6):801-17.
27. Hughes SL, Weaver FM, Giobbie-Hurder A, Manheim L, Henderson W, Kubal JD, et al. Effectiveness of team-managed home-based primary care: a randomized multicenter trial. *Jama.* 2000 Dec 13;284(22):2877-85.
28. Jordhoy M, Fayers P, Saltnes T, Ahlner-Elmqvist M, Jannert M, Kaasa S. A palliative-care intervention and death at home: a cluster randomised trial. *The Lancet.* 2000;356(9233):888-93.
29. Jordhoy MS, Fayers P, Loge JH, Ahlner-Elmqvist M, Kaasa S. Quality of life in palliative cancer care: results from a cluster randomized trial. *J Clin Oncol.* 2001 Sep 15;19(18):3884-94.
30. King MT, Hall J, Caleo S, Gurney HP, Harnett PR. Home or hospital? An evaluation of the costs, preferences, and outcomes of domiciliary chemotherapy. *International journal of health services : planning, administration, evaluation.* 2000;30(3):557-79.
31. Koffman J, Higginson I, Naysmith A. Hospice at home—a new service for patients with advanced HIV/AIDS: a pilot evaluation of referrals and outcomes. *Br J Gen Pract.* 1996;46:539-40.
32. Lloyd Williams M, Payne S. Can multidisciplinary guidelines improve the palliation of symptoms in the terminal phase of dementia? *International Journal of Palliative Nursing.* 2002;8:370-5.
33. Lowenthal RM, Piasczyk A, Arthur GE, O'Malley S. Home chemotherapy for cancer patients: cost analysis and safety. *The Medical journal of Australia.* 1996 Aug 19;165(4):184-7.
34. Lucas C, Glare PA, Sykes JV. Contribution of a liaison clinical pharmacist to an inpatient palliative care unit. *Palliat Med.* 1997 May;11(3):209-16.
35. McCann K. The work of a specialist AIDS home support team: the views and experiences of patients using the service. *J Adv Nurs* 1991;16(7):832-6. .
36. McCarthy M, Lay M, Addington-Hall J. Dying from heart disease: symptoms and hospital care in the last year of life reported by informal carers *J R Coll Physicians.* 1996;30:325-8.
37. McCorkle R, Hughes L, Robinson L, Levine B, Nuamah I. Nursing interventions for newly diagnosed older cancer patients facing terminal illness. *J Palliat Care.* 1998 Autumn;14(3):39-45.
38. McMillan S, Small B. Using the COPE intervention for family caregivers to improve symptoms of hospice homecare patients: a clinical trial. *Nurs Forum.* 2007;34(2):313-21.
39. McQuillan R, Finlay I, Roberts D, Branch C, Forbes K, Spencer M. The provision of a palliative care service in a teaching hospital and subsequent evaluation of that service. *Palliat Med.* 1996;10:231-39.
40. McWhinney IR, Bass MJ, Donner A. Evaluation of a palliative care service: problems and pitfalls. *BMJ.* 1994 Nov 19;309(6965):1340-2.
41. Micheels TA, Wheeler LM, Hays BJ. Linking quality and cost effectiveness: case management by an advanced practice nurse. *Clinical nurse specialist CNS.* 1995 Mar;9(2):107-11.

42. Miller DK, Chibnall JT, Videen SD, Duckro PN. Supportive-affective group experience for persons with life-threatening illness: reducing spiritual, psychological, and death-related distress in dying patients. *Journal of Palliative Medicine*. 2005 Apr;8(2):333-43.
43. Moons M, Kerkstra A, Biewenga T. Specialized home care for patients with AIDS: an experiment in Rotterdam, The Netherlands. *J Adv Nurs*. 1994 Jun;19(6):1132-40.
44. Moore S, Corner J, Haviland J, Wells M, Salmon E, Normand C, et al. Nurse led follow up and conventional medical follow up in management of patients with lung cancer: randomised trial. *BMJ*. 2002 Nov 16;325(7373):1145.
45. Nickel JT, Salsberry PJ, Caswell RJ, Keller MD, Long T, O'Connell M. Quality of life in nurse case management of persons with AIDS receiving home care. *Research in nursing & health*. 1996 Apr;19(2):91-9.
46. Rabow MW, Dibble SL, Pantilat SZ, McPhee SJ. The comprehensive care team: a controlled trial of outpatient palliative medicine consultation. *Arch Intern Med*. 2004 Jan 12;164(1):83-91.
47. Raftery JP, Addington-Hall JM, MacDonald LD, Anderson HR, Bland JM, Chamberlain J, et al. A randomized controlled trial of the cost-effectiveness of a district co-ordinating service for terminally ill cancer patients. *Palliat Med*. 1996 Apr;10(2):151-61.
48. Ringdal GI, Jordhoy MS, Kaasa S. Family satisfaction with end-of-life care for cancer patients in a cluster randomized trial. *J Pain Symptom Manage*. 2002 Jul;24(1):53-63.
49. Ritz LJ, Nissen MJ, Swenson KK, Farrell JB, Sperduto PW, Sladek ML, et al. Effects of advanced nursing care on quality of life and cost outcomes of women diagnosed with breast cancer. *Oncol Nurs Forum*. 2000 Jul;27(6):923-32.
50. Rummans TA, Clark MM, Sloan JA, Frost MH, Bostwick JM, Atherton PJ, et al. Impacting quality of life for patients with advanced cancer with a structured multidisciplinary intervention: a randomized controlled trial. *J Clin Oncol*. 2006 Feb 1;24(4):635-42.
51. Schwartz CE, Wheeler HB, Hammes B, Basque N, Edmunds J, Reed G, et al. Early intervention in planning end-of-life care with ambulatory geriatric patients: results of a pilot trial. *Arch Intern Med*. 2002 Jul 22;162(14):1611-8.
52. Seale C, Kelly M. A comparison of hospice and hospital care for people who die: views of the surviving spouse. *Palliat Med*. 1997 Mar;11(2):93-100.
53. Siegel K, Mesagno FP, Karus DG, Christ G. Reducing the prevalence of unmet needs for concrete services of patients with cancer. Evaluation of a computerized telephone outreach system. *Cancer*. 1992 Apr 1;69(7):1873-83.
54. Smeenk FW, Ament AJ, van Haastregt JC, de Witte LP, Crebolder HF. Cost analysis of transmural home care for terminal cancer patients. *Patient Educ Couns*. 1998 Nov;35(3):201-11.
55. Topp R, Tucker D, Weber C. Effect of a clinical case manager/clinical nurse specialist on patients hospitalized with congestive heart failure. *Nursing case management : managing the process of patient care*. 1998 Jul-Aug;3(4):140-5; quiz 6-7, 82.
56. Toseland RW, Blanchard CG, McCallion P. A problem solving intervention for caregivers of cancer patients. *Soc Sci Med*. 1995 Feb;40(4):517-28.
57. Tramarin A, Milocchi F, Tolley K, Vaglia A, Marcolini F, Manfrin V, et al. An economic evaluation of home-care assistance for AIDS patients: a pilot study in a town in northern Italy. *AIDS (London, England)*. 1992 Nov;6(11):1377-83.
58. Viney LL, Walker BM, Robertson T, Lilley B, Ewan C. Dying in palliative care units and in hospital: a comparison of the quality of life of terminal cancer patients. *Journal of consulting and clinical psychology*. 1994 Feb;62(1):157-64.
59. Volicer L, Collard A, Hurley A, Bishop C, Kern D, S. K. Impact of special care unit for patients with advanced Alzheimer's disease on patient's discomfort and costs. *J Am Geriatr Soc*. 1994;42:597-603.

3.6 DESCRIPTION OF THE SELECTED STUDIES

Study number 1.	
ADDINGTON-HALL, 1992⁷	
Country	☒ Europe (specify): UK ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	None reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	Measurement of effects on terminally ill cancer patients and their families coordinating the services available within the NHS and from local authorities and the voluntary sector.
Prognosis	Less than one year
Setting + organisational entity	☒ Home are ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify): NHS
Population	☒ Cancer: 554 ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases
Caregivers	☒ Nurse (certificate of care of the dying patient): 2 ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: Coordination of services by two nurse coordinators, tailored to individual needs and circumstances. ☒ CONTROL: Routinely available services
Needs	☒ Biological needs: symptoms and symptom control, activities of daily living, drugs ☒ Psychological needs: psychological distress ☒ Social needs: social support ☐ Spiritual needs: ☒ Health care related needs: sources of help, and income, service use

Outcomes	☒ Biological outcomes: presence and severity of physical symptoms ☒ Psycho-social outcomes: psychiatric morbidity, satisfaction ☒ Economic outcomes: use of services ☒ Other: carers' problems ☒ Positive on: vomiting, effective treatment for vomiting, concerns about itchy skin. Carers more likely to report on cough of patient in last week of life and effective treatment for constipation, less likely reporting on difficulty patient swallowing as severe or to report effective treatment for anxiety. Number of chiropractor and specialist nurse consulted. Carers less likely to feel angry about patient's death. ☐ Negative on: --- ☐ No effect on: Conclusion: Coordinating service made little difference to patient or family outcomes. The coordinating service may have had little opportunity to improve care given the comprehensive existing service provision for terminally ill patients. Coordinators should be able not only to assess need for services but also obtain the services.
-----------------	---

Study number 2.	
AHRONHEIM, 2000¹⁷²	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	None reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To evaluate the effectiveness of a palliative care team on patient's comfort.
Prognosis	Less than 6 months
Setting + organisational entity	☐ Home care ☐ Day care ☒ Hospital care: teaching hospital ☐ Nursing home ☐ Other (specify): NHS
Population	☐ Cancer ☐ Heart failure ☒ Neurodegenerative diseases: advanced dementia ☐ Respiratory diseases

Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☐ Other (specify): TEAM including clinical nurse specialist, geriatrician (2)
Interventions	☐ INTERVENTION: Recommendations by a palliative care team ☐ CONTROL: Routinely available services (care team without the input of the palliative care team)
Needs	☒ Biological needs: patient comfort (through pain medication, rehabilitation measures, massage therapy, prevention of contractures) ☒ Psychological needs: patient comfort ☒ Social needs: social support ☐ Spiritual needs: ☒ Health care related needs: sources of help, and income, service use Also needs assessed of family members or proxys.
Outcomes	☒ Biological outcomes: mortality ☐ Psycho-social outcomes: ☒ Economic outcomes: number of hospitalizations, length of stay, number of procedures and interventions ☐ Other: ☒ Positive on: number of palliative care plans and number of decisions to forgo medical treatments (intravenous hydration) ☐ No effect on: ---- Conclusion: difficult for a palliative care research team to influence the care of advanced dementia patients in the acute hospital care setting.

Study number 3.	
AIKEN, 2006¹⁷³	
Country	☐ Europe (specify): ☒ US: Arizona ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To document outcomes of a randomized trial of the PhoenixCare

	demonstration program of palliative care and coordinated care/case management for seriously chronically ill individuals who simultaneously received active treatment from managed care organizations (MCO's).
Prognosis	Estimated two year life expectancy
Setting + organisational entity	☒ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify) - Organisational entity: The Robert Wood Johnson initiative
Population	☐ Cancer ☒ Heart failure: 130 ☐ Neurodegenerative diseases ☒ Respiratory diseases: 62 - 240 adult patients > 18 years
Caregivers	☒ Nurse (case managers) supported by medical director, social worker, pastoral counsellor. ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: Intensive home-based case management provided by registered nurse case managers, in coordination with patients' existing source of medical care. ☒ CONTROL: Routinely available services from MCO's
Needs	☒ Biological needs: symptoms and symptom control, activities of daily living, drugs ☒ Psychological needs: psychological distress ☒ Social needs: social support ☐ Spiritual needs: ☒ Health care related needs: sources of help, and income, service use
Outcomes	☒ Biological outcomes: physical functioning: activities of daily living, symptom control, general health, vitality, bodily pain ☒ Psycho-social outcomes: mental functioning, social functioning, preparation for end of life ☒ Economic outcomes: emergency department visits ☐ Other: education, information to handle illness emergencies ☒ Positive on: self-management of illness, awareness of illness-related resources, and legal preparation for end of life. Lower symptom distress, greater vitality, better physical functioning and higher self-rated health compared to randomized controls. Patients with COPD showed stronger responsiveness to the intervention. ☒ No effect on: Emergency department utilization, hospitalizations, length of stay Conclusion: a novel model of patient care that combined greatly enhanced palliative care focused case management with ongoing MCO-based treatment was associated with improved functioning of chronically severely ill patients in the last years of life.

Study number 4.	
ARISTIDES, 1993¹⁷⁴	
Country	☐ Europe (specify): ☐ US ☐ Canada ☒ Australia: Western Sydney and Wentworth Area Health Services of AIW ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study:
Objectives	To assess the cost-effectiveness of a domiciliary palliative care nursing service
Prognosis	Not specified
Setting + organisational entity	☒ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify) Organisational entity: Australian Medicare Hospitals Agreement Incentive Package
Population	☒ Cancer: 153 patients in before group, 123 patients in after group ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases
Caregivers	☒ Nurse: 18, with experience in community nursing, oncology and palliative care. ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: after hours support and weekend nursing care with the aim to supplement existing community nursing provision. ☐ CONTROL: NA
Needs	☐ Biological needs: not specified ☐ Psychological needs: not specified ☐ Social needs: not specified

	☐ Spiritual needs: not specified ☐ Health care related needs: not specified
Outcomes	☐ Biological outcomes: ☐ Psycho-social outcomes: ☒ <u>Economic outcomes:</u> number of days in public hospitals during the last 90 days of patients' life and their costs ☐ Other: ☒ Positive on: A higher proportion of patients were admitted at least once before introduction of 4C than afterwards, but the difference was not statistically significant at conventional level ☒ No effect on: A higher proportion of patients were admitted at least once before introduction of 4C than afterwards, but the difference was not statistically significant at conventional level. No significant effect on average number of days spent in hospital. The difference in cost before and after introduction of 4C was not statistically significant.

Study number 5.	
BAKER, 2000¹⁷⁵	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Definition of quality medical care
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: A prospective cohort study with patients randomized to either usual care or a special designed intervention, and in this context after-death interviews were performed with family caregivers/proxys.
Objectives	To examine factors associated with family satisfaction with end-of-life care in the Study to Understand Prognoses and Preferences for Outcomes and Risks for Treatment (SUPPORT)
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☐ Day care ☒ Hospital care: 5 teaching hospitals ☐ Nursing home ☐ Other (specify) Organisational entity: SUPPORT study

Population	☒ Cancer ☒ Heart failure ☐ Neurodegenerative diseases ☒ Respiratory diseases + chronic liver disease with cirrhosis, nontraumatic coma, multiple organ system failure with sepsis Family caregivers of patients who died.
Caregivers	☒ Nurse specialists ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: clinical nurse specialists that assisted in symptom control and facilitation of communication and decision-making ☒ CONTROL: Routinely available services
Needs	☐ Biological needs: NA ☐ Psychological needs: NA ☐ Social needs: NA ☐ Spiritual needs: NA ☐ Health care related needs: NA
Outcomes	☐ Biological outcomes: ☒ Psycho-social outcomes: satisfaction with the patient's medical care (satisfaction with patient comfort and with communication and decision making) ☐ Economic outcomes: use of services ☐ Other: Results: 16% of respondents reported dissatisfaction with patient comfort and 30% reported dissatisfaction with communication and decision making. Conclusion: satisfaction scores suggest the need for improvement in end-of life care, especially in communication and decision making.

Study number 6.	
BRUMLEY, 2007¹⁷⁶	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To determine whether an in-home palliative care intervention for terminally ill patients can improve patient satisfaction, reduce medical costs and increase the proportion of patients dying at home
Prognosis	1 year or less
Setting + organisational entity	☒ Home are ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify) Organisational entity: Two Health Maintenance Organizations (HMO)
Population	☒ Cancer ☒ Heart failure ☐ Neurodegenerative diseases ☒ Respiratory diseases 718 patients were referred to the study.
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): team approach including physician, nurse, social worker, spiritual counsellor, chaplain, bereavement coordinator, home health aide, pharmacist, dietician, volunteer, physical therapist, occupational therapist and speech therapist with expertise in symptom management and biopsychosocial interventions.
Interventions	☒ INTERVENTION: In-home palliative care plus usual care delivered by an interdisciplinary team providing pain and symptom relief, patient and family education and training, and an array of medical and social support services ☒ CONTROL: Routinely available services following Medicare guidelines for home healthcare criteria.
Needs	☒ Biological needs: Not specified ☒ Psychological needs: Not specified

	☒ Social needs: Not specified ☒ Spiritual needs: Not specified ☒ Health care related needs: Not specified
Outcomes	☐ Biological outcomes: ☒ Psycho-social outcomes: satisfaction with care ☒ Economic outcomes: use of medical services, costs of care ☒ Other: site of death ☒ Positive on: greater improvement in satisfaction with care of intervention patients + more likely to die at home + less likely to visit emergency department + less likely for hospital admissions + lower costs ☐ No effect on: Conclusion: In-home palliative care significantly increased patient satisfaction while reducing use of medical services and costs of medical care at the end of life.

Study number 7.	
BUNCH, 1998¹⁷⁷	
Country	☒ Europe (specify): Norway ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: Comparing hospital care with home care through patient interviews, medical chart examination
Objectives	To evaluate the viability of home nursing care by hospital-employed nurses for HIV/AIDS patients hospitalized at the university hospital in Norway
Prognosis	Not specified
Setting + organisational entity	☒ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify)
Population	☐ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases ☒ HIV: 64 patients

Caregivers	☒ Nurse: 2, employed by hospitals ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: skilled nursing services for HIV/AIDS persons residing in the community ☐ CONTROL: NA
Needs	☒ Biological needs: reactions to medications, illness trajectory ☒ Psychological needs: psychological distress, anxiety, depression ☒ Social needs: social support, social network ☐ Spiritual needs: ☒ Health care related needs: management of medical equipment
Outcomes	☒ Biological outcomes: number and type of medical complications ☒ Psycho-social outcomes: patient satisfaction, social support and network ☒ Economic outcomes: cost of the team ☒ Other: nursing care requirements, collaboration with external agencies ☒ Positive on: costs ☒ No effect on: medical complications

Study number 8.	
BUTTERS, 1992¹⁷⁸	
Country	☒ Europe (specify): UK (London) ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study
Objectives	To evaluate the impact of to community teams who care for people with AIDS/HIV on four aspects of quality of life.
Prognosis	Not specified
Setting + organisational entity	☒ Home are ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify)

Population	☐ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases ☒ HIV/AIDS: 140 patients
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): TEAMS
Interventions	☒ INTERVENTION: community teams that support patients and their carers, and aim to increase their choices of place of care and death by offering symptom control, counselling for both patient and carer, 24 h on-call, bereavement follow-up, education and one-to-one advice on diagnosis, nursing and terminal care needs. They co-ordinate and support existing services liaising with hospital and outpatient clinics. ☐ CONTROL: NA
Needs	☒ Biological needs: pain control, symptom control ☒ Psychological needs: anxiety, psychological distress, patient insight, ☒ Social needs: social support ☐ Spiritual needs: spiritual needs ☒ Health care related needs: sources of help, and income, service use ☐ Also: family anxiety, family insight, communication between patient and family and between patient and caregivers
Outcomes	☒ Biological outcomes: pain control, symptom control ☒ Psycho-social outcomes: patient anxiety ☒ Economic outcomes: use of services (practical aid) ☒ Positive effect on: pain control, symptom control, patient anxiety, practical aid ☐ No effect on: ---

Study number 9.	
BUTTERS, 1993¹⁷⁹	
Country	☒ Europe (specify): UK (London) ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Based on palliative care models/hospice models (not specified)
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: cross-sectional study (interviews)

Objectives	To compare the views of palliative care reported by patients, informal carers and the Community Care Team (CCT)
Prognosis	Not specified
Setting + organisational entity	☒ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify)
Population	☐ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases ☒ AIDS (later stages of disease): 19 patients and 7 carers
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): TEAM consisting of two doctors, three clinical nurse specialists, a dietician, an occupational therapist, an administrator and a research assistant (= 9 team members)
Interventions	☒ INTERVENTION: the Community Care Team is a community based support team that assists in the care of people in the later stages of HIV/AIDS illness. The team aims to support patients and their carers, and to increase their choices of place of care and death by offering symptom control, counselling for both patients and carers, 24-hour on-call, bereavement follow-up, and education and advice on diagnosis, nursing and terminal care needs. The team coordinates existing services liaising with hospital and outpatient clinics. ☐ CONTROL: NA
	☒ Biological needs: uncontrolled pain or symptoms ☒ Psychological needs: psychological distress ☒ Social needs: social support, practical aid ☒ Spiritual needs: ☒ Health care related needs: continuing care at home
Outcomes	☒ Biological outcomes: presence and severity of physical symptoms including pain control, symptom control ☒ Psycho-social outcomes: anxiety, communication of support team with patient and family, communication of professionals with patient and family, patient insight on prognosis, satisfaction ☒ Economic outcomes: use of services (practical aid) ☒ Other: family anxiety, family insight ☒ Positive on: communication CCT to patient ☐ No effect on: ---

	Conclusion: there were no significant differences in totalled scores between patient, carer and CCT's ratings
--	--

Study number 10.	
BUTTERS, 1995¹⁸⁰	
Country	☒ Europe (specify): UK (London) ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Based on palliative care and hospice models without further specification
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study:
Objectives	To compare two teams, a Home Support Team and a Community Care Team in terms of characteristics and problems of patients with HIV/AIDS that were referred to these teams. COORDINATION OF CARE
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☒ Other (specify): TRANSMURAL CARE SYSTEMS , assisting patients in the community and in the hospital.
Population	☐ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases ☒ AIDS: patients from home support team for early diagnosis= 116 and from Community Care Team for late stage disease= 118. Total= 234.
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): - Home support Team: senior nurse educator, five nurses, general practitioner, and administrative support, welfare rights worker and occupational therapist - Community Care Team: consisting of two doctors, three clinical nurse specialists, a dietician, an occupational therapist, an administrator and a research assistant (= 9 team members)

Interventions	☒ INTERVENTION: - Home support Team and Community Care Team: community based support teams that assists in the care of people in the later stages of HIV/AIDS illness. The team aims to support patients and their carers, and to increase their choices of place of care and death by offering symptom control, counselling for both patients and carers, 24-hour on-call, bereavement follow-up, and education and advice on diagnosis, nursing and terminal care needs. The team coordinates existing services liaising with hospital and outpatient clinics. ☐ CONTROL: NA
Needs	☐ Biological needs: not specified ☐ Psychological needs: not specified ☐ Social needs: not specified ☐ Spiritual needs: not specified ☐ Health care related needs: not specified
Outcomes	☒ Biological outcomes: pain and symptom control ☒ Psycho-social outcomes: depression and anxiety, patient insight communication between patient and family, ☒ Economic outcomes: ☒ Other: family anxiety No formal evaluation of outcomes, since the two teams had different characteristics in terms of goals and patient populations.

Study number 11.	
CASARETT, 2005¹⁸¹	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To determine whether it is possible to increase hospice utilization and improve the quality of end-of-life care by identifying residents whose goals and preferences are consistent with hospice care. Assesses eligibility for hospice care!
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☐ Day care ☐ Hospital care ☒ Nursing home: 3

	☐ Other (specify)
Population	☐ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases ☒ Not specified (nursing home residents): 205
Caregivers	☐ Nurse: NA ☐ Family doctor: Na ☐ Specialist: NA ☐ Other (specify): NA
Interventions	☒ INTERVENTION: Assessment on eligibility for hospice care, and helping physicians to identify those residents whose goals, etc....would make them appropriate for hospice care. ☒ CONTROL: Routinely available services
Needs	☐ Biological needs: NA ☐ Psychological needs: NA ☐ Social needs: NA ☐ Spiritual needs: NA ☐ Health care related needs: NA
Outcomes	☐ Biological outcomes: ☐ Psycho-social outcomes: ☒ Economic outcomes: use of services: hospice enrolment within 30 days of the intervention ☒ Other: families' ratings of the quality of care for residents who died during the 6-month follow-up period ☒ Positive on: families' ratings of the quality of care that residents received at the end of life ☐ No effect on: ----

Study number 12.	
CORNBLEET, 2002¹⁸²	
Country	☒ Europe (specify): Scotland ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT + postal survey

	☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To evaluate prospectively the introduction of a patient-held record in the management of patients with advanced cancer and palliative care needs.
Prognosis	Prognosis of at least 6 months.
Setting + organisational entity	☐ Home care ☐ Day care: ☐ Hospital care ☐ Nursing home ☒ Other (specify): transmurial care systems = outpatient oncology centers + hospice home-care services
Population	☒ Cancer: 231 patients + 83 health care professionals ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases
Caregivers	☐ Nurse: NA ☐ Family doctor: NA ☐ Specialist: NA ☐ Other (specify: NA
Interventions	☒ INTERVENTION: Patient-held record ☐ CONTROL: Routinely available services
Needs	☐ Biological needs: NA ☐ Psychological needs: NA ☐ Social needs: NA ☐ Spiritual needs: NA ☐ Health care related needs: NA
Outcomes	☐ Biological outcomes: presence and severity of physical symptoms ☒ Psycho-social outcomes: patient satisfaction with communication and perception of communication between patient and health care professional ☐ Economic outcomes: use of services ☐ Other: carers' problems ☐ Positive on: ☒ No effect on: No improvement in the provision of information to patients, or patient satisfaction with information provided by out-patient doctors, GP's, practice and community nurses and hospice or palliative home care staff. The patient-held records made no difference to information passing between health professionals, between primary and secondary care, or to

	the degree of family involvement.
--	-----------------------------------

Study number 13.	
CUMMINGS, 1990¹⁸³	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT: randomized pretest/multiple posttest experimental design ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To examine the cost-effectiveness of Veterans Administration hospital-based home care; IMPROVING CONTINUITY OF CARE + EFFECTIVENESS
Prognosis	Six months (6) or less
Setting + organisational entity	☐ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☒ Other (specify): TRANSMURAL CARE SYSTEMS;
Population	☐ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases ☒ Not specified: terminal ill patients: 175, intervention (89) and control (86).
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): TEAM HOME CARE including physician, nurses and social worker:
Interventions	☒ INTERVENTION: Team home care that could monitor patient status in and outside of the acute care, implementing a home care plan. The team actively participate in inpatient care, facilitating hospital discharge planning and monitoring of continuity of care. ☐ CONTROL: Routinely available services
Needs	☐ Biological needs: Not specified ☐ Psychological needs: Not specified

	☐ Social needs: Not specified ☐ Spiritual needs: Not specified ☐ Health care related needs: Not specified
Outcomes	☒ Biological outcomes: functional status ☒ Psycho-social outcomes: cognitive status, satisfaction with care, patient morale ☒ Economic outcomes: use of services; total costs. ☒ Other: family morale ☒ Positive on: satisfaction and total costs, shorter hospital stays, ☒ No effect on: functional status

Study number 14.	
ENGELHARDT, 2006¹⁸⁴	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To evaluate the Advanced Illness Coordinated Care Program (AICCP) to improve care for patients coping with advanced illness and in the need of preparation for end-of-life care.
Prognosis	Not reported
Setting + organisational entity	☒ Home are ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer ☒ Heart failure ☐ Neurodegenerative diseases ☒ Respiratory diseases Total: 186 patients and 143 surrogates (carers)
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist

	☒ Other (specify): TEAM (physicians, nurses, social workers-number not specified), as part of physician-directed care plans.
Interventions	☒ INTERVENTION: care coordination and support through 6 functions. 1) physician support, which consists of helping patients develop well-organized questions to make economical use of provider time and ensuring that physicians have complete information about patients. 2) health literacy, 3) care coordination, 4) prevention, which refers to efforts to reduce or eliminate common psychosocial concerns related to advanced illness, 5) clarifying patient preferences for care, 6) emotional and social support and to reduce barriers to the use of palliative care and hospice services. ☐ CONTROL: Routinely available services
Needs	☒ Biological needs: symptoms and symptom control, activities of daily living, drugs ☒ Psychological needs: psychological distress ☒ Social needs: social support ☒ Spiritual needs: ☒ Health care related needs: sources of help, and income, service use
Outcomes	☒ Biological outcomes: Mortality ☒ Psycho-social outcomes: satisfaction with care ☒ Economic outcomes: use of services: willingness to participate in treatment planning + costs + number of advanced directives ☒ Other: effectiveness of patient/provider communication + surrogates experiences with patient care/program ☒ Positive on: increased patient satisfaction with care and communication, fewer problems with provider support, higher number of advanced directives ☒ No effect on: survival, and costs. Conclusion: the AICCP improved satisfaction with care, helped patients develop and revise more AD's, sooner, without affecting mortality.

Study number 15.	
FIELD 1992¹⁸⁵	
Country	☒ Europe (specify): UK ☐ US ☐ Canada ☐ Australia ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: interviews with family caregivers (59)
Objectives	To evaluate lay caregivers' satisfaction with community care compared to hospice care
Prognosis	Not specified
Setting + organisational entity	☒ Home are

	☐ Day care ☐ Hospital care ☒ Nursing home: hospice care ☐ Other (specify)
Population	☐ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases ☒ Not specified
Caregivers	☒ Nurse ☒ Family doctor ☐ Specialist ☒ Other (specify): hospice caregivers
Interventions	☒ INTERVENTION: evaluation of community and hospice care ☐ CONTROL: NA
Needs	☐ Biological needs: Not specified ☐ Psychological needs: Not specified ☐ Social needs: Not specified ☐ Spiritual needs: Not specified ☐ Health care related needs: Not specified
Outcomes	☐ Biological outcomes: presence and severity of physical symptoms ☐ Psycho-social outcomes: psychiatric morbidity, satisfaction ☐ Economic outcomes: use of services ☒ Other: carers' satisfaction with care ☒ Positive on: caregivers' satisfaction. Less satisfied with care and attention received from community nurses and general practitioners compared to hospice caregivers. ☐ No effect on: ----

Study number 16.	
FIELD, 1998¹⁸⁶	
Country	☒ Europe (specify): Ireland ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported

Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: interviews
Objectives	To evaluate palliative care services to cancer patients who died either at home or in the hospital.
Prognosis	Not specified
Setting + organisational entity	☒ Home care (patients who died at home) ☐ Day care ☒ Hospital care (patients who died in the hospital) ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer (who died): 15 types of cancer represented ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases 57 caregivers
Caregivers	☒ Nurse (district nurses) ☒ Family doctor ☒ Specialist: hospital in-patient care + nurses ☐ Other (specify)
Interventions	☒ INTERVENTION: interviews ☐ CONTROL: ---
Needs	☐ Biological needs: Not specified ☐ Psychological needs: Not specified ☐ Social needs: Not specified ☐ Spiritual needs: Not specified ☐ Health care related needs: Not specified
Outcomes	☐ Biological outcomes: ☐ Psycho-social outcomes: ☐ Economic outcomes: ☒ <u>Other:</u> ☒ Positive on: greater satisfaction with care from district nurses compared to care delivered by inpatient hospital care ☐ No effect on:

Study number 17.	
FOLEY, 1995¹⁸⁷	
Country	☐ Europe (specify): ☒ US: (New York) ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: interviews
Objectives	To evaluate the satisfaction with home healthcare services (At Home Options Program) for clients with HIV - enhancement of quality of care - reduction of admission rate to inpatient facilities through the provision of home care - the reduction of length of stay for patients who are in an inpatient setting - reduction of costs of treatment
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☒ Other (specify): TRANSMURAL CARE SYSTEMS
Population	☐ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases ☒ AIDS/HIV: 52
Caregivers	Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): TEAM: nurses; home health aide, housekeeping, physical therapist, mental health counsellor,
Interventions	☒ INTERVENTION: case management, pharmacy card without co-payment, nursing homecare service based on medical need, nutrition consultation, rehabilitation services, paraprofessional services, and medical equipment and supplies, social work services, respite care, mental health services and laboratory services. ☐ CONTROL: -----
Needs	☒ Biological needs: symptoms and symptom control, activities of daily living, drugs ☒ Psychological needs: psychological distress ☒ Social needs: social support

	☐ Spiritual needs: ☒ Health care related needs: sources of help, and income, service use
Outcomes	☐ Biological outcomes: ☒ Psycho-social outcomes: satisfaction ☐ Economic outcomes: ☐ Other: ☒ Positive on: satisfaction with overall quality of care, nursing quality of care, housekeeping/homehealth aides quality of care, and pharmacy card+ satisfaction with control over own decisions about hospital admissions. Reduction of hospital admissions ☐ No effect on: ----

Study number 18.	
GOODWIN, 2003¹⁸⁸	
Country	☒ Europe (specify): UK ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: Prospective comparative study
Objectives	To evaluate the effectiveness of palliative day care for a group of new referrals attending five centers.
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☒ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify)
Population	☐ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases ☒ Not specified: 120 patients in need of palliative care and attending 5 day care centers (new referrals) compared to patients attending the day care (using existing palliative home care services)

Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☐ Other (specify) ☒ Not specified
Interventions	☒ INTERVENTION: usual palliative care services (home-care, in-patient services, outpatient services) + <u>DAY CARE</u> ☒ CONTROL: usual palliative care services (home-care, in-patient services, outpatient services) <i>WITHOUT</i> DAY Care
Needs	☒ Biological needs: symptom management, therapeutic interventions ☒ Psychological needs: Psychological support ☒ Social needs: social support, time out of home ☐ Spiritual needs: Not reported ☐ Health care related needs: Not reported ☐ Other: respite for caregiver
Outcomes	☐ Biological outcomes: presence and severity of physical symptoms ☒ Psycho-social outcomes: quality of life, satisfaction ☐ Economic outcomes: use of services ☐ Other: carers' problems ☐ Positive on: ☒ No effect on: palliative day care was not found to improve overall health-related quality of life.

Study number 19.	
GRANDE, 1999¹⁸⁹	
Country	☒ Europe (specify): UK (Cambridge health district) ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT (pragmatic randomized controlled trial) ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To evaluate the impact on place of death of a hospital at home service for palliative care
Prognosis	Two weeks or less

Setting + organisational entity	☐ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☒ Other (specify): TRANSMURAL CARE SYSTEMS
Population	☒ Cancer ☐ Heart failure ☒ Neurodegenerative diseases ☐ Respiratory diseases ☒ AIDS A total of 229 patients of which 43 randomised to control group and 186 randomised to hospital at home.
Caregivers	☒ Nurse: 6 qualified nurses, two nursing auxiliaries and a nurse coordinator (total= 9) ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: Hospital at home + standard care. Providing up to 24h practical nursing care in the home for a maximum of 2 weeks. ☒ CONTROL: Routinely available services (standard care only)
Needs	☐ Biological needs: not specified ☐ Psychological needs: not specified ☐ Social needs: not specified ☐ Spiritual needs: not specified ☒ Health care related needs: practical nursing care
Outcomes	☐ Biological outcomes: ☐ Psycho-social outcomes: ☐ Economic outcomes: ☒ Other: place of death ☐ Positive on: ☒ No effect on: No significant difference between number of patients dying at home. Hospital at home did not increase the number of patients dying at home.

Study number 20.	
GRANDE, 2000¹⁹⁰	
Country	☒ Europe (specify): UK (Cambridge health district) ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To evaluate the impact of a Cambridge hospital at home service (CHAH) on patients' quality of care, likelihood of remaining at home in their final 2 weeks of life and general practitioner visits.
Prognosis	Two weeks or less
Setting + organisational entity	☐ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☒ Other (specify): TRANSMURAL CARE SYSTEMS
Population	☒ Cancer ☐ Heart failure ☒ Neurodegenerative diseases ☐ Respiratory diseases ☒ AIDS 262 patients (43 control) and (186 intervention)
Caregivers	☒ Nurse: 6 qualified nurses, two nursing auxiliaries and a nurse coordinator (total= 9) ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: Providing up to 24h practical nursing care in the home for a maximum of 2 weeks. ☒ CONTROL: Routinely available services (standard care)
Needs	☐ Biological needs: not specified ☐ Psychological needs: not specified ☐ Social needs: not specified ☐ Spiritual needs: not specified ☒ Health care related needs: practical nursing care

Outcomes	☒ <u>Biological outcomes</u>: presence of pain, nausea, vomiting, constipation, diarrhoea, breathlessness ☒ <u>Psycho-social outcomes</u>: anxiety, depression ☐ Economic outcomes: ☒ <u>Other</u>: district nurse, general practitioner and informal carer ratings of need for more support during final 2 weeks ☒ Positive on: fewer general practitioner out of hour visits, CHAH was rated favourably compared to standard care. District nurses rated CHAH as better than standard care, GPs in terms of anxiety and depression and informal carers in terms of control of pain and nausea. ☒ No effect on: Place of death Conclusion: CHAH was not found to increase the likelihood of remaining at home, but is associated with better quality home care.
-----------------	--

Study number 21.	
HANKS, 2002¹⁹¹	
Country	☒ Europe (specify): UK (SW of England) ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To assess the effectiveness of a hospital Palliative Care Team (PCT) on physical symptoms and health-related quality of life (HRQoL); patient, family carer and primary care professional reported satisfaction with care and health service resource use.
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☐ Day care ☒ Hospital care ☐ Nursing home ☐ Other (specify) The United Bristol Healthcare Trust (UBHT), teaching hospital trust
Population	☒ Cancer ☒ Heart failure ☒ Neurodegenerative diseases ☒ Respiratory diseases All diagnostic groups. A total of 261 patients (175 intervention); (86 control)

Caregivers	☒ Nurse: clinical nurse specialists (3) ☐ Family doctor ☒ Specialist (clinical academic consultants)= 2 + one specialist registrar ☐ Other (specify) Total caregivers= 6 (2,5 FTE) Also close links with clinical psychologist, local hospice and community based palliative care services, social workers, rehabilitation staff and the chaplaincy in the hospital.
Interventions	☒ INTERVENTION: Broad assessment of needs + development of individual treatment plan + liaison with the community ☒ CONTROL: telephone consultation between medical staff (no direct contact with patients)
Needs	☐ Biological needs: not specified ☐ Psychological needs: not specified ☐ Social needs: not specified ☐ Spiritual needs: not specified ☐ Health care related needs
Outcomes	☒ Biological outcomes: symptom control, most important symptom identified by patients, HRQoL ☒ Psychological outcomes: mood, emotional bother, satisfaction with care ☒ Health care related needs: length of hospital stay and readmission ☒ Positive on: Highly significant improvements in symptoms, HRQoL, mood and emotional bother in full PCT ☒ No effect on: satisfaction

Study number 22.	
HELGESEN, 2000¹⁹²	
Country	☒ Europe (specify): Sweden ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To evaluate medical safety, patient satisfaction and resource utilization in an on-demand follow-up by a specialist nurse compared with traditional follow-up by an urologist.

Prognosis	Expected survival of more than 3 months
Setting + organisational entity	☒ Home are ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer (prostate) ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases Total: 400 (200 intervention); (200 control)
Caregivers	☒ Nurse (specialist nurse) ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: On-demand telephone follow-up every six months by specialist nurse ☒ CONTROL: Follow-up by a urologist
Needs	☐ Biological needs: not specified ☐ Psychological needs: not specified ☐ Social needs: not specified ☐ Spiritual needs: not specified ☐ Health care related needs
Outcomes	☒ Biological outcomes: Complication frequency ☒ Psycho-social outcomes: patient satisfaction ☒ Economic outcomes: resource utilization, lag time from symptoms to intervention ☐ Other: accessibility of care ☒ Positive on: costs= mean outpatient cost per patient, especially among patients without metastases at inclusion. ☒ No effect on: Complication frequency and lag time from symptoms to intervention or the total number of interventions, accessibility of care

Study number 23.	
HIGGINSON, 1990¹⁹³	
Country	☒ Europe (specify): UK, Inner London and north Kent ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: interviews
Objectives	To investigate the current problems and needs of terminally ill cancer patients and their family members, and to discover the views of hospital, community and support team services. COORDINATION OF CARE, PROVIDING SUPPORT AND ADVICE, MEET PRACTICAL AND FINACIAL NEEDS AND TO EDUCATE + BEREAVEMENT SUPPORT
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☒ Other (specify): TRANSMURAL CARE SYSTEMS
Population	☒ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases Total: 65 + informal caregiver
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): TEAM , including doctors, nurse specialists, social worker, an administrator and volunteers.
Interventions	☒ INTERVENTION: control of symptoms, support and advice, coordinate care, meeting practical and financial need and to provide education and bereavement support ☐ CONTROL: NA
Needs	☐ Biological needs: ☐ Psychological needs:

	☐ Social needs: ☐ Spiritual needs: ☒ Health care related needs: practical and financial needs
Outcomes	☒ Biological outcomes: pain control, symptom control ☒ Psycho-social outcomes: satisfaction, patient anxiety ☒ Economic outcomes: use of services ☒ Other: caregivers satisfaction, family caregiver anxiety, communication from support team and other professionals ☒ Positive on: satisfaction with support team and other care providers (support team highest ranking in terms of satisfaction). Family caregivers more satisfied with services than patients. --Results on needs reported in other chapter of study. ☐ No effect on:

Study number 24.	
HIGGINSON, 1992¹⁹⁴	
Country	☒ Europe (specify): UK- London ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study:
Objectives	To evaluate the care by two Support Teams according to 17 key indicators.
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☒ Other (specify): TRANSMURAL CARE SYSTEMS Teams operational with National Healthservice funds
Population	☒ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases
Caregivers	☐ Nurse

	☐ Family doctor ☐ Specialist ☒ Other (specify): TEAM (support teams including medical director, 4 clinical nurses, clinical assistant, social worker, volunteer coordinator, secretary and statistician and family doctor)
Interventions	☒ INTERVENTION: Support Teams assist and advise in the care of terminally ill patients, working with hospital and community staff ☐ CONTROL: NA
Needs	☒ Biological needs: pain control, symptom control ☒ Psychological needs: patient anxiety, patient insight ☐ Social needs: social support ☒ Spiritual needs: ☒ Health care related needs: practical, financial, ☒ Other: family anxiety, family insight, predictability, planning, communication between family and patient, communication between professionals and patient
Outcomes	☒ Biological outcomes: pain control, symptom control ☒ Psychological outcomes: patient anxiety, patient insight ☒ Economic outcomes: days in home, hospital, hospice ☒ Other: family anxiety, family insight, predictability, planning, communication between family and patient, communication between professionals and patient ☒ Positive on: All items showed significant improvements, except for family and spiritual needs. ☐ No effect on: ----

Study number 25.	
HIGGINSON, 1997¹⁹⁵	
Country	☒ Europe (specify): Ireland and UK (international multicenter study) ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study:
Objectives	To evaluate the effectiveness of Support teams on pain management
Prognosis	Not specified
Setting + organisational entity	☒ Home are ☐ Day care

	☒ Hospital care ☐ Nursing home ☐ Other (specify) Teams from home care and hospital care
Population	☒ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases Total: 695 cancer patients.
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): <u>TEAM</u> , including doctors, nurses (clinical nurse specialist), volunteers. Number not specified.
Interventions	☒ INTERVENTION: 5 teams based in England, and six teams in Ireland visited and advised patients (no clear description provided). ☐ CONTROL: NA
Needs	☐ Biological needs: not specified ☐ Psychological needs: not specified ☐ Social needs: not specified ☐ Spiritual needs: not specified ☐ Health care related needs: not specified
Outcomes	☒ Biological outcomes: presence of pain ☐ Psycho-social outcomes: ☐ Economic outcomes: use of services ☐ Other: carers' problems ☒ Positive on: significant reduction in the level of pain experienced by patients, and no patient had overwhelming pain. ☐ No effect on:

Study number 26.	
HUGHES, 1992¹⁹⁶	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: Before-after
Objectives	To evaluate the effectiveness of a hospital-based team in home care
Prognosis	Less than six months
Setting + organisational entity	☐ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☒ Other (specify): TRANSMURAL CARE SYSTEMS
Population	☒ Cancer ☒ Heart failure ☒ Neurodegenerative diseases ☒ Respiratory diseases All disease categories, not specified, but terminally ill patients (total: 175)
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): TEAM: including physician (lead), nurses, social worker, physical therapist, a dietician and 'health technicians'.
Interventions	☒ INTERVENTION: development of goal-oriented, interdisciplinary patient care plans at team meetings and schedules visits according to individual patient needs. The team provides <i>comprehensive services</i> based on need. Patients are managed in and out the hospital. ☐ CONTROL: NA
Needs	☐ Biological needs: not specified ☐ Psychological needs: not specified ☐ Social needs: not specified ☐ Spiritual needs: not specified

	☐ Health care related needs: not specified
Outcomes	☒ Biological outcomes: patient functioning (activities of daily living) , patient survival ☒ Psycho-social outcomes: patient morale and satisfaction, cognitive functioning ☒ Economic outcomes: use of services + costs ☐ Other: ☒ Positive on: significant increase in patient and caregiver satisfaction with care at one month + less hospital days resulting is cost savings ☒ No effect on: patient survival, activities of daily living, cognitive functioning or morale

Study number 27.	
HUGHES 2000¹⁹⁷	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To assess the impact of Team-managed home-based primary care.
Prognosis	Not specified
Setting + organisational entity	☐ Home are ☐ Day care ☐ Hospital care ☐ Nursing home ☒ Other (specify): TRANSMURAL CARE SYSTEMS
Population	☐ Cancer ☒ Heart failure ☐ Neurodegenerative diseases ☒ Respiratory diseases Terminal illness (not specified). Total: 1966 patients (intervention); 985 (control)
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): <u>TEAM</u> , primary care manager
Interventions	☒ INTERVENTION: home-based primary care with 24-hour contact for patients, prior approval of hospital readmissions, and HBPC team participation in discharge planning

	☒ CONTROL: customary care and private sector care
Needs	☐ Biological needs: not specified ☐ Psychological needs: not specified ☐ Social needs: not specified ☐ Spiritual needs: not specified ☐ Health care related needs: not specified
Outcomes	☒ Biological outcomes: functional status, health- related quality of life ☒ Psycho-social outcomes: satisfaction with care ☒ Economic outcomes: cost of care, hospital readmissions ☒ Other: caregiver health-related quality of life, caregiver burden ☒ Positive on: health-related quality of life (emotional role function, social function, bodily pain, mental health vitality and general health) and satisfaction with care. The caregivers improved significantly in HR-QoL measures and reported reduced caregiver burden. Hospital readmissions reduced at 6 months. Costs were higher. ☒ No effect on: functional status

Study number 28.	
JORDHOY, 2000¹⁹⁸	
Country	☒ Europe (specify): Norway (Trondheim) ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT: cluster randomized trial ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	- To assess the effectiveness of an intervention programme that aims to enable patients to spend more time at home and die there if they prefer. - COORDINATION OF CARE
Prognosis	Expected survival of 2 to 9 months
Setting + organisational entity	☐ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☒ Other (specify): TRANSMURAL CARE SYSTEMS Norwegian Public Health Service

Population	☒ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases Incurable malignant disease, total: 434 (intervention: 235); (control: 199)
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): <u>TEAM</u> , including nurses (2), social worker (1), priest (1), and psychotherapist (1), linked to physicians
Interventions	☒ INTERVENTION: multidisciplinary approach to patients' needs applying a holistic philosophy. Team developed plans for treatment and care + follow-up consultations by the community staff was planned. Coordination of care was performed and the team was available for supervision and advice and to join visits at home. Educational programme for community staff included bedside training and 6-12 hours of lectures every 6 months. ☒ CONTROL: Routinely available services, a palliative medicine unit of 12 beds and an outpatient clinic.
Needs	☐ Biological needs: ☐ Psychological needs: ☐ Social needs: ☐ Spiritual needs: ☐ Health care related needs: Holistic approach but needs not specified.
Outcomes	☐ Biological outcomes: presence and severity of physical symptoms ☐ Psycho-social outcomes: psychiatric morbidity, satisfaction ☒ Economic outcomes: time spent in institutions in the last month of life ☒ Other: place of death ☒ Positive on: More intervention than control patients died at home ☒ No effect on: the time spent at home was not significantly increased, although intervention patients spent a smaller proportion of time in nursing homes in the last month of life. Hospital use was similar in both groups.

Study number 29.	
JORDHOY, 2001¹⁹⁹	
Country	☒ Europe (specify): Norway (Trondheim) ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT: cluster randomized trial ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	- To assess the effectiveness of an intervention programme that aims to enable patients to spend more time at home and die there if they prefer. - COORDINATION OF CARE
Prognosis	Expected survival of 2 to 9 months
Setting + organisational entity	☐ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☒ Other (specify): TRANSMURAL CARE SYSTEMS Norwegian Public Health Service
Population	☒ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases Incurable malignant disease, total: 434 (intervention: 235); (control: 199)
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): TEAM , including nurses (2), social worker (1), priest (1), and psychotherapist (1), linked to physicians
Interventions	☒ INTERVENTION: multidisciplinary approach to patients' needs applying a holistic philosophy. Team developed plans for treatment and care + follow-up consultations by the community staff was planned. Coordination of care was performed and the team was available for supervision and advice and to join visits at home. Educational programme for community staff included bedside training and 6-12 hours of lectures every 6 months. ☒ CONTROL: Routinely available services, a palliative medicine unit of 12 beds and an

	outpatient clinic.
Needs	☐ Biological needs: ☐ Psychological needs: ☐ Social needs: ☐ Spiritual needs: ☐ Health care related needs: Holistic approach but needs not specified.
Outcomes	☒ Biological outcomes: quality of life= physical functioning, pain ☒ Psycho-social outcomes: quality of life= emotional functioning, psychologic distress ☐ Economic outcomes: ☐ Other: ☐ Positive on: ---- ☒ No effect on: No significant differences were found between intervention and control on quality of life scores

Study number 30.	
KING, 2000²⁰⁰	
Country	☐ Europe (specify): ☐ US ☐ Canada ☒ Australia (Sydney) ☐ Asia (specify)
CB	Not reported
Design	☒ RCT: prospective randomised cross-over design ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To compare the costs and outcomes of domiciliary and hospital-based chemotherapy CONTINUITY OF CARE
Prognosis	Not specified
Setting + organisational entity	☒ Home care ☐ Day care ☒ Hospital care ☐ Nursing home ☐ Other (specify):
Population	☒ Cancer

	☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases
Caregivers	☒ Nurse: oncology nurses ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: domiciliary visits were fitted around clinic schedules and nurses travelled from the oncology unit to the patients' home. ☒ CONTROL: Routinely available services
Needs	☐ Biological needs: not specified ☐ Psychological needs: not specified ☐ Social needs: not specified ☐ Spiritual needs: not specified ☐ Health care related needs: not specified
Outcomes	☐ Biological outcomes: quality of life ☒ Psycho-social outcomes: satisfaction, unmet needs ☒ Economic outcomes: use of services, costs of domiciliary chemotherapy relative to hospital chemotherapy ☒ Other: preference and satisfaction of the carer ☒ Positive on: home based care was more expensive, patients preferred domiciliary care, ☒ No effect on: quality of life, and type and number of needs, satisfaction with care provided in either home or hospital by patients/carers.

Study number 31.	
KOFFMAN, 1996²⁰¹	
Country	☒ Europe (specify): UK (central and north-west London) ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: descriptive pilot evaluation
Objectives	Evaluation of effectiveness of hospice at home service
Prognosis	Not specified

Setting + organisational entity	☒ Home are ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify)
Population	☐ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases ☒ AIDS Total: 40 patients
Caregivers	☒ Nurse (palliative nurses + bank nurses) ☐ Family doctor ☒ Specialist (from local hospice) ☐ Other (specify)
Interventions	☒ INTERVENTION: hospice at home service including nurses trained in palliative care and HIV/AIDS and bank nurses who provide a night-sitting service. Specialist medical input is provided by two consultants in palliative medicine from local hospices. ☐ CONTROL: ---
Needs	☐ Biological needs: not specified ☐ Psychological needs: not specified ☐ Social needs: not specified ☐ Spiritual needs: not specified ☐ Health care related needs: not specified
Outcomes	☒ Biological outcomes: presence and severity of physical symptoms: pain control, other symptom control ☒ Psycho-social outcomes: patient anxiety, patient insight ☐ Economic outcomes: use of services ☐ Other: family anxiety, family insight, communication between professionals and patient and family ☒ Positive on: control of other symptoms (except pain) and family insight ☐ No effect on: ----

Study number 38.	
LUCAS, 1997²⁰²	
Country	☐ Europe (specify): ☐ US ☐ Canada ☒ Australia: Eversleigh ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study:
Objectives	Effectiveness of a liaison clinical pharmacist on patient care interventions in a palliative care inpatient unit
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☐ Day care ☒ Hospital care: inpatient palliative care unit in public hospital ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer: 264 ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases ☒ AIDS: 61 Also end-stage chronic diseases not specified: 9
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): liaison clinical pharmacist
Interventions	☒ INTERVENTION: advice to rationalize inappropriate drug regimens, warnings about drug interactions and advice about therapeutic drug monitoring. No comprehensive approach to care as such, but part of total care package. ☐ CONTROL: ----
Needs	☐ Biological needs: not specified ☐ Psychological needs: not specified ☐ Social needs: not specified

	☐ Spiritual needs: not specified ☐ Health care related needs: not specified
Outcomes	☐ Biological outcomes ☐ Psycho-social outcomes ☐ Economic outcomes ☒ Other: compliance to recommendations ☒ Positive on: Compliance by the medical and nursing staff of the hospital with the recommendations of the liaison clinical pharmacist was 55% ☐ No effect on:

Study number 33.	
LOWENTHAL, 1996²⁰³	
Country	☐ Europe (specify): ☐ US ☐ Canada ☒ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: retrospective overview
Objectives	To assess the safety and to analyse the cost-effectiveness of home treatment for cancer patients
Prognosis	Not specified
Setting + organisational entity	☒ Home care ☐ Day care ☒ Hospital care (teaching hospital) ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases Total: 424 patients
Caregivers	☒ Nurse (oncology nurses) ☐ Family doctor ☐ Specialist

	☐ Other (specify)
Interventions	☒ INTERVENTION: Home oncology nursing service: Counselling, education, and support were provided at each visit, and each patient's general practitioner was kept fully informed. ☐ CONTROL: NA
Needs	☐ Biological needs: not specified ☐ Psychological needs: not specified ☐ Social needs: not specified ☐ Spiritual needs: not specified ☐ Health care related needs: not specified
Outcomes	☒ Biological outcomes: the rate of major complications ☐ Psycho-social outcomes: ☒ Economic outcomes: direct costs of chemotherapy administration ☐ Other: carers' problems ☒ Positive on: home chemotherapy less expensive compared to in-hospital care ☐ No effect on: ----

Study number 34.	
LLOYD-WILLIAMS, 2002²⁰⁴	
Country	☒ Europe (specify): UK, (Liverpool) ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study:
Objectives	Evaluation of implementation of multidisciplinary guideline for patients with dementia
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☐ Day care ☒ Hospital care (Long stay unit of a psychiatric hospital) ☐ Nursing home ☐ Other (specify)

Population	☐ Cancer ☐ Heart failure ☒ Neurodegenerative diseases: dementia: total number of patients : 27 ☐ Respiratory diseases
Caregivers	☒ Nurse ☐ Family doctor ☒ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: implementation of multidisciplinary guidelines in hospital unit ☐ CONTROL: -----
Needs	☒ Biological needs: symptoms and symptom control: pain, drugs ☒ Psychological needs: psychological distress ☐ Social needs: social support ☐ Spiritual needs: ☐ Health care related needs:
Outcomes	☒ Biological outcomes: presence and severity of physical symptoms ☒ Psycho-social outcomes: psychological distress ☒ Economic outcomes: drug use ☐ Other: carers' problem ☒ Positive on: significant decrease in the prescribing of antibiotics in the last two weeks of life. ☐ No effect on: ----

Study number 35.	
MCCANN, 1991²⁰⁵	
Country	☒ Europe (specify): UK (London) ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: structured interviews
Objectives	To evaluate an AIDS home support team: views and experiences of patients using the service COORDINATION OF CARE BETWEEN SERVICES AND CONTINUITY OF CARE BETWEEN HOSPITAL AND HOME
Prognosis	Not specified
Setting + organisational	☐ Home care

entity	☐ Day care ☐ Hospital care ☐ Nursing home ☒ Other (specify): TRANSMURAL CARE SYSTEMS (outpatient clinic, home care, wards in hospital)
Population	☐ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases ☒ AIDS Total: 119
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): hospital-based team
Interventions	☒ INTERVENTION: AIDS homes support team providing counselling and psychological and social support + practical help ☐ CONTROL: ----
Needs	☒ Biological needs: advice about medicine, taking blood, dressings, taking temperature, ☒ Psychological needs: giving reassurance and support and bereavement support ☒ Social needs: social support ☐ Spiritual needs: ☒ Health care related needs: arrange meals and transport
Outcomes	☐ Biological outcomes ☒ Psycho-social outcomes: patient satisfaction ☐ Economic outcomes ☐ Other: ☒ Positive on: patient satisfaction (49% saying the team gave excellent care, and 37% very good care) ☐ No effect on: ---- Conclusion: The strength of the HST was seen in offering general support. Liaison between hospital and home care considered essential in care for patients with AIDS.

Study number 36.	
MCCARTHY, 1996²⁰⁶	
Country	☒ Europe (specify): UK ☐ US

	☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: interviews
Objectives	To describe symptoms experienced in the last year of life by people with heart disease/informal carers' satisfaction with hospital services.
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☐ Day care ☒ Hospital care ☐ Nursing home ☐ Other (specify)
Population	☐ Cancer ☒ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases Informal carers: 600
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): TEAM (doctors and nurses)
Interventions	☒ INTERVENTION: hospital care team ☐ CONTROL: NA
Needs	☐ Not specified
Outcomes	☐ Biological outcomes: ☐ <u>Psycho-social outcomes: satisfaction</u> ☐ Economic outcomes: ☐ Other: carers' problems ☒ Positive on: satisfaction ☐ No effect on: Conclusion: Only satisfaction is withdrawn as an outcome measure to evaluate care provided in the hospital

Study number 37.	
MCCORCLE, 1998²⁰⁷	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	The Trajectory Framework of Strauss et al. provides a conceptual basis for understanding and shaping the experience of older people living with and dying from cancer.
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To evaluate the effects of a nursing intervention on quality of life outcomes of older cancer patients. COORDINATION OF CARE
Prognosis	Greater than six months
Setting + organisational entity	☒ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer: surgical treatment of cancer: 37 patients who died after receiving the complete home nursing intervention ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases
Caregivers	☒ Nurse (advanced nurses in oncology) ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: postsurgical follow-up of care + a short-term home nursing intervention (8 scheduled contacts)—including 3 home visits and 5 telephone calls, provided by advanced practice nurses in oncology, including a comprehensive clinical assessment that focused on patient symptom management, coordination of care with the family, patient, primary physician, community resources, home health agency ☒ CONTROL: post surgical follow-up of care
Needs	☒ Biological needs: symptom management, functional ability

	☒ Psychological needs: mental health ☐ Social needs: social support ☐ Spiritual needs: ☐ Health care related needs: ☒ Caregivers needs:
Outcomes	☒ Biological outcomes: functional status ☒ Psycho-social outcomes: symptom distress, social competence including housework, work and recreational activities, depression ☐ Economic outcomes: use of services ☒ Other: survival ☒ Positive on: symptom distress ☐ No effect on: ----

Study number 38.	
MCMILLAN, 2007²⁰⁸	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Stress process model wherein patients' symptoms and symptom distress were viewed as stressors for caregivers.
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: Before-after: three group repeated measures design
Objectives	To assess an intervention for hospice caregivers designed to help them manage symptoms experienced by patients with cancer.
Prognosis	Not specified
Setting + organisational entity	☒ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases

	- 160 patient-caregivers dyads - Intervention 1: 109, intervention 2: 111, control: 109
Caregivers	☒ Nurse ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: treatment group I: standard care from the hospice staff + 3 visits + individual emotional support to caregivers. Treatment group II/ standard care + COPE intervention method to assist them in assessing and managing patient problems. The COPE intervention has four components (<i>creativity/optimism/planning/expert-information</i>) that caregivers receive over 9 days to assist with symptom management. ☒ CONTROL: I. standard care from hospice staff (some caregiver education and support about symptom management)
Needs	☒ Biological needs: pain, dyspnoe, constipation, quality of life ☒ Psychological needs: psychological distress, quality of life ☒ Social needs: social well-being ☒ Spiritual needs: spiritual well-being ☐ Health care related needs: sources of help, and income, service use
Outcomes	☒ Biological outcomes: presence and severity of physical symptoms: pain intensity, dyspnoe intensity, constipation ☒ Psycho-social outcomes: distress ☐ Economic outcomes: ☒ Other: carers' problems= distress caused by all symptoms of patient ☒ Positive on: symptom distress was significantly improved in the COPE intervention group. ☒ No effect on: quality of life, symptom intensity for pain, dyspnoe and constipation.

Study number 39.	
MCQUILLAN, 1996²⁰⁹	
Country	☒ Europe (specify): UK ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study:
Objectives	Evaluation of the effectiveness of a palliative care service

	EFFECTIVENESS
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☐ Day care ☒ Hospital care: a large tertiary referral hospital ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases ☒ HIV Total: 350 patients
Caregivers	☐ Nurse ☐ Family doctor ☒ Specialist ☒ Other (specify): pharmacist
Interventions	☒ INTERVENTION: Palliative care service providing assistance and consultancy to hospital staff. ☐ CONTROL: ----
Needs	☒ Biological needs: symptoms and symptom control, drugs ☒ Psychological needs: psychological distress ☐ Social needs: social support ☐ Spiritual needs: ☐ Health care related needs: sources of help, and income, service use
Outcomes	☒ Biological outcomes: presence and severity of physical symptoms ☐ Psycho-social outcomes: ☐ Economic outcomes: ☒ Other: satisfaction of the hospital staff ☒ Positive on: patients' symptom scores during hospital stay and increase in the use of appropriate opioid analgesics and NSAIDs, satisfaction of hospital staff ☐ No effect on: Conclusion: The introduction of a Palliative care service providing assistance and consultancy to hospital staff is feasible.

Study number 40.	
MCWHINNEY, 1994²¹⁰	
Country	☒ Europe (specify): UK ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To evaluate a palliative care home support team based on an inpatient unit. CONTINUITY OF CARE
Prognosis	Expected to survive for two months .
Setting + organisational entity	☐ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☒ Other (specify): TRANSMURAL CARE SYSTEMS
Population	☒ Cancer (metastasised): 146 randomised + 74 caregivers ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): TEAM, including 2 palliative care nurses, 1 physician, 1 social worker.
Interventions	☒ INTERVENTION: Palliative care home support team: a consulting and support service for family physicians and home care nurses + night service for patients. One of the team nurses was available 24-hours a day. Immediate intervention after enrolment. ☒ CONTROL: Palliative care home support team (after one month)
Needs	☐ Biological needs: symptoms and symptom control, activities of daily living, drugs ☐ Psychological needs: psychological distress ☐ Social needs: social support ☐ Spiritual needs:

	☐ Health care related needs: sources of help, and income, service use
Outcomes	☒ Biological outcomes: pain and nausea levels, quality of life ☐ Psycho-social outcomes: ☐ Economic outcomes: ☒ Other: caregiver's health ☐ Positive on: ☒ No effect on: no clinically or statistically significant differences between experimental and control groups on any of the measures at one month. No other results reported

Study number 41.	
MICHEELS, 1995²¹¹	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: a retrospective chart review
Objectives	To assess the relationships between case management and length of hospital stay among patients with colon resection. EFFECTIVENESS
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☐ Day care ☒ Hospital care: 450-bed, tertiary care, not-for-profit hospital in the Midwest ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer: colon resection ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases Intervention: 35, control: 43

Caregivers	☒ Nurse ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: case management by an advanced practice nurse ☐ CONTROL: no case management
Needs	☐ Biological needs: not specified ☐ Psychological needs: not specified ☐ Social needs: not specified ☐ Spiritual needs: not specified ☐ Health care related needs: not specified
Outcomes	☐ Biological outcomes: ☐ Psycho-social outcomes: ☒ Economic outcomes: use of services: required nursing care hours per patient per day (= patient acuity) and length of stay. ☐ Other: ☐ Positive on: ---- ☒ No effect on: patient acuity and length of stay

Study number 42.	
MILLER, 2005⁵⁴	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To evaluate the effects of an innovative program to address psycho-socio-spiritual needs in patients with life-threatening illnesses EFFECTIVENESS
Prognosis	'Limited life expectancy'
Setting + organisational entity	☒ Home are ☐ Day care

	☐ Hospital care ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer ☒ Heart failure ☐ Neurodegenerative diseases ☒ Respiratory diseases ☒ AIDS Also: frail elderly, kidney disease, liver disease Total: 69 (intervention: 37; control: 32)
Caregivers	☒ Nurse ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: LTI-sage groups. Monthly meetings for 12 months (75 minutes per session) in groups of 3-8 patients and 1 to 2 group facilitators + informal caregiver receiving adult affective education and support. The process relied on discussing experiences, expressing feelings and sharing support. ☒ CONTROL: Routinely available services
Needs	☐ Biological needs: ☒ Psychological needs: emotional well-being ☒ Social needs: social well-being ☒ Spiritual needs: spiritual well-being ☐ Health care related needs
Outcomes	☐ Biological outcomes ☒ Psycho-social outcomes: depression symptoms, anxiety, spiritual well-being and death related emotional stress ☐ Economic outcomes ☐ Other ☒ Positive on: symptoms of depression and death-related feelings of meaninglessness and spiritual well-being. ☐ No effect on: ---

Study number 43.	
MOONS, 1994²¹²	
Country	☒ Europe (specify): The Netherlands - Rotterdam ☐ US ☐ Canada

	☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: exploratory study: semi-structured interviews with patient and caregiver
Objectives	To evaluate a new palliative care service for patients with AIDS at home EFFECTIVENESS
Prognosis	Not reported
Setting + organisational entity	☒ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify):
Population	☐ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases ☒ AIDS Total: 10 patients
Caregivers	☒ Nurse (2) specializing in the care of AIDS patients ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: Two specialized hospital nurses visited the patients at home and worked in close collaboration with community nurses. They provided technical-medical care at home. This care included special treatment (blood samples, sputum culture,...), education on treatment, medication, ... and support (acceptance of illness and death) to patient and family. Two physicians specializing in internal medicine were part of the organization of the outpatient clinic for internal medicine. ☐ CONTROL: Routinely available services
Needs	☒ Biological needs: symptoms and symptom control, activities of daily living, drugs ☒ Psychological needs: psychological distress ☒ Social needs: social support ☒ Spiritual needs: ☒ Health care related needs: sources of help, and income, service use

Outcomes	☐ Biological outcomes: ☒ Psycho-social outcomes: patient satisfaction ☐ Economic outcomes: use of services ☒ Other: carers' satisfaction ☒ Positive on: patient and caregiver satisfaction (informal and formal caregivers) ☐ No effect on: ----
-----------------	--

Study number 44.	
MOORE, 2002²¹³	
Country	☒ Europe (specify): UK ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To assess the effectiveness of nurse led follow-up in the management of patients with lung cancer EFFECTIVENESS
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☐ Day care ☒ Hospital care: specialized cancer hospital and three cancer units in Southeastern England. ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer: lung cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases
Caregivers	☒ Nurse ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: Nurse led follow up of outpatients + allocation of patients to nurse and monthly assessment over the phone based on a protocol to identify signs of disease

	progression, symptoms warranting intervention or serious complications. Patients had access to the nurses in the nurse led clinic or by phone without an appointment. ☒ CONTROL: Routinely available services
Needs	☒ Biological needs: symptoms and symptom control, activities of daily living, drugs ☒ Psychological needs: psychological distress ☒ Social needs: social support ☐ Spiritual needs: ☒ Health care related needs: sources of help, and income, service use
Outcomes	☒ Biological outcomes: quality of life, symptom free survival, progression free survival ☒ Psycho-social outcomes: patient satisfaction ☒ Economic outcomes: use of resources= number of consultations ☒ Other: general practitioners satisfaction, place of death ☒ Positive on: Dyspnoe, emotional functioning, peripheral neuropathy, satisfaction, place of death, number of consultations. ☒ No effect on: general practitioners satisfaction, survival or rates of objective progression.

Study number 45.	
NICKEL, 1996²¹⁴	
Country	☐ Europe (specify): ☒ US: Ohio ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To evaluate the effectiveness of a case management model for patients with AIDS EFFECTIVENESS
Prognosis	Not Specified
Setting + organisational entity	☒ Home are ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify)
Population	☐ Cancer ☐ Heart failure ☐ Neurodegenerative diseases

	☐ Respiratory diseases ☒ AIDS: 57 (intervention: 29; control: 28)
Caregivers	☒ Nurse (case managers) ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: a supplementary level of care monitoring and direction with both direct services by the nurse case manager and consultation to the agency nurse assigned to the patient. The protocol included procedures of a) comprehensive assessment, b) care planning with monthly review by an interdisciplinary team consisting of nurse case managers, agency home care nurse, infectious disease and public health physicians, a social worker, psychiatrist, nutritionist, member of the clergy, pharmacist, and dentist; c) twicemonthly review of subject needs and services by a team core group consisting of the case manager, social worker, and public health physician d) ongoing case manager observation and monitoring of subject reports of service quality. Close follow-up of patient progress and service delivery was provided through telephone calls and home visits. ☒ CONTROL: Routinely available services by agency home care nurses.
Needs	☒ Biological needs: ☒ Psychological needs: ☒ Social needs: ☒ Spiritual needs: ☒ Health care related needs: Comprehensive assessment
Outcomes	☒ Biological outcomes: Quality of Well-being index scores ☐ Psycho-social outcomes: ☐ Economic outcomes: ☐ Other: ☒ Positive on: quality of life ☐ No effect on: Conclusion: Case management in patients with AIDS is effective on quality of life.

Study number 46.	
RABOW, 2004²¹⁵	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported

Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To evaluate the effectiveness of outpatient palliative medicine consultation teams EFFECTIVENESS
Prognosis	One to 5 years life expectancy
Setting + organisational entity	☐ Home care ☐ Day care ☒ Hospital care/ GENERAL MEDICINE OUTPATIENT CLINIC (University Medical Centre) ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer ☒ Heart failure ☐ Neurodegenerative diseases ☒ Respiratory diseases Intervention: 50, Control: 40
Caregivers	☐ Nurse ☒ Family doctor in liaison with Comprehensive Care Team-CCT- (including social worker, nurse chaplain, pharmacist, psychologist, art therapist, volunteer coordinator and 3 physicians). Total: 9 ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: Primary care physicians received multiple palliative care team consultations, and patients received care planning, psychosocial support and family caregiver training. The CCT intervention included 7 main components: 1) Consultation with PCP 2) Social worker provided case management and psychological support 3) Nurse provided family caregiver training and support 4) Pharmacist performed medical chart review of patient medications 5) Chaplain offered spiritual and psychological support 6) Patients and their families were invited monthly to support groups 7) Medical and pharmacy students provided volunteer patient support ☒ CONTROL: Routinely available services
Needs	☒ Biological needs: symptoms and symptom control, activities of daily living, drugs ☒ Psychological needs: psychological distress ☒ Social needs: social support ☒ Spiritual needs: spiritual well-being ☒ Health care related needs: sources of help, and income, service use
Outcomes	☒ Biological outcomes: presence and severity of physical symptoms: dyspnoea, pain, quality of life ☒ Psycho-social outcomes: psychiatric morbidity: anxiety, sleep quality, depression,

	satisfaction ☒ Economic outcomes: use of services: primary care and urgent care visits, emergency department visits, specialty clinic visits, hospitalizations, number of days in hospital ☐ Other: ☒ Positive on: dyspnoe, anxiety, improved sleep quality and spiritual well-being, primary care and urgent care visits, emergency department visits, specialty clinic visits, hospitalizations, number of days in hospital ☒ No effect on: pain, depression, quality of life and satisfaction
--	--

Study number 47.	
RAFTERY, 1996²¹⁶	
Country	☒ Europe (specify): UK –South London-- ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To compare the cost-effectiveness of a coordination service with standard services for terminally ill cancer patients COORDINATION OF CARE/
Prognosis	Prognosis of less than one year.
Setting + organisational entity	☒ Home are ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases Total: 167 patients, Intervention: 86, control 81
Caregivers	☒ Nurse: nurse coordinators WITH A CERTIFICATE IN CARE OF THE DYING PATIENT ☐ Family doctor ☐ Specialist ☐ Other (specify)

Interventions	☒ INTERVENTION: nurses acted as brokers of services. Their role was to assess the need for services from NHS, local authority and voluntary sector agencies. To offer advice on how to obtain services and to contact the agencies themselves if necessary, to ensure that services were provided and were well co-ordinated, to monitor the changing needs of the patient and family for services. The co-ordinators did not provide practical nursing care, specialist palliative care advice or counselling services. ☐ CONTROL: Routinely available services
Needs	☒ Biological needs: symptoms and symptom control, activities of daily living, drugs ☒ Psychological needs: psychological distress ☒ Social needs: social support ☒ Spiritual needs: ☒ Health care related needs: sources of help, and income, service use Comprehensive assessment
Outcomes	☐ Biological outcomes: ☐ Psycho-social outcomes: ☒ Economic outcomes: use of services ☐ Other: ☒ Positive on: costs: coordination group used significantly fewer inpatient days and nurse home visits. Mean cost per coordinated patient was almost half of that of the control groups patients. ☐ No effect on: ---- Conclusion: a coordination service is effective on costs.

Study number 48.	
RINGDAL, 2002²¹⁷	
Country	☒ Europe (specify): NORWAY (Trondheim) ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To examine the satisfaction with care of family members with a comprehensive palliative care program. COORDINATION OF CARE
Prognosis	Not specified

Setting + organisational entity	☐ Home care ☐ Day care ☐ Hospital care: ☐ Nursing home ☒ Other (specify): TRANSMURAL CARE SYSTEMS organized by University hospital
Population	☒ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases Family members of patients with cancer: 112 intervention, and 68 control
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): TEAM , including nurses (2), social worker (1), priest (1), and psychotherapist (1), linked to physicians
Interventions	☒ INTERVENTION: multidisciplinary approach to patients' needs applying a holistic philosophy. Team developed plans for treatment and care + follow-up consultations by the community staff was planned. Coordination of care was performed and the team was available for supervision and advice and to join visits at home. Educational programme for community staff included bedside training and 6-12 hours of lectures every 6 months. ☒ CONTROL: Routinely available services, a palliative medicine unit of 12 beds and an outpatient clinic.
Needs	☐ Biological needs ☐ Psychological needs ☐ Social needs ☐ Spiritual needs ☐ Health care related needs
Outcomes	☐ Biological outcomes ☐ Psycho-social outcomes ☐ Economic outcomes ☒ Other: satisfaction of family caregiver ☒ Positive on: satisfaction ☐ No effect on: ---- Conclusion: a multidisciplinary team approach is effective on satisfaction in family caregivers of patients with cancer.

Study number 49.	
RITZ, 2000²¹⁸	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To evaluate quality of life and cost outcomes of advanced practice nurses' (APN's) interventions with woman diagnosed with breast cancer CONTINUITY OF CARE/ CARE COORDINATION
Prognosis	Not specified
Setting + organisational entity	☒ Home are ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer: breast cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases
Caregivers	☒ Nurse: advanced practice nurse ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: standard medical care + APN care = a) assessment/b) education/c) care coordination: written en verbal information about breast cancer, what to expect in consultation with physicians, decision-making support, answering questions and presence for support. Contacts were made with the patients (clinic visits, home visits) ☒ CONTROL: Routinely available services
Needs	☒ Biological needs: symptoms and symptom control, activities of daily living, drugs ☒ Psychological needs: psychological distress ☒ Social needs: social support ☐ Spiritual needs: ☒ Health care related needs: sources of help, and income, service use

Outcomes	☒ Biological outcomes: quality of life (uncertainty, perceptions of complexity, inconsistency and unpredictability of information about their illness and outcome) ☒ Psycho-social outcomes: mood, well-being ☒ Economic outcomes: use of services ☐ Other: carers' problems ☒ Positive on: quality of life (moods and well-being) ☒ No effect on: cost-differences between intervention and control Conclusion: The APN interventions had positive effect on quality of life, but not on costs.
-----------------	---

Study number 50.	
RUMMANS, 2006²¹⁹	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To evaluate the feasibility and effectiveness of a structured multidisciplinary intervention targeted to maintain overall quality of life of patient with cancer.
Prognosis	Survival time of at least 6 months, estimated 5 year survival rate of 0% to 50%
Setting + organisational entity	☐ Home care ☐ Day care ☒ Hospital care: ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer: radiation therapy for patients with advanced cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases Total: 103, intervention: 49, control: 54
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist

	☒ Other (specify): TEAM: social worker, nurse, physical therapist, psychiatrist, psychologist, chaplain.
Interventions	☒ INTERVENTION: Structured sessions including different topics under cognitive interventions, emotional interventions, physical intervention, social intervention and spiritual intervention (education, lifestyle changes, health lifestyle, stress management, etc....) ☒ CONTROL: standard medical care as recommended by the radiation oncologist
Needs	☒ Biological needs: symptoms and symptom control, activities of daily living, drugs ☒ Psychological needs: psychological distress ☒ Social needs: social support ☒ Spiritual needs: ☒ Health care related needs: sources of help, and income, service use
Outcomes	☒ Biological outcomes: quality of life: physical functioning ☒ Psycho-social outcomes: quality of life: cognitive and emotional functioning, spiritual and social functioning ☐ Economic outcomes ☐ Other ☒ Positive on: quality of life ☐ No effect on: ---- Conclusion: a structured multidisciplinary intervention can help maintain or even improve QOL in patients with advanced cancer who are undergoing cancer treatment.

Study number 51.	
SEALE, 1997²²⁰	
Country	☒ Europe (specify): UK ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: interviews
Objectives	To compare the quality of inpatient care through interviews with spouses of people who had died from cancer
Prognosis	
Setting + organisational entity	☐ Home care ☐ Day care ☒ Hospital care ☐ Nursing home

	☐ Other (specify)
Population	☒ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases 33 patients who died in hospice and 33 who died in hospitals
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☐ INTERVENTION: hospice care and hospital care ☐ CONTROL: ----
Needs	☐ Biological needs: not specified ☐ Psychological needs: not specified ☐ Social needs: not specified ☐ Spiritual needs: not specified ☐ Health care related needs: not specified
Outcomes	☐ Biological outcomes ☐ Psycho-social outcomes ☐ Economic outcomes ☒ Other: satisfaction of caregivers (spouses) ☒ Positive on: communication by hospice staff was judged better than that by hospital doctors. ☐ No effect on:

Study number 52.	
SCHWARTZ, 2002²²¹	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT

	☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To evaluate the feasibility of early intervention in planning end-of-life care with ambulatory geriatric patients.
Prognosis	Not specified
Setting + organisational entity	☒ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify)
Population	☐ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases <i>Geriatric patients with chronic or life threatening disease (n=61)</i>
Caregivers	☒ Nurse facilitator ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: nurse discusses advanced care planning with patient ☒ CONTROL: a healthcare proxy form
Needs	☒ Biological needs: symptoms and symptom control, activities of daily living, drugs ☒ Psychological needs: psychological distress ☒ Social needs: social support ☒ Spiritual needs: ☒ Health care related needs: sources of help, and income, service use
Outcomes	☐ Biological outcomes: presence and severity of physical symptoms ☒ Psycho-social outcomes: patient preferences ☐ Economic outcomes: use of services ☐ Other: carers' problems ☒ Positive on: higher congruence between agents and patients in understanding of patients' end-of-life care preferences. Intervention patients became less willing to undergo life-sustaining treatments for a new serious medical problem, more willing to undergo such treatments for an incurable progressive disease, and less willing to tolerate poor health states. ☐ No effect on: ---- Conclusion: a facilitated discussion about end-of-life care between patients and their health agents helps define and document the patient's wishes for both patient and agent.

Study number 53.	
SIEGEL, 1992²²²	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	Evaluation of a program to address the unmet needs of cancer patients
Prognosis	Not specified
Setting + organisational entity	☒ Home are ☐ Day care ☐ Hospital care ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer: patients who were receiving chemotherapy ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases = Intervention: 109; control: 130
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): social worker
Interventions	☒ INTERVENTION: Automated telephone needs assessment coupled with social worker follow-up. Intervention patients received three automated surveys. ☒ CONTROL: comprehensive needs assessment but not through survey
Needs	☒ Biological needs: symptoms and symptom control, activities of daily living, drugs ☒ Psychological needs: psychological distress ☒ Social needs: social support ☒ Spiritual needs: ☒ Health care related needs: sources of help, and income, service use

Outcomes	☐ Biological outcomes ☐ Psycho-social outcomes ☐ Economic outcomes ☒ Other: number of unmet needs ☒ Positive on: Patients in the experimental group reported fewer unmet needs in a comprehensive assessment than those in the control group. ☐ No effect on: Conclusion: The computerized telephone outreach system provided to be a cost-effective for the early identification of unmet patient needs soon after they emerge and efficient deployment of limited professional staff.
-----------------	---

Study number 54.	
SMEENK, 1998²²³	
Country	☒ Europe (specify): The Netherlands - Eindhoven ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☒ Controlled study: experimental design ☐ Descriptive/Observational study:
Objectives	To evaluate the cost of a transmural programme intended to optimize COMMUNICATION, COOPERATION AND COORDINATION between the intra and extra mural health care organizations.
Prognosis	Prognosis of less than 6 months
Setting + organisational entity	☐ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☒ Other (specify): TRANSMURAL CARE SYSTEMS
Population	☒ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases Intervention: 79 and control:37

Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): TEAM including a specialist nurse coordinator, general practitioner, specialist, a 24 h telephone service in the hospital with access to the transmural home team, a collaborative home care dossier (case file) and protocols designed for specific care.
Interventions	☒ INTERVENTION: standard care for oncology patients + primary care team that works in close collaboration with a team from the hospital. The team offered care tailored to individual needs of the patient. ☒ CONTROL: Only standard care for oncology patients.
Needs	☒ Biological needs: symptoms and symptom control, activities of daily living, drugs ☒ Psychological needs: psychological distress ☒ Social needs: social support ☒ Spiritual needs: ☒ Health care related needs: sources of help, and income, service use
Outcomes	☐ Biological outcomes ☐ Psycho-social outcomes ☐ Economic outcomes: costs, use of services ☐ Other ☒ Positive on: rehospitalization rate, costs for drugs ☐ No effect on: No significant difference could be found for total health care costs between the groups Conclusion: a transmural care program significantly reduces costs for drugs and rehospitalization, but community nursing and home help costs were significantly higher.

Study number 55.	
TOPP, 1998²²⁴	
Country	☐ Europe (specify): ☒ US (Ohio) ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: review of records
Objectives	To evaluate the effect of case management by a clinical case manager on hospitalized length of stay and hospital charge for patient with congestive

	heart failure.
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☐ Day care ☐ Hospital care ☐ Nursing home ☒ Other (specify): TRANSMURAL CARE SYSTEMS starting from a 700-bed acute urban care facility
Population	☐ Cancer ☒ Heart failure: congestive heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases = Intervention: 88; Control: 403
Caregivers	☒ Nurse (clinical nurse specialist) ☐ Family doctor ☐ Specialist ☐ Other (specify)
Interventions	☒ INTERVENTION: case management, with the definition of 4 groups: a) case management with cardiologist involvement b) case management without cardiologist involvement c) no case management with cardiologist involvement d) no case management and no cardiologist involvement The clinical nurse specialist executed the following interventions: - assessment of resources and assuring the coordination of care between inpatient, outpatient and home care settings - assistance with communication of patient information throughout the health care system to assure continuity of care - assessment of patient/family educational needs and recommendation or provision of appropriate education - evaluation and feedback regarding critical thinking and delegation skills among RN care providers to enhance care of the patients with CHF - suggestions to other health care providers and hospital administrators for improving customer satisfaction and patient outcomes - functioning as a patient advocate and liaison between patient/family and the health care team to ensure that patient needs were met ☐ CONTROL: ----
Needs	☒ Biological needs: symptoms and symptom control, activities of daily living, drugs ☒ Psychological needs: psychological distress ☒ Social needs: social support ☐ Spiritual needs: ☒ Health care related needs: sources of help, and income, service use
Outcomes	☐ Biological outcomes

	☐ Psycho-social outcomes ☒ Economic outcomes: length of stay, hospital charges ☐ Other ☒ Positive on: length of stay and hospital charges. A significant interaction between case management and the involvement of a cardiologist was noted. Patients whose care involved a cardiologist without case management demonstrated significantly greater length of stay and hospital charges than patients who were case managed by a clinical nurse specialist and patients whose care did not involve a cardiologist. ☐ No effect on: ---- Conclusion: the group of patients who were case managed by a clinical nurse specialist demonstrated significantly shorter length of stay and lower hospital charges than the patients who were not case managed.
--	--

Study number 56.	
TOSELAND, 1995²²⁵	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☒ RCT: a three factor RCT ☐ Controlled study: ☐ Descriptive/Observational study:
Objectives	To assess the impact of a short-term individual counselling program for cancer caregivers of both the caregiver and the cancer patient. EFFECTIVENESS, REDUCING UNMET NEEDS
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☐ Day care ☒ Hospital care ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer: breast, lung and prostate cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases Total : 78 participants, Intervention: 40, Control: 38, caregivers

Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): SOCIAL WORKER
Interventions	☒ INTERVENTION: an experienced oncology social worker provided six 1-h individual counselling sessions. The social worker used a problem solving model within the context of a supportive helping relationship. ☒ CONTROL: Did not receive individual sessions (problem solving intervention).
Needs	☒ Biological needs: health status (physical functioning), pain ☒ Psychological needs: depression, anxiety, role functioning, mental health, health perceptions, burden of caregiver, coping, pressing (=stressful) problems ☒ Social needs: social functioning, marital satisfaction ☐ Spiritual needs: ☒ Health care related needs: help-seeking: sources of help, and income, service use
Outcomes	☐ Biological outcomes: presence and severity of physical symptoms ☐ Psycho-social outcomes: psychiatric morbidity, satisfaction ☐ Economic outcomes: use of services ☐ Other: carers' problems ☐ Positive on: --- ☒ No effect on: the intervention had no significant impact on caregivers and care recipients.

Study number 57.	
TRAMARIN, 1992²²⁶	
Country	☒ Europe (specify): Italy (Vincenza) ☐ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Approach based on the principles of palliative care
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: a six month prospective study
Objectives	To evaluate the costs and cost-effectiveness of home-care assistance as an alternative to hospital-based care only for patients with AIDS EFFICIENCY AND EFFICACY IMPROVING QUALITY OF LIFE
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☐ Day care

	☐ Hospital care ☐ Nursing home ☒ Other (specify): TRANSMURAL CARE SYSTEMS, inpatient and outpatient services.
Population	☐ Cancer ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases ☒ AIDS Intervention: 10, control: 32
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): TEAM including nurses (4), family doctor, psychologist (1), volunteers (10), social workers, and specialists (2)
Interventions	☒ INTERVENTION: hospital-based care + home services ☒ CONTROL: hospital-based care
Needs	☒ Biological needs: symptoms and symptom control, activities of daily living, drugs ☒ Psychological needs: psychological distress ☒ Social needs: social support ☐ Spiritual needs: ☒ Health care related needs: sources of help, and income, service use
Outcomes	☐ Biological outcomes ☐ Psycho-social outcomes ☒ Economic outcomes: costs ☐ Other: carers' problems ☒ Positive on: Costs. ☐ No effect on: ---- Conclusion: Home-care assistance appears to be a cost-effective strategy for the treatment and care of patients with AIDS

Study number 58.	
VINEY, 1994²²⁷	
Country	☐ Europe (specify): ☐ US ☐ Canada ☒ Australia:

	☐ Asia (specify)
CB	Personal construct model of good dying was chosen as a guide to the research program
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study:
Objectives	To evaluate the quality of life of terminal cancer patients in two palliative care units with that of those in a general hospital.
Prognosis	4 months or less.
Setting + organisational entity	☐ Home care ☐ Day care ☒ Hospital care: a specialist 10-bed palliative care unit within a 90-bed hospital. ☐ Nursing home ☐ Other (specify)
Population	☒ Cancer: terminal cancer patients. ☐ Heart failure ☐ Neurodegenerative diseases ☐ Respiratory diseases Total: 183 patients. 62 patients used the small palliative care unit and 60 used the large Sydney-based palliative care unit. A third group of 61 patients were interviewed in a small general hospital.
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): TEAM (no specifications on composition)
Interventions	☒ INTERVENTION: palliative care operationalized as support to patients, support of family and friends, awareness of patients' emotions, awareness of emotions of family and friends. ☐ CONTROL: ----
Needs	☐ Biological needs: ☒ Psychological needs: ☒ Social needs: ☐ Spiritual needs: ☐ Health care related needs: sources of help, and income, service use
Outcomes	☐ Biological outcomes: ☒ Psycho-social outcomes: quality of life consisting of a set of nine psychological states: uncertainty, anxiety, depression, anger expressed directly and indirectly, helplessness indicating distress, competence, sociability and good feelings. ☐ Economic outcomes

	☐ Other ☒ Positive on: the cancer patients dying in the two specialized palliative care services showed better quality of life than patients dying in the hospital (non-specialized care unit): less expression of indirect expression of anger. Cancer patients in the smaller palliative care unit showed greater frustration in their helplessness and anger. ☒ No effect on: direct expression of anger. Patients in the smaller unit expressed significantly more helplessness than those dying in the hospital. Conclusions: Terminal cancer patients in palliative care units show less indirectly expressed anger and better morale than those who died in the hospital.
--	--

Study number 59.	
VOLICER, 1994²²⁸	
Country	☐ Europe (specify): ☒ US ☐ Canada ☐ Australia: ☐ Asia (specify)
CB	Not reported
Design	☐ RCT ☐ Controlled study: ☒ Descriptive/Observational study: Two year prospective cohort study.
Objectives	To compare outcomes in patients with the clinical diagnosis of dementia of the Alzheimer type cared for in a Dementia Special Care Unit (DSCU) with those in traditional long-term care.
Prognosis	Not specified
Setting + organisational entity	☐ Home care ☐ Day care ☒ Hospital care: Two Veterans Administration Hospitals ☐ Nursing home ☐ Other (specify)
Population	☐ Cancer ☐ Heart failure ☒ Neurodegenerative diseases: Alzheimer's disease ☐ Respiratory diseases
Caregivers	☐ Nurse ☐ Family doctor ☐ Specialist ☒ Other (specify): TEAM (not specified)

Interventions	☒ INTERVENTION: maintenance of patients' comfort based on advanced proxy planning, with limited medical interventions ☐ CONTROL: Routinely available services
Needs	☐ Biological needs ☐ Psychological needs ☐ Social needs ☐ Spiritual needs ☐ Health care related needs ☒ Not specified
Outcomes	☒ Biological outcomes: disease severity, patient discomfort, mortality rate ☐ Psycho-social outcomes ☒ Economic outcomes: use of medical resources ☐ Other ☒ Positive on: levels of discomfort. Costs of medications, radiology and laboratory procedures were lower in the DSCU than in TLTC patients. DSCU were transferred less frequently to an acute medical setting. ☒ No effect on: DSCU patients with lower severity of DAT had a higher mortality rate than TLCT patients. Conclusions: the management of patients with advanced DAT on a DSCU using a palliative care philosophy may result in less patient discomfort and lower costs than management on a TLTC.

4 APPENDIX EPIDEMIOLOGICAL SURVEYS

4.1 APPENDICES WEB SURVEY

4.1.1 Web based questionnaire in Dutch

Geachte dokter,

In het kader van een onderzoek naar de organisatie van palliatieve zorg in België (KCE project nr. PPF07-18) doen we een oproep tot medewerking.

Het doel van dit onderzoek is zicht te krijgen op de wijze waarop palliatieve zorg in ons land is georganiseerd. Troeven en tekorten worden op deze manier in kaart gebracht waardoor gericht advies kan worden gegeven aan overheidsinstanties in het treffen van beleidsmaatregelen.

Over palliatieve zorg is de laatste decennia heel veel geschreven en gedebateerd. Een groot deel van onze studie zal daar aan besteed worden. Maar wat we echter missen in deze debatten is de visie van de hulpverlener op het veld. Als huisarts bent u vaak de eerste hulpverlener die merkt dat de patiënt zijn laatste levensfase ingaat. Wat wij van u willen weten is hoe u deze inschatting maakt, wat uw werkdefinitie is, welke belemmeringen en moeilijkheden u ervaart in het contact met deze patiënten en hun familie.

We zijn ervan overtuigd dat uw mening hierover van onschatbare waarde zal zijn, niet enkel voor de concrete zorg voor deze patiënten en hun familie, doch ook voor de internationale literatuur en debatten over de zorg bij het einde van het leven.

Deze vragenlijst bestaat uit 3 delen.

In het eerste deel vragen we naar uw werkdefinitie van palliatieve, terminale en stervende patiënten.

In het tweede deel hebben we het over de rol van de huisarts bij het einde van het leven en uw persoonlijk idee hierover.

In het laatste deel bevragen we u omtrent de moeilijkheden die u ervaart bij deze groep van mensen.

Hartelijk dank even de tijd te nemen om deze vragenlijst in te vullen.

Persoonlijke gegevens: Omcirkel wat voor u van toepassing is.

Man /vrouw

Leeftijdsgroep: < 30 30 tot 40 40 tot 50 50 tot 60 > 60

Praktijkvorm: solo, duo, groep , WGC, andere

Opleiding in palliatieve zorg Ja / Nee

Inschatting van het aantal patiënten waar u, of de praktijk, zorg voor verleent:....

Inschatting van het aantal patiënten in de laatste levensfase, incl stervensproces, die U tot nu toe gedurende uw loopbaan thuis palliatief begeleidde:

Hebt u op dit ogenblik patiënten die volgens u in de laatste levensfase verkeren: ja /nee

Indien ja aantal:

Werkdefinitie

De laatste levensfase wordt door verschillende hulpverleners vaak verschillend benoemd. We willen graag uw definitie van palliatieve patiënt, terminale patiënt en stervende patiënt kennen.

1. Maakt u in uw dagdagelijks werk onderscheid tussen een palliatieve, terminale en stervende patiënt?

Ja / Nee

Indien Nee, ga direct naar vraag 3

Indien Ja, ga over naar vraag 2

2. Onderstaande criteria kunnen belangrijk zijn in het benoemen van een patiënt. Geef aan welke van deze criteria voor u van belang zijn. Duid de voor u 3 belangrijkste criteria aan.

“Bij het benoemen van een patiënt als palliatief, terminaal of stervend hou ik rekening met volgende criteria”

	Palliatieve pt	Terminale pt	Stervende pt
Aard van de aandoening			
Ingeschatte overlevingstijd			
Behoeft aan zorg			
Eigen inschatting van mogelijk (patiënt) herstel			
Eigen inschatting van de kwaliteit van leven van de patiënt			
Andere, aub benoem			

Indien u vindt dat de ingeschatte overlevingstijd een rol speelt in de benoeming van de patiënt gelieve hieronder te specificeren.

Een patiënt is palliatief /terminaal/ stervend als hij/zij een ziekte heeft met een geschatte overlevingsduur van:

	> 5 jaar	> 1 jaar < 5 jaar	≤ 1 jaar	≤ 3 maanden	≤ 2 weken	≤ 1 week	≤ 24 uur	≤ 12 uur
Palliatief								
Terminaal								
Stervend								

1. De literatuur is het erover eens dat patiënten in de laatste fase van hun leven behoefte hebben aan zorg op fysisch of somatisch vlak (pijn en symptoombestrijding), psychisch vlak (angst, depressie, verwerking), sociaal vlak (financiële ondersteuning, hulp van vrijwilligers) en op existentieel vlak (geloof, praten over sterven)

Hebt u het idee dat de zorgvraag van patiënten anders is naarmate ze palliatief, terminaal of stervend zijn?

Nee, deze patiënten kunnen voor totaal gelijk gesteld worden.

Ja, voor mij is de zorgbehoefte verschillend

Indien u ja antwoordde:

Duid aan op een schaal hoe belangrijk deze facetten zijn.

5 = meest belangrijk, 1 = minst belangrijk

	Zorgbehoeftevooral fysisch	Zorgbehoeftevooral psychisch	Zorgbehoeftevooral sociaal	Zorgbehoeftevooral existentieel
Palliatieve patiënt				
Terminale patiënt				
Stervende patiënt				

De rol van de huisarts bij het einde van het leven.

Voor de volgende vragen zullen we de term 'patiënt in de laatste levensfase' gebruiken om zowel palliatieve, terminale als stervende patiënten aan te duiden..

Duid aan op een schaal van 1 tot 5,

5 = absoluut akkoord, 4 = akkoord, 3 = noch het een, noch het ander, 2 = niet akkoord, 1 = absoluut niet akkoord

1. Zorg voor de patiënt in de laatste levensfase is volgens u:

	1-5
hoe dan ook een onderdeel van het takenpakket van de huisarts	
een gedeelde taak voor de huisarts en de behandelende specialist	
uitsluitend de taak van gespecialiseerde hulpverleners (palliatieve zorgteam, oncologen, palliatieve centra, huisartsen met speciale opleiding...)	
een meerwaarde in uw beroep	
iets dat u liever vermijdt	
andere	

2. Hoe omschrijft u uw rol als huisarts binnen het totaalpakket van zorg bij het einde van het leven? Duid aan volgens belangrijkheid van 1 tot 5;

5 = zeer belangrijk, 4 = belangrijk, 3 = noch belangrijk noch onbelangrijk, 2 = niet belangrijk, 1 = absoluut niet belangrijk

Mijn rol als huisarts bij een patiënt in de laatste levensfase is:

	1-5
Hoofdzakelijk medisch informeren en de medische behandeling ondersteunen	
Luisteren en steunen van patiënt in alle domeinen van het leven (fysisch, psychisch, existentieel en sociaal)	
Een aanspreekpunt zijn voor patiënt en familie	
Een aanspreekpunt zijn voor andere hulpverleners	
Coördineren van alle zorg rond de patiënt	

3. Weet u welk initiatief u kan aanspreken om tegemoet te komen aan specifieke noden? Duid aan met X Ja of Nee

Duid aan bij hoeveel patiënten u in 2007 deze zorg voorstelde

	Ja	Nee	Heb ik bij ... patiënten voorgesteld in 2007
Palliatief supportteam van een ziekenhuis			
Palliatief forfait			
Palliatief dagcentrum			
Palliatieve eenheid			
Palliatieve thuiszorg			
Palliatieve referent binnen een woon- en zorgcentrum			
Vrijwilligers als gezelschap bij mensen op het einde van hun leven			

4. In welke mate bepalen volgende criteria uw aanvraag tot palliatieve zorg bij het einde van iemands leven Duid aan op een schaal van 1 tot 5;

5 = absoluut bepalend, 4 = bepalend, 3 = neutraal, 2 = niet bepalend, 1 = absoluut niet bepalend

	1-5
de vraag van de patiënt	
de vraag van de familie	
de vraag van een andere hulpverlener	
de te verwachten overlevingstijd	
de sociale situatie van het gezin	
de sociaal economische status van het gezin	
het opleidingsniveau van de patiënt	
de door u ingeschatte nood aan ondersteuning	
de leeftijd van de patiënt	
kennis van het aanbod bij de patiënt/familie	
kennis van het aanbod bij u als hulpverlener	

Moeilijkheden die u als arts ondervindt met patiënten in de laatste fase van hun leven.

Palliatieve zorg aanvragen of aanbieden aan mensen in de laatste fase van hun leven is vaak niet gemakkelijk. Welke moeilijkheden ervaart u als arts? Neem voor het antwoorden op volgende vragen uw eigen ervaringen als leidraad. De patiënten hierna bedoeld zijn doorsnee patiënten (het gaat hier niet over dementerende of psychiatrische patiënten)

(op schaal van 1 tot 5: 5 = zeer belangrijk, 4 = belangrijk, 3 = noch belangrijk noch onbelangrijk, 2 = niet belangrijk, 1 = absoluut niet belangrijk)

	1 - 5
Ik vind het moeilijk om met een patiënt over het einde van zijn/haar leven te spreken	
Ik vind het moeilijk om met de familie over het einde van het leven van de patiënt te spreken	
Vaak verhindert de familie mij om klare taal naar de patiënt te gebruiken	
Als ik bovenstaande vraag gewettigd vind volg ik die op en praat ik niet met de patiënt	
Ik praat altijd en met elke patiënt in de laatste levensfase over de naderende dood	
Ik verken de emotionele draagkracht van de patiënt voor ik over het einde van het leven praat	
Ik verken de emotionele draagkracht van de familie voor ik over het einde van het leven praat	
Ik laat mij leiden door mijn inschatting van draagkracht van de patiënt in het al dan niet praten over het einde van het leven	

Ik laat mij leiden door mijn inschatting van draagkracht van de familie in het al dan niet praten over het einde van het leven	
Als sterven een taboe onderwerp is, respecteer ik dat en praat ik er niet over	

Welke problemen of belemmeringen ervaart u bij het aanvragen van palliatieve zorg bij het einde van het leven? (op schaal van 1 tot 5: 5 = zeer belangrijk, 4 = belangrijk, 3 = noch belangrijk noch onbelangrijk, 2 = niet belangrijk, 1 = absoluut niet belangrijk)

Ik vraag geen palliatieve zorg aan als:	1 - 5
De patiënt niet op de hoogte is van zijn toestand	
De familie niet op de hoogte is van de toestand	
De familie niet wil dat de patiënt op de hoogte gebracht wordt	
Ik als hulpverlener geen ondersteuning van andere hulpverleners krijg	
Ik vrees dat ik dan voor de continuïteit zal moeten zorgen (24 uur beschikbaarheid)	
Ik te weinig tijd heb voor de patiënt aan het einde van het leven	
Ik vrees dat de patiënt of de familie weerstand zal hebben	
De administratieve procedures onduidelijk zijn	
De administratieve procedures zwaar zijn	
Ik vraag vaak geen palliatieve zorg aan omdat:	1 - 5
Ik te weinig kennis heb van de mogelijkheden	
Ik vind dat deze fase emotioneel zeer belastend is	
Ik toegeven dat er curatief niets meer te doen is, als falen ervaar	
Ik altijd wil blijven hoop geven op genezing	
Ik voorheen reeds slechte ervaringen met palliatieve zorg had	
Mijn eigen morele/religieuze overtuiging hiermee in strijd is	

4.1.2 Results of the principal components analysis on the web-based questionnaire, part 3.

Principal Component analysis with Varimax rotation of the questionnaire on difficulties

	Component				
I find it difficult to talk about end of life issues with family members	-,011	,240	,697	-,018	,255
Sometimes I feel that the family is hindering me to be honest with the patient	-,016	,325	,219	,002	,318
If the family do not wish that I am honest with the patient, I follow their advice	,181	-,039	-,009	,173	,583
I talk with every palliative patient about coming dead	-,179	,017	-,061	,130	-,682
I assess the emotional strength of the patient before talking about end of life issues	-,141	,037	-,142	,651	-,065
I assess the emotional strength of the family before talking about end of life issues	-,093	,085	,086	,719	-,184
My assessment of the emotional strength of the patient is determining my talking or not about end of life issues	,028	-,032	-,022	,727	,257

My assessment of the emotional strength of the family is determining my talking or not about end of life issues	,041	-,059	,056	,769	,209
If dead is a taboo, I respect this taboo and will not talk about it	,008	-,153	,080	,111	,589
If the patient is not aware of his condition, I have difficulties with offering palliative care	,153	,864	,019	,003	-,128
If the family is not aware of the condition of the patient, I have difficulties with offering palliative care	,142	,859	,028	,022	-,033
I have difficulties offering palliative care if the family does not want the patient to be informed	,246	,796	,031	,012	-,072
I have difficulties offering palliative care if I am not supported by other caregivers	,561	,188	,103	,064	,047
I have difficulties offering palliative care because I have to be available 24 hours a day	,606	,123	,186	-,060	,083
I have difficulties offering palliative care due to lack of time	,701	,071	,176	-,001	,018
I have difficulties offering palliative care, because I fear resistance of the patient and/or family	,537	,216	,174	-,008	,205
I have difficulties offering palliative care due to unclear administrative procedures	,838	,066	-,115	-,117	,074
I have difficulties offering palliative care, due to complex administrative procedures	,816	,070	-,080	-,105	,087
I have difficulties offering palliative care, due to own lack of knowledge about palliative services	,750	,058	,117	-,025	,171
I have difficulties offering palliative care, because this period will be emotionally stressing for me	,562	,182	,394	-,028	-,007
I have difficulties offering palliative care, because I experience the lack of medical treatment as a fail	,504	-,026	,558	-,006	-,009
I have difficulties offering palliative care, because I want to give hope for recovery	,459	-,031	,616	,032	-,013
I have difficulties offering palliative care, due to previously bad experiences with palliative care	,558	-,117	,516	-,037	-,028
I have difficulties offering palliative care, due to my own religious and/or spiritual conviction	,479	-,220	,544	-,017	-,146
I find it difficult to talk about end of life issues with the patient	-,008	,175	,637	-,016	,468

4.2 APPENDICES SURVEY HOME SETTING

4.2.1 Sample size calculation: GPs and nursing homes

Objectives: to estimate the population of palliative patients (total & prevalence) who are cared for by general practitioners (GPs), and to describe the distribution of these patients according to medical (diagnosis) and demographic (region, urban/rural, ...) characteristics, and "setting" category (home care under solo GP or group GP supervision, nursing homes). Other objectives are to describe the care such patients receive and use of resources.

The study is interested in "setting" level characteristics (care, use of resources) as well as population parameters (prevalence of palliative patients).

Estimates were

- average physician-to-population ratio = 1:850
- average prevalent palliative patients per GP = 2 (1-3), i.e. prevalence = 0.0023
- number of active GPs in Belgium = 12,000 (presently, this is controversial figure).

Due to the low proportion of palliative patients (0.0023), the probability for a GP of having currently no palliative patient is 0.18 (binomial distribution). In other words, given the above estimates, the probability for a GP of having at least one palliative patient is 0.82. We can start with the estimate of one GP = one palliative patient, and correct afterwards for the risk of no current palliative patient, i.e. dividing the resulting sample size by 0.82.

According to Hubert (les Cahiers Scientifiques du Transport, N° 45/2004), 59% of the Belgian territory is defined as "countryside", with 21% of the population, and 41% of the territory is urban or suburban ("fringe"), with 79% of the population. Note that definitions of what is urban or rural are, is questionable and context-dependent. Therefore the issue of urban vs. rural palliative care might not be very relevant, and any comparison would be difficult (for example, we cannot exclude that rural palliative patients are more often transferred to hospitals or nursing homes) and would result in a poorly cost-effective increase in sample size.

According to the INAMI/RIZIV, there were 125,000 nursing homes beds in 2004, for a total of 1,700 settings (about 70 beds/nursing home). Occupation rate is close to 100%, i.e. one bed = one patient. Estimates of the prevalence of palliative patients in nursing homes range roughly from 10 to 20%.

Litterature shows variations in the proportion of cancer patients among palliative inpatients, around an average of 50%. Let us use the same estimate in GP-cared palliative patients.

4.2.1.1 *Palliative patients at home*

With the hypothesis that the prevalence of cancer palliative patients is 0.50 (on a total of 12000 GP-patient dyads), and using the following formula

$$n = N z^2 p (1-p) / [d^2(N-1) + z^2 p (1-p)]$$

where n = effective sample

N = population size (number of acute hospital beds)

z = z score corresponding to confidence level (i.e. 0.95 or 0.99)

p = prevalence

d = accuracy (in %)

several sample size can be estimated, depending on hypotheses about accuracy and confidence :

1. Moderate confidence (0.95)

- a. moderate accuracy
 - precision (%) : 5.0
 - confidence : 95%
 - sample size : 373
- b. high accuracy
 - precision (%) : 2.0
 - confidence : 95%
 - sample size : 2001
- c. very high accuracy
 - precision (%) : 1.0
 - confidence : 95%
 - sample size : 5335

2. Higher confidence level (0.99)

- a. moderate accuracy
 - precision (%) : 5.0
 - confidence : 99%
 - sample size : 629
- b. higher accuracy
 - precision (%) : 2.0
 - confidence : 99%
 - sample size : 3083

4.2.1.2 B. Nursing home palliative patients

With the hypothesis that the prevalence of palliative patients is 0.15 (on a total of 125000 beds), and using the following formula

$$ne = n \cdot DE = N z^2 p (1-p) / [d^2(N-1) + z^2 p(1-p)]$$

where ne = effective sample

DE = design effect, or cluster effect

N = population size (number of acute hospital beds)

z = z score corresponding to confidence level (i.e. 0.95 or 0.99)

p = prevalence

d = accuracy (in %)

several sample sizes can be estimated, depending on hypotheses about accuracy and confidence (given the small size of clusters, we do not introduce a design effect) :

1. Moderate confidence (0.95)

- a. moderate accuracy
 - precision (%) : 5.0
 - confidence : 95%
 - sample size : 196

- b. higher accuracy
 - precision (%) : 2.0
 - confidence : 95%
 - sample size : 1213
- c. very high accuracy
 - precision (%) : 1.0
 - confidence : 95%
 - sample size : 4714

2. Higher confidence level (0.99)

- a. moderate accuracy
 - precision (%) : 5.0
 - confidence : 99%
 - sample size : 338
- b. higher accuracy
 - precision (%) : 2.0
 - confidence : 99%
 - sample size : 2080
- c. very high accuracy
 - precision (%) : 1.0
 - confidence : 99%
 - sample size : 7925

4.2.1.3 Conclusion: sample size in home and home replacement settings

The above calculations show that high accuracy increases dramatically sample size.

As regards GP-cared palliative patients, hypotheses A1a and A2a require an effective sample size of 373 and 629 GPs, respectively. Correcting for the risk of no current palliative patient, figures become 455 and 767 GPs, respectively.

As regards nursing homes, hypotheses B1b and c would require to survey 1213 and 4714 patients, respectively, or 12 and 67 nursing homes, respectively. According to hypotheses B2b and c, 2080 and 7925 patients should be surveyed, respectively, or 30 and 113 nursing homes respectively. A sample of 30 to 60 nursing homes (2100 to 4200 patients, among which there would be about 315 to 630 palliative patients) would allow to get a reliable picture of the situation of palliative patients in Belgian nursing homes.

4.2.2 General questionnaire for GPs HA 2 (in Dutch)

Persoonlijke gegevens van de arts:

Naam

Voornaam

Adres

Telefoon nr

Email

Geslacht:

Leeftijd:

Praktijkvorm:

Inschatting van het totaal aantal patiënten waar u, of de praktijk, zorg voor verleent:

Hebt u specifieke opleiding in palliatieve zorg genoten?

☐ ja (welke)

☐ nee

Inschatting van het aantal patiënten in de laatste levensfase, die u tot nu toe gedurende uw loopbaan thuis palliatief begeleidde:

Hebt u op dit ogenblik patiënten die in de laatste levensfase verkeren (oncologische en andere):

☐ ja aantal:

☐ nee

4.2.3 Initial questionnaire GP HA3a (in Dutch)

Patiënt nr:

Leeftijd

Geslacht

☐ mannelijk

☐ vrouwelijk

Burgelijke staat

☐ gehuwd of samenwonend

☐ weduwe(naar)

☐ gescheiden (wettelijk of feitelijk)

☐ alleenstaande

Leefsituatie

☐ woont thuis

☐ leeft met naasten onder één dak (preciseer wie, verwantschap)

☐ leeft in een ROB/RVT

Hoofd pathologie ⁱⁱ

☐ kanker

☐ tumor

☐ hemo-lymphopathie

☐ terminale hartinsufficiëntie

☐ CVA

☐ andere terminale vasculaire pathologie

☐ terminale respiratoire insufficiëntie (COPC...)

☐ terminale lever insufficiëntie (cirrhose...)

☐ terminale nier insufficiëntie

☐ dementie

☐ andere degeneratieve neurologische aandoeningen (MS, ALS...)

☐ infectie ziekte (HIV/AIDS...)

☐ andere pathologie

Eerdere verblijven in ziekenhuis

☐ ja aantal keer:

☐ nee

ⁱⁱ Pathologie die de term 'palliatief' moet aantonen

Eerdere verblijven in intensieve zorgen

- ☐ ja aantal keer:
- ☐ nee

Tijd tussen de initiële diagnose en heden

- ☐ ≤ 1 maand
- ☐ > 1 maand en ≤ 3 maanden
- ☐ > 3 maanden en ≤ 6 maanden
- ☐ > 6 maanden en ≤ 12 maanden
- ☐ > 12 maanden en ≤ 24 maanden
- ☐ > 2 jaar en ≤ 5 jaar
- ☐ > 5 jaar en ≤ 10 jaar
- ☐ > 10 jaar

Status

- ☐ palliatieve fase
- ☐ terminale fase
- ☐ overlijden verwacht binnen de 3 maanden
- ☐ overlijden verwacht binnen enkele dagen

Afspraken ivm verdere behandeling

- ☐ schriftelijk vastgelegd
- ☐ met patiënt
- ☐ met familielid (specificeer wie)
- ☐ mondeling overlegd
- ☐ met patiënt
- ☐ met familielid (specificeer wie)
- ☐ niet bepaald

Cardiopulmonaire resuscitatie

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Kunstmatige voeding - peroraal

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Kunstmatig vochttoediening - parenteraal

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Toediening van antibiotica

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Bloedtransfusie

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Nierdialyse

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Toedienen van vasopressoren

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Specifieke behandeling t.o.v. de hoofdpathologie

- ☐ Definitief onderbroken
- ☐ verdere behandeling kan overwogen worden
- ☐ verdere behandeling vastgelegd
- ☐ verdere behandeling aan de gang

Reden voor deze specifieke behandeling

- ☐ remissie of stabilisatie beoogd
- ☐ enkel symptomatisch
- ☐ enkel psychologisch
- ☐ met een andere bedoeling

Verwijzing naar palliatieve eenheid

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ niet bepaald

Wensen van de patiënt t.o.v. de verdere medische zorgen

- ☐ levensverlengende zorgen
- ☐ enkel comfortverhogende zorgen
- ☐ heeft geen enkele wens geuit
- ☐ onbekend

Wensen van de naasten t.o.v. de verdere medische zorg

- ☐ levensverlengende zorgen
- ☐ enkel comfortverhogende zorgen
- ☐ geen enkele wens geuit
- ☐ onbekend

Wilsbeschikking betreffende verzorging en behandelingen

- ☐ ja ☐ schriftelijk
- ☐ mondeling
- ☐ nee

Wilsbeschikking betreffende euthanasie

- ☐ ja ☐ schriftelijk
- ☐ mondeling
- ☐ nee

Aanvraag palliatief forfait

- ☐ ja, is gebeurd
- ☐ nee

Interventie van een thuiszorg equipe

- ☐ equipe komt reeds tussen
- ☐ kan overwogen worden
- ☐ uitgesloten
- ☐ niet bepaald

Reden voor interventie van de thuiszorg equipe ⁱⁱ

- ☐ hulp bij symptoomcontrole
- ☐ psychologische ondersteuning van de patiënt
- ☐ psychologische ondersteuning van de naasten
- ☐ hulp bij de verdere oriëntatie van de patiënt
- ☐ hulp bij de organisatie van de overdracht naar een palliatieve eenheid
- ☐ hulp bij het zorgtraject
- ☐ andere redenen
- ☐ onbekend

Wens van de patiënt t.o.v. de plaats van overlijden

- ☐ in het ziekenhuis
- ☐ eenheid voor palliatieve zorgen
- ☐ thuis
- ☐ RVT
- ☐ andere plaats
- ☐ heeft geen enkele wens geuit
- ☐ onbekend

Wens van de naasten t.o.v. de plaats van overlijden

- ☐ in het ziekenhuis
- ☐ eenheid voor palliatieve zorgen
- ☐ thuis
- ☐ RVT
- ☐ andere plaats
- ☐ hebben geen enkele wens geuit
- ☐ onbekend

Te voorziene toekomstige acties:

- ☐ thuisverblijven
 - ☐ met palliatieve thuiszorg
 - ☐ zonder palliatieve thuiszorg
 - ☐ onbekend
- ☐ overdracht naar een ziekenhuis
 - ☐ met palliatief supportteam
 - ☐ zonder palliatief supportteam
 - ☐ onbekend
 - ☐ overdracht naar een palliatieve eenheid

ⁱⁱ Enkel indien de tussenkomst van een palliatieve equipe reeds plaatsgehad heeft, op dit ogenblik gebeurt of kan overwogen worden

- ☐ overdracht naar een revalidatie centrum
- ☐ overdracht naar een RVT
- ☐ niet bepaald

4.2.4 Questionnaire GP HA3b at follow-up (in Dutch)

Patiënt nr:

Huidige situatie van de patiënt:

- ☐ verblijft thuis
 - ☐ met palliatieve thuiszorg
 - ☐ zonder palliatieve thuiszorg
- ☐ verblijft in een ziekenhuis
 - ☐ met palliatief supportteam
 - ☐ zonder palliatief supportteam
- ☐ verblijft op een eenheid intensieve zorgen
- ☐ verblijft in een palliatieve eenheid
- ☐ verblijft in een RVT/ROB
 - ☐ met palliatief referent
 - ☐ zonder palliatief referent
- ☐ verblijft in een revalidatie centrum
- ☐ is overleden

Reden van de transfer

- ☐ vraag van de patiënt
- ☐ vraag van de naasten
- ☐ medische problemen die gespecialiseerde zorg vereisen
- ☐ vordering van de aandoening eiste gespecialiseerde hulp die thuis niet mogelijk was
- ☐ specificeer welke hulp
 - ☐ zorg thuis psychisch te belastend voor de patiënt
 - ☐ thuiszorg psychisch te belastend voor de omgeving
 - ☐ thuiszorg fysisch te belastend voor de omgeving
 - ☐ de huisarts vond de thuiszorg onvoldoende
 - ☐ de specialist vond de thuiszorg onvoldoende
 - ☐ andere
 - ☐ onbekend

Aanvraag palliatief forfait

- ☐ ja, is gebeurd
- ☐ nee

Tussenkost van de palliatieve thuiszorg

- ☐ ja
- ☐ nee
- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ onbekend

Reden van tussenkomst kk

- ☐ hulp bij symptoombestrijding
- ☐ psychologische steun voor de patiënt
- ☐ psychologische steun voor de naasten
- ☐ hulp bij de verdere oriëntatie van de patiënt
- ☐ hulp bij de organisatie voor overbrenging naar een eenheid palliatieve zorgen
- ☐ hulp bij het uitwerken van het zorgtraject
- ☐ steun van en hulp bij het opstarten van het zorgtraject
- ☐ bijstaan van huisarts en thuisverpleegkundig team
- ☐ andere reden
- ☐ onbekend

Verloop in de tijd tussen DI en heden:

- ☐ ziekenhuisopname ☐ aantal:
- ☐ opname intensieve zorgen ☐ aantal :
- ☐ cardio pulmonaire resuscitatie
- ☐ toediening antibiotica
- ☐ bloedtransfusie
- ☐ kunstmatige voeding –peroraal
- ☐ kunstmatige vochttoediening – parenteraal
- ☐ nierdialyse
- ☐ toediening vassopressoren

Evolutie

- ☐ palliatieve fase
- ☐ terminale fase
 - ☐ overlijden verwacht binnen de 3 maanden
 - ☐ overlijden verwacht binnen enkele dagen

Afspraken ivm verdere behandeling

- ☐ Schriftelijk vastgelegd
 - ☐ met patiënt
 - ☐ met familielid (specifieer wie)
- ☐ Mondeling overlegd
 - ☐ met patiënt
 - ☐ met familielid (specifieer wie)
- ☐ Niet bepaald

Cardiopulmonaire resuscitatie

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Kunstmatige voeding - Peroraal

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

kk Enkel indien de tussenkomst van een palliative equipe reeds plaatsgehad heeft, op dit ogenblik gebeurt of kan overwogen worden

Kunstmatig vochttoediening - parenteraal

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Toediening van antibiotica

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Bloedtransfusie

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Nierdialyse

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Toedienen van vasopressoren

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Specifieke behandeling van de hoofdpathologie

- ☐ definitief onderbroken
- ☐ kan overwogen worden
- ☐ geprogrammeerd
- ☐ aan de gang

Reden van de specifieke behandeling

- ☐ met als doel remissie of stabilisatie
- ☐ enkel symptoombestrijding
- ☐ enkel psychologisch
- ☐ met een ander doel

Verwijzing naar palliatieve eenheid

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ niet bepaald

Wilsbeschikking betreffende verzorging en behandelingen

- ☐ ja
 - ☐ schriftelijk
 - ☐ mondeling
- ☐ nee

Wilsbeschikking betreffende euthanasie

- ☐ ja
 - ☐ schriftelijk
 - ☐ mondeling
- ☐ nee

Wensen van de patiënt t.o.v. de verdere medische zorgen

- ☐ levensverlengende zorgen
- ☐ enkel comfortverhogende zorgen
- ☐ heeft geen enkele wens geuit
- ☐ onbekend

Wensen van de naasten t.o.v. de verdere medische zorgen

- ☐ levensverlengende zorgen
- ☐ enkel comfortverhogende zorgen
- ☐ geen enkele wens geuit
- ☐ onbekend

Wens van de patiënt t.o.v. de plaats van overlijden

- ☐ in het ziekenhuis
- ☐ eenheid voor palliatieve zorgen
- ☐ thuis
- ☐ RVT
- ☐ andere plaats
- ☐ heeft geen enkele wens geuit
- ☐ onbekend

Wens van de naasten t.o.v. de plaats van overlijden

- ☐ in het ziekenhuis
- ☐ eenheid voor palliatieve zorgen
- ☐ thuis
- ☐ RVT
- ☐ andere plaats
- ☐ hebben geen enkele wens geuit
- ☐ onbekend

Te voorziene toekomstige acties

- ☐ thuisverblijven
 - ☐ met palliatieve thuiszorg
 - ☐ zonder palliatieve thuiszorg
 - ☐ onbekend
- ☐ overdracht naar een ziekenhuis
 - ☐ met palliatief support
 - ☐ zonder palliatief support
 - ☐ onbekend
- ☐ overdracht naar een palliatieve eenheid
- ☐ overdracht naar een revalidatie centrum
- ☐ overdracht naar een RVT
- ☐ niet bepaald

4.3 APPENDICES SURVEY NURSING HOMES

4.3.1 General questionnaire ROB/RVT I (in Dutch)

Naam van de organisatie:

Adres:

Telefoonnummer:

Website:

Contactpersoon:

Juridische vorm

- OCMW
- Privé
- VZW

Indeling:

Aantal rustoordplaatsen

Aantal rust en verzorgingstehuis plaatsen

Aantal éénpersoonkamers

Aantal meerpersoonkamers

Aantal serviceflats

Bezettingsgraad van bewoners:

Aantal individuen

Aantal koppels

Aantal werknemers per beroepsgroep:

	Voltijds	Halftijds	Deeltijds:Uren per maand
Verpleegkundigen			
Verzorgenden			
Ergotherapeuten			
Kinésitherapeuten			
Logopedisten			
Animatoren			
Referente Pall zorg			
Andere			

Zorgprofiel:

Verdeling van de zorgbehoefte van de bewoners volgens de CAT-schaal

ROB	Aantal	RVT	Aantal
O		B	
A		C	
B			
C			

Zijn er speciale faciliteiten voor:

- Alzheimer aantal:
- Dementie aantal:

Dossiersamenstelling bij intake, is een blanco exemplaar beschikbaar?

- ...
- ...
- ...
- ...

Palliatieve Zorg**Palliatief referent:**

Wie is de referente palliatieve zorg:

Aantal vrijgestelde uren voor de referente Palliatieve zorg:

CRA

Aantal uren/week dat de Coördinerende en Raadgevende Arts aanwezig is:

Taak van de CRA:

Samenwerkende/bezoekende artsen:

- CRA
- Huisartsen van bewoners
- Artsen van het Netwerk PZ
- Andere:

Visie van de voorziening op palliatieve zorgen:

Is een visietekst geformaliseerd?

Is de visietekst gecommuniceerd? Op welke wijze?

Informatieverstrekking

brochures

mondeling

Is er een protocol rond het levenseinde?

- Wilsverklaring
- NTR/DNR
- Euthanasiedocument
- Andere

Palliatief dossier:

Wanneer start je een palliatief dossier?

Is er een overlegstructuur?

Palliatief supportteam

Werkgroep Palliatief zorg

Andere

Taken van:

Palliatief supportteam:

Werkgroep Palliatieve zorg:

Opleiding van het team:

Aantal vormingsuren algemeen

Aantal vormingsuren voor palliatieve zorg en hoe worden die besteed?

4.3.2 Initial Questionnaire ROB/RVT 2a (in Dutch)

Document ingevuld door: ☐ directie
☐ verpleegkundige
☐ referent palliatieve zorg

Nr bewoner:**Leeftijd:**

Geslacht: ☐ mannelijk
☐ vrouwelijk

Burgelijke staat ☐ gehuwd of samenwonend
☐ weduwe(naar)
☐ gescheiden (wettelijk of feitelijk)
☐ alleenstaande

Hoofd pathologie ^{II}

- ☐ kanker
 - ☐ tumor
 - ☐ hemo-lymphopathie
 - ☐ Terminale hartinsufficiëntie
 - ☐ CVA
 - ☐ andere terminale vasculaire pathologie
- ☐ Respiratoire insufficiëntie (COPC...)
- ☐ Terminale lever insufficiëntie (cirrhose...)
- ☐ Terminale nier insufficiëntie
- ☐ Dementie
- ☐ Andere degeneratieve neurologische aandoeningen (MS, ALS...)
- ☐ Infectie ziekte (HIV/AIDS...)
- ☐ Andere pathologie

Eerdere verblijven in ziekenhuis

- ☐ ja aantal:
- ☐ nee

Eerdere verblijven in intensieve zorgen

- ☐ ja aantal
- ☐ nee

Tijd tussen de initiële diagnose en heden

- ☐ ≤ 1 maand
- ☐ > 1 maand en ≤ 3 maanden
- ☐ > 3 maanden en ≤ 6 maanden
- ☐ > 6 maanden en ≤ 12 maanden
- ☐ > 12 maanden en ≤ 24 maanden
- ☐ > 2 jaaret ≤ 5 jaar
- ☐ > 5 jaar et ≤ 10 jaar
- ☐ > 10 jaar

Status

- ☐ palliatieve fase
- ☐ terminale fase
 - ☐ overlijden verwacht binnen de 3 maanden
 - ☐ overlijden verwacht binnen enkele dagen

Is de bewoner expliciet op de hoogte gebracht van zijn eigen toestand?

- ☐ ja, door wie:
- ☐ neen, waarom niet:

BEHANDELING

Afspraken ivm verdere behandeling

- ☐ Schriftelijk vastgelegd
 - ☐ met bewoner
 - ☐ met familielid (specificeer wie)
- ☐ Mondeling overlegd
 - ☐ met bewoner
 - ☐ met familielid (specificeer wie)

^{II} Pathologie die de term 'palliatief' moet aantonen

- ☐ Niet bepaald

Cardiopulmonaire resuscitatie

- ☐ uitgesloten
 - ☐ kan overwogen worden
 - ☐ niet bepaald
 - ☐ niet in detail met patiënt besproken

Kunstmatige voeding

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Kunstmatig vochttoediening

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Toediening van antibiotica

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Bloedtransfusie

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Nierdialyse

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Toedienen van vasopressoren

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Specifieke behandeling t.o.v. de hoofdpathologie

- ☐ Definitief onderbroken
- ☐ verdere behandeling kan overwogen worden
- ☐ verdere behandeling vastgelegd
- ☐ verdere behandeling aan de gang

Reden voor deze specifieke behandeling

- ☐ remissie of stabilisatie beoogd
- ☐ enkel symptomatisch
- ☐ enkel psychologisch
- ☐ met een andere bedoeling

Is een ziekenhuisopname nog gewenst?

- ☐ ja
- ☐ ja, maar niet meer voor behandeling van de hoofdpathologie
- ☐ neen, uitgesloten
- ☐ niet bepaald

PALLIATIEVE ZORG

Verwijzing naar palliatieve eenheid

- ☐ uitgesloten
- ☐ kan overwogen worden, als de zorg in de organisatie te zwaar wordt
- ☐ niet bepaald

Wilsbeschikking

- ☐ ja
- ☐ nee

NTR/DNR

- ☐ ja
- ☐ nee

Euthanasiedocument

- ☐ ja
- ☐ nee

Wensen van de bewoner t.o.v. de verdere medische zorgen

- ☐ levensverlengende zorgen
- ☐ enkel comfortverhogende zorgen
- ☐ heeft geen enkele wens geuit
- ☐ onbekend

Wensen van de naasten t.o.v. de verdere medische zorgen

- ☐ levensverlengende zorgen
- ☐ enkel comfortverhogende zorgen
- ☐ geen enkele wens geuit
- ☐ niet in detail met patiënt besproken onbekend

Coördinerende zorgfiguur:

- ☐ ja, wie:
- ☐ neen

Gestructureerde overlegmomenten:

- ☐ Ja
 - ☐ op wekelijkse basis
 - ☐ op tweewekelijkse basis
 - ☐ op maandelijkse basis
 - ☐ andere:
- ☐ neen

Interventie van CRA

- ☐ adviesering aan het verzorgende team
- ☐ medische ondersteuning van de bewoner
- ☐ psychologische ondersteuning van de bewoner

- ☐ psychologische ondersteuning van de familie
- ☐ informeren van bewoner
- ☐ informeren van familie
- ☐ geen tussenkomst

Interventie van bezoekende arts (eigen huisarts bewoner)

- ☐ medische behandeling
- ☐ pijnbestrijding
- ☐ psychologische ondersteuning van de bewoner
- ☐ psychologische ondersteuning familie
- ☐ informeren bewoner
- ☐ informeren familie
- ☐ geen tussenkomst van de huisarts
- ☐ geen eigen huisarts

Interventie van het Netwerk Palliatieve Zorg

- ☐ adviesverlening
- ☐ praktische ondersteuning
- ☐ technische ondersteuning
- ☐ geen tussenkomst

Interventie van referent palliatieve zorg

- ☐ psychologische ondersteuning bewoner
- ☐ psychologische ondersteuning naasten
- ☐ informeren bewoner
- ☐ informeren naasten
- ☐ informeren andere hulpverleners
- ☐ geen tussenkomst

Voornaamste doelstelling referent palliatieve zorg bij deze bewoner

- ☐ werken rond comfort (aromatherapie, ...)
- ☐ pijnbestrijding
- ☐ symptoombestrijding (anti-decubitus, ...)

Ondersteunende interventies van andere teamleden (kiné, ergo, ...)

- ...
- ...
- ...
- ...

Wens van de bewoner t.o.v. de plaats van overlijden

- ☐ in het ziekenhuis
- ☐ eenheid voor palliatieve zorgen
- ☐ thuis, bij familie
- ☐ RVT
- ☐ andere plaats
- ☐ heeft geen enkele wens geuit
- ☐ onbekend

Wens van de naasten t.o.v. de plaats van overlijden

- ☐ in het ziekenhuis
- ☐ eenheid voor palliatieve zorgen
- ☐ thuis, bij familie
- ☐ RVT
- ☐ andere plaats
- ☐ hebben geen enkele wens geuit
- ☐ onbekend

Te voorziene toekomstige acties:

- ☐ verder in het ROB/RVT
 - ☐ met palliatieve zorg
 - ☐ zonder palliatieve zorg
 - ☐ onbekend
- ☐ overdracht naar een ziekenhuis
 - ☐ met palliatief supportteam
 - ☐ zonder palliatief supportteam
 - ☐ onbekend
- ☐ terug naar huis of bij familie
 - ☐ met palliatief supportteam
 - ☐ zonder palliatief supportteam
 - ☐ onbekend
- ☐ overdracht naar een palliatieve eenheid
- ☐ overdracht naar een revalidatie centrum
- ☐ overdracht naar een RVT3
- ☐ niet bepaald
- ☐ opvang en begeleiding van de familie in de periode voor, tijdens en na het overlijden van de bewoner

4.3.3 Follow-up questionnaire ROB/RVT2b (in Dutch)

Naam van het rusthuis:

Nr bewoner:

Indien dit nog niet het geval was, is de bewoner expliciet op de hoogte gebracht van zijn eigen toestand?

- ☐ ja, door wie:
- ☐ neen, waarom niet:

Huidige situatie van de bewoner:

- ☐ verblijft thuis
 - ☐ met palliatieve thuiszorg
 - ☐ zonder palliatieve thuiszorg
- ☐ verblijft in een ziekenhuis
 - ☐ met palliatief supportteam
 - ☐ zonder palliatief supportteam
- ☐ verblijft op een eenheid intensieve zorgen
- ☐ verblijft in een palliatieve eenheid
- ☐ verblijft in een RVT/ROB
 - ☐ met palliatief supportteam
 - ☐ zonder palliatief supportteam
- ☐ verblijft in een revalidatie centrum
- ☐ is overleden

Reden van de transfer

- ☐ vraag van de bewoner
- ☐ vraag van de naasten
- ☐ acute medische problemen die gespecialiseerde zorg vereisten
- ☐ vordering van de aandoening eiste gespecialiseerde hulp die in RVT niet mogelijk

was

- ☐ specificeer welke hulp:
 - ☐ zorg psychisch te belastend voor de bewoner
 - ☐ zorg psychisch te belastend voor de omgeving
 - ☐ zorg fysisch te belastend voor de omgeving
 - ☐ de huisarts vond de zorg onvoldoende
 - ☐ de specialist vond de zorg onvoldoende
 - ☐ andere
 - ☐ onbekend

Is een ziekenhuisopname nog gewenst?

- ☐ ja
- ☐ ja, maar niet meer voor behandeling van de hoofdpathologie
- ☐ neen uitgesloten
- ☐ niet bepaald

Verloop in de tijd tussen DI en heden:

- ☐ ziekenhuisopname ☐ aantal:
- ☐ opname intensieve zorgen ☐ aantal :
- ☐ cardio pulmonaire resuscitatie
- ☐ toediening antibiotica
- ☐ bloedtransfusie
- ☐ kunstmatige voeding
- ☐ kunstmatige vochttoediening
- ☐ nierdialyse
- ☐ toediening vassopressoren

Evolutie

- ☐ palliatieve fase
- ☐ terminale fase
 - ☐ overlijden verwacht binnen de 3 maanden
 - ☐ overlijden verwacht binnen enkele dagen

Afspraken ivm verdere behandeling

- ☐ Schriftelijk vastgelegd
 - ☐ met bewoner
 - ☐ met familielid (specificeer wie)
- ☐ Mondeling overlegd
 - ☐ met bewoner
 - ☐ met familielid (specificeer wie)
- ☐ Niet bepaald

Cardiopulmonaire resuscitatie

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Kunstmatige voeding

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Kunstmatig vochttoediening

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Toediening van antibiotica

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Bloedtransfusie

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Nierdialyse

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Toedienen van vasopressoren

- ☐ uitgesloten
- ☐ kan overwogen worden
- ☐ wordt gegeven
- ☐ niet bepaald
- ☐ niet in detail met patiënt besproken

Specifieke behandeling van de hoofdpathologie

- ☐ definitief onderbroken
- ☐ kan overwogen worden
- ☐ geprogrammeerd
- ☐ aan de gang

Reden van de specifieke behandeling

- ☐ met als doel remissie of stabilisatie
- ☐ enkel symptoombestrijding
- ☐ enkel psychologisch
- ☐ met een ander doel

PALLIATIEVE ZORG**Verwijzing naar palliatieve eenheid**

- ☐ uitgesloten
- ☐ kan overwogen worden, als de zorg in de organisatie te zwaar wordt
- ☐ niet bepaald

Wilsbeschikking

- ☐ ja
- ☐ nee

NTR/DNR

- ☐ ja
- ☐ nee

Euthanasiedocument

- ☐ ja
- ☐ nee

Wensen van de bewoner t.o.v. de verdere medische zorgen

- ☐ levensverlengende zorgen
- ☐ enkel comfortverhogende zorgen
- ☐ heeft geen enkele wens geuit
- ☐ onbekend

Wensen van de naasten t.o.v. de verdere medische zorgen

- ☐ levensverlengende zorgen
- ☐ enkel comfortverhogende zorgen
- ☐ geen enkele wens geuit
- ☐ niet in detail met patiënt besproken onbekend

Coördinerende zorgfiguur:

- ☐ ja, wie:
- ☐ neen

Gestructureerde overlegmomenten:

- ☐ Ja
 - ☐ op wekelijkse basis
 - ☐ op tweewekelijkse basis
 - ☐ op maandelijkse basis
 - ☐ andere:
- ☐ neen

Interventie van CRA

- ☐ adviesering aan het verzorgende team
- ☐ medische ondersteuning van de bewoner
- ☐ psychologische ondersteuning van de bewoner
- ☐ psychologische ondersteuning van de familie
- ☐ informeren van bewoner
- ☐ informeren van familie
- ☐ geen tussenkomst

Interventie van bezoekende arts (eigen huisarts bewoner)

- ☐ medische behandeling
- ☐ pijnbestrijding
- ☐ psychologische ondersteuning van de bewoner
- ☐ psychologische ondersteuning familie
- ☐ informeren bewoner
- ☐ informeren familie
- ☐ geen tussenkomst van de huisarts
- ☐ geen eigen huisarts

Interventie van het Netwerk Palliatieve Zorg

- ☐ adviesverlening
- ☐ praktische ondersteuning
- ☐ technische ondersteuning
- ☐ geen tussenkomst

Interventie van referent palliatieve zorg

- ☐ psychologische ondersteuning bewoner
- ☐ psychologische ondersteuning naasten
- ☐ informeren bewoner
- ☐ informeren naasten
- ☐ informeren andere hulpverleners
- ☐ geen tussenkomst

Voornaamste doelstelling referent palliatieve zorg bij deze bewoner

- ☐ werken rond comfort (aromatherapie, ...)
- ☐ pijnbestrijding
- ☐ symptoombestrijding (anti-decubitus, ...)

Ondersteunende interventies van andere teamleden (kiné, ergo, ...)

- ...
- ...
- ...
- ...

Wens van de bewoner t.o.v. de plaats van overlijden

- ☐ in het ziekenhuis
- ☐ eenheid voor palliatieve zorgen
- ☐ thuis, bij familie
- ☐ RVT
- ☐ andere plaats
- ☐ heeft geen enkele wens geuit
- ☐ onbekend

Wens van de naasten t.o.v. de plaats van overlijden

- ☐ in het ziekenhuis
- ☐ eenheid voor palliatieve zorgen
- ☐ thuis, bij familie
- ☐ RVT
- ☐ andere plaats
- ☐ hebben geen enkele wens geuit
- ☐ onbekend

Te voorziene toekomstige acties:

- ☐ verder in het ROB/RVT
 - ☐ met palliatieve zorg
 - ☐ zonder palliatieve zorg
 - ☐ onbekend
- ☐ overdracht naar een ziekenhuis
 - ☐ met palliatief supportteam
 - ☐ zonder palliatief supportteam
 - ☐ onbekend
- ☐ terug naar huis of bij familie
 - ☐ met palliatief supportteam
 - ☐ zonder palliatief supportteam
 - ☐ onbekend
- ☐ overdracht naar een palliatieve eenheid
- ☐ overdracht naar een revalidatie centrum
- ☐ overdracht naar een RVT³
- ☐ niet bepaald
- ☐ opvang en begeleiding van de familie in de periode voor, tijdens en na het overlijden van de bewoner

4.4 APPENDICES HOSPITALS

4.4.1 Patients selection in hospitals

4.4.1.1 Questionnaire in French

Numéro d'identification de l'institution _____

I. IDENTIFICATION DU TYPE ET DU NOMBRE DE LITS HOSPITALIERS DONT DISPOSE LE SERVICE

Une seule réponse est possible. Si le service visité comporte plusieurs types de lits hospitaliers, il faut remplir un questionnaire par type de lits identifié.

Type

Nombre

☐ Lit de soins aigus (lit de court séjour) _____ lits

☐ Médecine interne

☐ Médecine interne générale (polyvalente) _____ lits

☐ Cardiologie _____ lits

☐ Gastro-entérologie _____ lits

☐ Gériatrie _____ lits

☐ Hématologie _____ lits

☐ Neurologie _____ lits

☐ Néphrologie _____ lits

☐ Oncologie _____ lits

☐ Pneumologie _____ lits

☐ Autre _____ lits

☐ Chirurgie

☐ Chirurgie générale _____ lits

☐ Chirurgie cardio-thoracique _____ lits

☐ Chirurgie digestive _____ lits

☐ Neurochirurgie _____ lits

☐ Chirurgie orthopédique _____ lits

☐ Autre chirurgie _____ lits

☐ Autre _____ lits

☐ Lit de moyen séjour _____ lits

☐ Gériatrie _____ lits

☐ Psycho-gériatrie _____ lits

☐ Revalidation locomotrice _____ lits

☐ Revalidation neurologique _____ lits

☐ Revalidation cardiorespiratoire _____ lits

☐ Revalidation « générale » _____ lits

☐ Autre _____ lits

2. DONNEES CONCERNANT LES PATIENTS HOSPITALISES DANS LE SERVICE

Pouvez-vous identifier parmi les patients hospitalisés dans votre service depuis plus de 48 heures, quels sont les patients qui répondent à la définition de « patient palliatif »

Le « patient palliatif » est un patient qui est atteint d'une maladie grave, d'origine cancéreuse ou non, évolutive, qui ne répond plus à un traitement curatif et qui met en jeu le pronostic vital du malade.

[illegible]

4.4.1.2 Questionnaire in Dutch

Identificatienummer van de organisatie _____

1. IDENTIFICATIE VAN TYPE EN AANTAL BESCHIKBARE ZIEKENHUISBEDDEN

Slechts één antwoord mogelijk. Indien de bezochte dienst meerdere types ziekenhuisbedden heeft, dient men per type een vragenlijst in te vullen.

Type

Aantal

☐ Acute bedden (kortverblijf) _____ bedden

☐ Interne geneeskunde

☐ Algemene inwendige geneeskunde _____ bedden

☐ Cardiologie _____ bedden

☐ Maag-darm ziekten _____ bedden

☐ Geriatrie _____ bedden

☐ Hematologie _____ bedden

☐ Neurologie _____ bedden

☐ Nefrologie _____ bedden

☐ Oncologie _____ bedden

☐ Pneumologie _____ bedden

☐ Andere _____ bedden

☐ Heelkunde

☐ Algemene heelkunde _____ bedden

☐ Cardio- thoracale heelkunde _____ bedden

☐ Digestieve heelkunde _____ bedden

☐ Neurochirurgie _____ bedden

☐ Orthopedische heelkunde _____ bedden

☐ Andere heelkunde _____ bedden

☐ Andere _____ bedden

☐ Middellang verblijf _____ bedden

☐ Geriatrie _____ bedden

☐ Psychogeriatric _____ bedden

☐ Locomotorische revalidatie _____ bedden

☐ Neurologische revalidatie _____ bedden

☐ Cardiorespiratoire revalidatie _____ bedden

☐ Algemene revalidatie _____ bedden

☐ Andere _____ bedden

I. GEGEVENS OVER GEHOSPITALISEERDE PATIËNTEN OP DE AFDELING

Kan u uit de patiënten die langer dan 48 uur opgenomen zijn op uw dienst, mensen aanduiden die lijden aan een ernstig evolutieve ziekte (zowel oncologische als andere pathologieën), die niet meer beantwoordt aan de curatieve behandeling en die de levensverwachting ernstig in het gedrang brengt .

[illegible]

4.4.2 Questionnaires on patients

4.4.2.1 Questionnaires in French

Questionnaire concernant les patients palliatifs et destiné aux équipes soignantes (J ₁)
--

1. Identification du patient

Clé d'identification du patient _____

1.1. Ce patient a été identifié comme un « patient palliatif » (une seule réponse possible)

- ☐ Par le médecin et par l'infirmier, sans recherche d'un consensus
- ☐ Par le médecin et par l'infirmier, après recherche d'un consensus
- ☐ Uniquement par le médecin
- ☐ Uniquement par l'infirmier

2. Identification de l'institution de soin et du type de lit hospitalier

Numéro d'identification de l'institution _____

2.1. Le patient est hospitalisé dans un lit de :

- ☐ Soins aigus (court séjour)
- ☐ Médecine interne
 - ☐ Médecine interne générale (polyvalente)
 - ☐ Cardiologie
 - ☐ Gastro-entérologie
 - ☐ Gériatrie
 - ☐ Hématologie
 - ☐ Neurologie
 - ☐ Néphrologie
 - ☐ Oncologie
 - ☐ Pneumologie
 - ☐ Autre _____
- ☐ Chirurgie
 - ☐ Chirurgie générale
 - ☐ Chirurgie cardio-thoracique
 - ☐ Chirurgie digestive
 - ☐ Neurochirurgie
 - ☐ Chirurgie orthopédique
 - ☐ Autre chirurgie
- ☐ Autre _____
- ☐ Moyen séjour

- ☐ Gériatrie
- ☐ Psycho-gériatrie
- ☐ Revalidation locomotrice
- ☐ Revalidation neurologique
- ☐ Revalidation cardiorespiratoire
- ☐ Revalidation « générale »
- ☐ Autre _____

1. RENSEIGNEMENTS SOCIODEMOGRAPHIQUES CONCERNANT LE PATIENT

- 3.1. Le patient est âgé de : _____ ans
- 3.2. Le patient est de sexe ☐ Masculin
☐ Féminin
- 3.3. Le patient est ☐ Marié ou cohabitant
☐ Veuf
☐ Divorcé ou séparé
☐ Célibataire
- 3.4. Avant d'être hospitalisé, le patient séjournait
- ☐ A domicile
 - ☐ Seul ou avec une personne mineure
 - ☐ Avec au moins une personne majeure
 - ☐ Je ne dispose pas de cette information
 - ☐ En maison de repos (et soins)
 - ☐ Dans un autre lieu _____
 - ☐ Je ne dispose pas de cette information

2. RENSEIGNEMENTS CONCERNANT LA PATHOLOGIE ET LE PRONOSTIC DE VIE DU MALADE

- 4.1. Quelle est la nature de la pathologie justifiant le statut « palliatif » ? *Une seule réponse possible*
- ☐ Un cancer ☐ Un cancer solide
 - ☐ Une hémolympathie
 - ☐ Une insuffisance cardiaque terminale
 - ☐ Un accident vasculaire cérébral
 - ☐ Une autre affection vasculaire terminale (artériopathie des membres inférieurs, coronaropathie...)
 - ☐ Une insuffisance respiratoire terminale (BPCO,...)
 - ☐ Une insuffisance hépatique terminale (cirrhose,...)
 - ☐ Une insuffisance rénale terminale
 - ☐ Une démence
 - ☐ Une autre maladie neurologique dégénérative (SLA, PKS, SEP...)
 - ☐ Une maladie infectieuse incurable (SIDA...)
 - ☐ Une autre pathologie _____
- 4.2. Combien de temps s'est écoulé depuis le diagnostic initial de cette pathologie ?
- ☐ ≤ 3 mois
 - ☐ > 3 et ≤ 6 mois
 - ☐ > 6 et ≤ 12 mois
 - ☐ > 1 et ≤ 2 ans

- ☐ > 2 et ≤ 5 ans
☐ > 5 et ≤ 10 ans
☐ > 10 ans

4.3. A combien de temps estimez-vous le pronostic de vie du malade ?

- ☐ < 7 jours
☐ > 1 et ≤ 4 semaines
☐ > 1 et ≤ 3 mois
☐ > 3 et ≤ 6 mois
☐ > 6 et ≤ 12 mois
☐ > 1 et ≤ 5 ans
☐ > 5 ans

3. RENSEIGNEMENTS CONCERNANT LES SOINS ET TRAITEMENTS

5.1. Quel est le souhait des différents intervenants à l'égard du projet thérapeutique ?

	Prolonger la vie	Uniquement améliorer le confort	N'a exprimé aucun souhait particulier	Je ne dispose pas de ce renseignement	
Patient	☐	☐	☐	☐	☐ incapable d'exprimer un avis
Proche(s)	☐	☐	☐	☐	☐ pas de proche présent
Equipe médicale	☐	☐	☐	☐	
Equipe infirmière	☐	☐	☐	☐	

5.2. Quels sont la nature et le type de soins et de traitements qu'il est prévu d'administrer ?

	Exclu	Envisageable	Programmé	En cours	Non défini
Réanimation cardiorespiratoire	☐	☐	-	-	☐
Admission en unité de soins intensifs	☐	☐	☐	-	☐
Traitement « actif » de la pathologie « palliative »	☐	☐	☐	☐	☐
Alimentation artificielle (entérale ou parentérale)	☐	☐	☐	☐	☐
Antibiothérapie	☐	☐	☐	☐	☐
Transfusion d'un dérivé sanguin	☐	☐	☐	☐	☐

Répondre à la question 5.3 si le traitement est envisageable, programmé ou en cours

5.3. Avec quel objectif ces traitements sont-ils administrés ?

	Pour prolonger la vie	Uniquement pour contrôler un symptôme	Uniquement pour soutenir psychologiquement le malade	Avec un autre objectif	Sans objectif précis
Admission en unité de soins intensifs					
Traitement « actif » de la pathologie « palliative »					
Alimentation artificielle entérale ou parentérale					
Antibiothérapie					
Transfusion d'un dérivé sanguin					

- 5.4. Le projet thérapeutique ☐ A été discuté en équipe pluridisciplinaire
☐ A été discuté uniquement au sein de l'équipe médicale
☐ N'a pas été discuté
- Le projet thérapeutique ☐ Est formalisé par écrit
☐ N'est pas formalisé par écrit

4. RENSEIGNEMENTS CONCERNANT LES CIRCONSTANCES D'ADMISSION DU PATIENT

6.1. A quelle date le patient a-t-il été admis dans le service _____ / _____ / 200____

6.2. Pour quelle(s) raison(s) le patient a-t-il été admis (*Répondre soit au 6.2a soit au 6.2b*)

6.2a. Pour un patient hospitalisé dans un lit de soins aigus (*Plusieurs réponses possibles*)

- ☐ Bilan médical programmé
☐ Traitement médical programmé
☐ Traitement chirurgical programmé
☐ Symptôme ou complication médicale aiguë
☐ Motif psychosocial
☐ Autre raison _____

6.2b. Pour un patient hospitalisé dans un lit de soins de moyen séjour (*Plusieurs réponses possibles*)

- ☐ Réadaptation, revalidation
☐ Attente d'un placement en maison de repos
☐ Autre raison _____

6.3. Le patient est-il passé par le service d'urgence de l'institution ☐ Oui
☐ Non

6.4. Le patient est-il passé par un autre service de la même institution ☐ Oui
☐ Non

6.5. Avant cette hospitalisation, le patient était-il connu de l'équipe soignante ☐ Oui
☐ Non

5. RENSEIGNEMENTS CONCERNANT LE DEVENIR ET L'ORIENTATION DONNÉE AU PATIENT

7.1. Quel est le souhait des différents intervenants à l'égard du devenir du patient ?

	Maintien dans le service jusqu'au décès	Retour à domicile	Transfert en maison de repos (et soins)	Transfert vers un service de soins palliatifs	Transfert vers un service de moyen séjour	Transfert vers un service de soins aigus	Transfert vers un autre lieu	N'a exprimé aucun souhait particulier	Je ne dispose pas de ce renseignement
Patient	☐	☐	☐	☐	☐	☐	☐	☐	☐
Proche(s)	☐	☐	☐	☐	☐	☐	☐	☐	☐
Equipe médicale	☐	☐	☐	☐	☐	☐	☐	☐	☐
Equipe infirmière	☐	☐	☐	☐	☐	☐	☐	☐	☐

☐ Incapable d'exprimer un avis☐ aucun proche présent

7.2. Comment envisagez-vous le devenir du patient ?

- ☐ Le patient restera hospitalisé dans le service jusqu'à son décès
- ☐ Le patient rentrera à domicile
- ☐ Le patient sera transféré vers une maison de repos (et de soins)
- ☐ Le patient sera transféré vers un service de soins palliatifs
- ☐ Le patient sera transféré vers un service de moyen séjour (revalidation)
- ☐ Le patient sera transféré vers un service de soins aigus (court séjour)
- ☐ Le patient sera transféré vers un autre lieu _____
- ☐ Cet aspect de la prise en charge n'a pas été envisagé
- ☐ Je ne dispose pas de ce renseignement

Questionnaire concernant les patients palliatifs et destiné aux équipes soignantes (J₁₄ ou 42)

I IDENTIFICATION DU PATIENT

Clé d'identification du patient

I.1. Le patient (une seule réponse possible)

- ☐ Est décédé dans le service Date du décès : ____ / ____ / 2008
☐ Est sorti du service le Date de sortie : ____ / ____ / 2008
☐ Est toujours hospitalisé dans le service

2 RENSEIGNEMENTS CONCERNANT L'INTERVENTION DE L'EQUIPE MOBILE DE SOINS PALLIATIFS

Au moment du décès du patient, de sa sortie ou à ce jour (si le patient est toujours hospitalisé)

2.1. Une intervention de l'équipe mobile de soins palliatifs :

- ☐ Avait/a eu lieu et était/est clôturée
- ☐ Etait/est en cours
- ☐ Avait/a été programmée mais n'a pas eu lieu
- ☐ Etait/est envisageable mais n'a pas été programmée
- ☐ Etait/est exclue (passer à la section 3)
- ☐ N'avait/a pas été discutée (passer à la section 3)
- ☐ Je ne dispose pas de ce renseignement (passer à la section 3)

2.2. L'équipe mobile de soins palliatifs est/devait intervenir pour (Plusieurs réponses sont possibles)

- ☐ Contrôler un ou plusieurs symptômes
 - ☐ Soutenir psychologiquement le patient
 - ☐ Soutenir psychologiquement les proches
 - ☐ Organiser un retour à domicile
 - ☐ Avec une équipe de soins palliatifs de 2^{ème} ligne
 - ☐ Sans équipe de soins palliatifs de 2^{ème} ligne
 - ☐ Je ne dispose pas de ce renseignement
 - ☐ Organiser un transfert vers une maison de repos (et soins)
 - ☐ Avec une équipe de soins palliatifs de 2^{ème} ligne
 - ☐ Sans équipe de soins palliatifs de 2^{ème} ligne
 - ☐ Je ne dispose pas de ce renseignement
 - ☐ Organiser un transfert vers un service de soins palliatifs
 - ☐ Organiser la sortie du patient vers un autre lieu
- ☐ Aider l'équipe soignante à élaborer le projet thérapeutique
☐ Autre motif _____
☐ Je ne dispose pas de ce renseignement

3 RENSEIGNEMENTS CONCERNANT LES SOINS ET TRAITEMENTS

Durant les jours précédant le décès du patient, le jour de sa sortie, aujourd'hui :

3.1. Quel est/était le souhait des différents intervenants à l'égard du projet thérapeutique?

	Prolonger la vie	Uniquement améliorer le confort	N'a exprimé aucun souhait particulier	Je ne dispose pas de ce renseignement	
Patient	☐	☐	☐	☐	☐ incapable d'exprimer un avis
Proche(s)	☐	☐	☐	☐	☐ pas de proche présent
Equipe médicale	☐	☐	☐	☐	
Equipe infirmière	☐	☐	☐	☐	

3.2. Quels sont/étaient la nature et le type de soins et de traitements qu'il était/est prévu d'administrer ?

	Exclu	Envisageable	Programmé	En cours	Non défini
Réanimation cardiorespiratoire	☐	☐	☐	☐	☐
Admission en unité de soins intensifs	☐	☐	☐	☐	☐
Traitement « actif » de la pathologie « palliative »	☐	☐	☐	☐	☐
Alimentation artificielle (entérale ou parentérale)	☐	☐	☐	☐	☐
Antibiothérapie	☐	☐	☐	☐	☐
Transfusion d'un dérivé sanguin	☐	☐	☐	☐	☐

Répondre à la question 3.3 si le traitement est/était envisageable, programmé ou en cours

3.3. Avec quel objectif ces traitements ont-ils/sont-ils administrés ?

	Pour prolonger la vie	Uniquement pour contrôler un symptôme	Uniquement pour soutenir psychologiquement le malade	Avec un autre objectif	Sans objectif précis
Admission en unité de soins intensifs	☐	☐	☐	☐	☐
Traitement « actif » de la pathologie « palliative »	☐	☐	☐	☐	☐
Alimentation artificielle entérale ou parentérale	☐	☐	☐	☐	☐
Antibiothérapie	☐	☐	☐	☐	☐
Transfusion d'un dérivé sanguin	☐	☐	☐	☐	☐

- 3.4. Le projet thérapeutique ☐ A été discuté en équipe pluridisciplinaire
☐ A été discuté uniquement au sein de l'équipe médicale
☐ N'a pas été discuté

- Le projet thérapeutique ☐ Est formalisé par écrit
☐ N'est pas formalisé par écrit

4 RENSEIGNEMENTS CONCERNANT LE DEVENIR ET L'ORIENTATION DONNÉE AU PATIENT

La question 4.1 concerne uniquement les patients qui sont décédés dans le service

4.1. Le jour du décès, avait-on prévu antérieurement un projet de sortie pour le patient?

- ☐ Non, il était prévu que le patient décède dans le service
☐ Oui (*préciser quel était le projet prévu*)
- ☐ Le patient était en attente d'un retour à domicile
☐ Avec l'intervention d'une équipe de soins palliatifs de 2ème ligne
☐ Sans l'intervention d'une équipe de soins palliatifs de 2ème ligne
☐ Je ne dispose pas de ce renseignement
- ☐ Le patient était en attente d'un transfert vers une maison de repos (et de soins)
☐ Avec l'intervention d'une équipe de soins palliatifs de 2ème ligne
☐ Sans l'intervention d'une équipe de soins palliatifs de 2ème ligne
☐ Je ne dispose pas de ce renseignement
- ☐ Le patient était en attente d'un transfert vers un service de soins palliatifs
☐ Le patient était en attente d'un transfert vers un service de moyen séjour (revalidation)
☐ Le patient était en attente d'un transfert vers un service de soins aigus (court séjour)
☐ Le patient était en attente d'un transfert vers un autre lieu _____
☐ Je ne dispose pas de ce renseignement

La question 4.2 concerne uniquement les patients qui sont sortis du service

4.2. Qu'est devenu le patient après sa sortie du service ?

- ☐ Le patient est rentré à domicile
☐ Avec l'intervention d'une équipe de soins palliatifs de 2ème ligne
☐ Sans l'intervention d'une équipe de soins palliatifs de 2ème ligne
☐ Je ne dispose pas de ce renseignement
- ☐ Le patient a été transféré vers une maison de repos (et de soins)
☐ Avec l'intervention d'une équipe de soins palliatifs de 2ème ligne
☐ Sans l'intervention d'une équipe de soins palliatifs de 2ème ligne
☐ Je ne dispose pas de ce renseignement
- ☐ Le patient a été transféré vers un service de soins palliatifs
☐ Le patient a été transféré vers un service de moyen séjour (revalidation)
☐ Le patient a été transféré vers un service de soins aigus (court séjour)
☐ Le patient a été transféré vers un autre lieu _____
☐ Je ne dispose pas de ce renseignement

La question 4.3 concerne uniquement les patients qui sont toujours hospitalisés dans le service

4.3. Comment envisagez-vous le devenir du patient ?

- ☐ Le patient restera hospitalisé dans le service jusqu'à son décès
- ☐ Le patient rentrera à domicile
- ☐ Avec l'intervention d'une équipe de soins palliatifs de 2^{ème} ligne
 - ☐ Sans l'intervention d'une équipe de soins palliatifs de 2ème ligne
 - ☐ Cet aspect de la prise en charge n'a pas été envisagé
 - ☐ Je ne dispose pas de ce renseignement
- ☐ Le patient sera transféré vers une maison de repos (et de soins)
- ☐ Avec l'intervention d'une équipe de soins palliatifs de 2ème ligne
- ☐ Sans l'intervention d'une équipe de soins palliatifs de 2ème ligne
- ☐ Cet aspect de la prise en charge n'a pas été envisagé
- ☐ Je ne dispose pas de ce renseignement
- ☐ Le patient sera transféré vers un service de soins palliatifs
- ☐ Le patient sera transféré vers un service de moyen séjour (revalidation)
- ☐ Le patient sera transféré vers un service de soins aigus (court séjour)
- ☐ Le patient sera transféré vers un autre lieu _____
- ☐ Cet aspect de la prise en charge n'a pas été envisagé
- ☐ Je ne dispose pas de ce renseignement

Questionnaires destinés à la direction de l'établissement hospitalier
et aux personnes en charge de l'équipe mobile et de l'unité de soins palliatifs
(si de telles structures existent au sein de l'hôpital)

Numéro d'identification de l'institution _____

Merci de bien vouloir remplir ce questionnaire et de nous le retourner dans l'enveloppe ci-jointe.

I. RENSEIGNEMENTS CONCERNANT LA STRUCTURE DE L'INSTITUTION

Types de lit au 1 ^{er} janvier 2008			Nombre de lits au 1 ^{er} janvier 2008
Lits de soins aigus (court séjour)	C	C	
		C i	
		C U	
	D	D	
		D i	
		D U	
	G	G	
		G U	
	C+D	C+D	
		C+D U	
Lits de moyen séjour (revalidation)	H		
	L		
	Autre :		
	S1		
	S2		
	S3		
Total	S5		
	S6		
	Autre		

Veuillez tourner la page, SVP.

2. RENSEIGNEMENTS CONCERNANT LE FONCTIONNEMENT DE L'INSTITUTION

Les équipes soignantes travaillant au sein de l'institution disposent-elles, au 1^{er} janvier 2008, d'un formulaire destiné à préciser le projet thérapeutique des malades hospitalisés :

- ☐ Oui
☐ Non (*passer aux questions de la section 3*)

L'utilisation du formulaire indiquant le projet thérapeutique des malades hospitalisés est-il

- ☐ Obligatoire
☐ Fortement conseillé
☐ Laissé au libre choix de l'équipe soignante

Depuis combien d'année l'utilisation de ce formulaire a-t-elle été initiée ?

- ☐ < 5 ans
☐ > 5 ans et < 10 ans
☐ > 10 ans

3. RENSEIGNEMENTS CONCERNANT LES STRUCTURES DE SOINS PALLIATIFS PRESENTES AU SEIN DE L'INSTITUTION

3. Une équipe mobile hospitalière de soins palliatifs est-elle présente dans l'institution ?

☐ Non (passer à la question 3.2)

☐ Oui Préciser le nombre d'équipes : _____

Quelle est la composition de cette équipe au 1^{er} janvier 2008 ?

☐ Médecin(s)	_____ personnes	_____ ETP
☐ Infirmier(s)	_____ personnes	_____ ETP
☐ Psychologue(s)	_____ personnes	_____ ETP
☐ Assistant ou infirmier social	_____ personnes	_____ ETP
☐ Personnel administratif	_____ personnes	_____ ETP
☐ Autre	_____ personnes	_____ ETP

Depuis combien d'année cette équipe fonctionne-t-elle ?

☐ < 5 ans

☐ > 5 ans et < 10 ans

☐ > 10 ans

3.1 UNE UNITÉ SPÉCIALISÉE SOINS PALLIATIFS est-elle présente dans l'institution ?

☐ Non (Merci d'avoir répondu à ce questionnaire)

☐ Oui

Combien de lits cette unité comporte-t-elle au 1^{er} janvier 2008 _____ lits

Sous quelle catégorie ces lits sont-ils agréés

☐ S 4 (soins palliatifs)

☐ C

☐ Autre _____

Depuis combien d'année l'unité de soins palliatifs fonctionne-t-elle ?

☐ < 5 ans

☐ > 5 ans et < 10 ans

☐ > 10 ans

Nous vous remercions d'avoir répondu à ce questionnaire.
Pouvez-vous adresser les questionnaires suivants aux personnes responsables de l'équipe mobile et de l'unité de soins palliatifs de votre institution ? Merci

**QUESTIONNAIRE DESTINE A LA PERSONNE RESPONSABLE DE L'EQUIPE MOBILE
DE SOINS PALLIATIFS**

Numéro d'identification de l'institution _____

Avez-vous enregistré de façon systématique, l'activité de l'équipe mobile de soins palliatifs en 2007 :

- ☐ Non (Merci, d'avoir répondu à ce questionnaire)
☐ Oui (Dans ce cas, pouvez-vous répondre aux questions suivantes ?)

POUR LA PERIODE QUI S'EST ETALEE DU 1 JANVIER AU 31 DECEMBRE 2007

1. RENSEIGNEMENTS CONCERNANT LE NOMBRE DE PATIENTS SUIVIS PAR L'EQUIPE MOBILE

Nombre total de patients suivis par l'équipe mobile : _____
patients

2. RENSEIGNEMENTS CONCERNANT LE PROFIL DES PATIENTS SUIVIS PAR L'EQUIPE MOBILE

Nombre de patients atteints de

Un cancer _____ patients

Une pathologie non cancéreuse _____ patients

Nombre de patients de sexe Masculin _____ patients

Féminin _____ patients

Age moyen des patients suivis par l'équipe mobile de soins palliatifs _____ ans

3. RENSEIGNEMENTS CONCERNANT LES SERVICES HOSPITALIERS REFERANT LES PATIENTS

Spécialisation des (trois) services où l'équipe mobile a effectué le plus grand nombre de suivis

1. _____

2. _____

3. _____

4. RENSEIGNEMENTS CONCERNANT LE TYPE D'INTERVENTIONS EFFECTUÉES PAR L'EQUIPE MOBILE

Nombre de patients suivis en vue de :

Contrôler un ou plusieurs symptômes _____ patients

Soutenir psychologiquement le malade _____ patients

Soutenir psychologiquement les proches _____ patients

Aider l'équipe soignante à élaborer un projet thérapeutique _____ patients

Organiser la sortie d'hospitalisation du malade _____ patients

Autre type d'intervention _____ patients

5. DONNÉES CONCERNANT LE MOTIF DE CLÔTURE DES SUIVIS

Nombre de suivis clôturés par :

Un décès du patient au sein du service _____ suivis

Un transfert du patient vers une unité de soins palliatifs _____ suivis

Un retour à domicile ou en maison de repos (et soins) _____ suivis

Avec l'intervention d'une équipe d'accompagnement _____ suivis

Sans intervention d'une équipe d'accompagnement _____ suivis

Nous vous remercions d'avoir répondu à ce questionnaire

**QUESTIONNAIRE DESTINE A LA PERSONNE RESPONSABLE DE L'UNITE
HOSPITALIERE DE SOINS PALLIATIFS**

Numéro d'identification de l'institution _____

Avez-vous enregistré de façon systématique, l'activité de l'équipe mobile de soins palliatifs en 2007 :

- ☐ Non (Merci, d'avoir répondu à ce questionnaire)
- ☐ Oui (Dans ce cas, pouvez-vous répondre aux questions suivantes ?)

POUR LA PERIODE QUI S'EST ETALEE DU 1 JANVIER AU 31 DECEMBRE 2007

1. RENSEIGNEMENT CONCERNANT L'ACTIVITE DE L'UNITE DE SOINS PALLIATIFS

Nombre total de patients hospitalisés _____ patients

Durée moyenne de séjour dans l'unité de soins palliatifs _____ jours

Taux d'occupation des lits de l'unité de soins palliatifs _____ %

Délai d'admission moyen des patients _____ jours

2. RENSEIGNEMENTS CONCERNANT LE PROFIL DE PATIENTS HOSPITALISÉS DANS L'UNITÉ DE SOINS PALLIATIFS

Nombre de patients atteints de

Un cancer _____ patients

Une pathologie non cancéreuse _____ patients

Nombre de patients de sexe Masculin _____ patients

Féminin _____ patients

Age moyen des patients hospitalisés dans l'unité de soins palliatifs _____ ans

3. RENSEIGNEMENTS CONCERNANT LES STRUCTURES DE SOINS REFERANT LES PATIENTS

Nombre de patients adressés depuis :

L'hôpital dont dépend l'unité _____ patients

Un autre hôpital _____ patients

Le domicile _____ patients

Une maison de repos (et soins) _____ patients

Un autre lieu _____ patients

Nommer les (3) services appartenant à l'institution et ayant référé le plus grand nombre de patients :

1. _____
2. _____
3. _____

4. RENSEIGNEMENTS CONCERNANT LE MOTIF DE CLÔTURE DES HOSPITALISATIONS

Nombre d'hospitalisations clôturées par :

Le décès du patient _____ hospitalisations

Un retour à domicile du patient _____ hospitalisations

Un transfert du patient en maison de repos (et soins) _____ hospitalisations

Nous vous remercions d'avoir répondu à ce questionnaire

4.4.2.2 *Questionnaires in Dutch*

Vragenlijst aan het verzorgingsteam betreffende het zorgtraject voor palliatieve patiënten (D₁)

PATIËNTGEGEVENS

Identificatienummer van de patiënt _____

1.1. Deze patiënt wordt als 'palliatief' benoemd door (slecht één antwoord mogelijk)

- ☐ zowel de arts als de verpleegkundige (zonder overleg)
- ☐ zowel de arts als de verpleegkundige (met overleg)
- ☐ de arts
- ☐ de verpleegkundige

IDENTIFICATIE VAN DE ZORGINSTELLING EN VAN HET TYPE ZIEKENHUISBEDDEN

Identificatienummer van het ziekenhuis _____

2.1 De patiënt verblijft op volgende afdeling :

- ☐ Acute zorgen (kortverblijf)
- ☐ Interne geneeskunde
 - ☐ Algemene inwendige
 - ☐ Hart- en vaatziekten
 - ☐ Maag- darmziekten
 - ☐ Geriatrie
 - ☐ Hematologie
 - ☐ Neurologie
 - ☐ Nefrologie
 - ☐ Oncologie
 - ☐ Pneumologie
 - ☐ Andere _____
- ☐ Heelkunde
 - ☐ Algemene heelkunde
 - ☐ Cardiothoracale heelkunde
 - ☐ Digestieve heelkunde
 - ☐ Neurochirurgie
 - ☐ Orthopedische heelkunde
 - ☐ Andere heelkunde
- ☐ Andere _____
- ☐ Middellang verblijf
- ☐ Geriatrie
- ☐ Psychogeriatric
- ☐ Locomotorische revalidatie
- ☐ Neurologische revalidatie
- ☐ Cardiorespiratoire revalidatie
- ☐ Algemene revalidatie
- ☐ Autre _____

SOCIODEMOGRAFISCHE GEGEVENS VAN DE PATIËNT

- 3.1. Leeftijd: _____ jaar
- 3.2. Geslacht ☐ Mannelijk
☐ Vrouwelijk
- 3.3. De patiënt is ☐ Gehuwd of samenwonend
☐ Weduwe/ weduwnaar
☐ Feitelijk/wettelijk gescheiden
☐ Alleenstaand
- 3.4. Voor de ziekenhuisopname verbleef de patiënt
- ☐ Thuis
 - ☐ Alleen of met een minderjarige
 - ☐ Samenwonend (met een volwassene)
 - ☐ Ik beschik niet over deze informatie
 - ☐ In een rust- en/of verzorgingstehuis
 - ☐ Op een andere afdeling _____
 - ☐ Ik beschik niet over deze informatie

INFORMATIE OVER DE AANDOENING EN VERWACHTE LEVENSDUUR VAN DE ZIEKE

- 4.1. Welke soort pathologie zorgt ervoor dat de patiënt als palliatief wordt beschouwd?
Slechts één antwoord is mogelijk.

- ☐ Kanker
 - ☐ Tumoraal
 - ☐ Hematologische kanker
- ☐ Terminale hartinsufficiëntie
- ☐ CVA
- ☐ Andere terminale vasculaire pathologie (arteriopathie van de onderste ledematen, coronaropathie...)
- ☐ Respiratoire insufficiëntie (COPD...)
- ☐ Terminaal leverfalen (cirrhose...)
- ☐ Terminaal nierfalen
- ☐ Dementie
- ☐ Andere degeneratieve neurologische aandoeningen (MS, ALS...)
- ☐ Ongeneeslijke infectieziekte (HIV/AIDS...)
- ☐ Andere pathologie _____

- 4.2. Hoeveel tijd is er verstreken sinds de eerste diagnose van deze pathologie ?

- ☐ ≤ 3 maanden
- ☐ > 3 en ≤ 6 maanden
- ☐ > 6 en ≤ 12 maanden
- ☐ > 1 en ≤ 2 jaar
- ☐ > 2 en ≤ 5 jaar
- ☐ > 5 en ≤ 10 jaar
- ☐ > 10 jaar

- 4.3. Hoe schat u de levensduur bij deze patiënt in?

- ☐ < 7 dagen
- ☐ > 1 en ≤ 4 weken
- ☐ > 1 en ≤ 3 maanden
- ☐ > 3 en ≤ 6 maanden

☐ > 6 en ≤ 12 maanden

☐ > 1 en ≤ 5 jaar

☐ > 5 jaar

INLICHTINGEN OVER DE ZORG EN BEHANDELING

5.1. Wat wensen de verschillende partijen te bereiken binnen dit therapeutisch project ?

	Levensduur verlengen	Vooraf comfortverhogende zorgen	Heeft geen enkele specifieke wens geuit	Ik beschik niet over deze informatie
Patiënt	☐	☐	☐	☐
Naaste(n)	☐	☐	☐	☐
De geneeskundige ploeg	☐	☐	☐	☐
De verpleegkundigen	☐	☐	☐	☐

☐ is niet in de mogelijkheid om een wens uit te drukken

☐ geen naasten aanwezig of niet in de mogelijkheid een wens uit te drukken

5.2. Welke zorg is voor deze patiënt voorzien?

	uitgesloten	Kan overwogen worden	Gepland	Wordt uitgevoerd	Niet bepaald
Cardiopulmonaire reanimatie	☐	☐	-	-	☐
Verwijzing naar palliatieve eenheid	☐	☐	☐	-	☐
Actieve behandeling van de hoofdpathologie	☐	☐	☐	☐	☐
Kunstmatige voeding (oraal of parenteraal)	☐	☐	☐	☐	☐
Toediening van antibiotica	☐	☐	☐	☐	☐
Bloedtransfusie	☐	☐	☐	☐	☐

Beantwoord vraag 5.3 indien: de behandeling te overwegen valt, opgenomen is in de planning of opgestart is.

5.3. Welk zijn de beschreven doelstellingen van de behandeling ?

	Levensduur verlengen	Louter symptoomcontrole	Louter psychologische ondersteuning van de patiënt	Andere doelstelling	Zonder specifieke doelstelling
Verwijzing naar een intensieve eenheid	☐	☐	☐	☐	☐
Specifieke behandeling van de pathologie	☐	☐	☐	☐	☐
Kunstmatige voeding (oraal of parenteraal)	☐	☐	☐	☐	☐
Toediening van antibiotica	☐	☐	☐	☐	☐
Bloedtransfusie	☐	☐	☐	☐	☐

5.4. Het behandelingsplan ☐ is besproken met het multidisciplinaire team
☐ is enkel besproken binnen het betrokken medische team
☐ is niet besproken

Het behandelplan ☐ is schriftelijk vastgelegd
☐ is mondeling afgesproken met het volledige verzorgingsteam
☐ is niet doorgegeven aan het volledige verzorgingsteam

INLICHTINGEN OVER DE OPNAME VAN DE PATIËNT

6.1. Op welke datum is de patiënt opgenomen op deze zorgafdeling ?
 ____ / ____ / 200__

6.2. Om welke reden(en) is deze patiënt opgenomen (Beantwoord of vraag 6.2.1 of vraag 6.2.)

6.2.1. Een patiënt opgenomen op een dienst kortverblijf (Meerdere antwoorden mogelijk)

- ☐ Geplande onderzoeken
- ☐ Geplande medische behandeling
- ☐ Geplande chirurgische ingreep
- ☐ Acute ziektesymptomen of complicaties
- ☐ Psychosociale reden
- ☐ Andere reden _____

6.2.2. Een patiënt opgenomen op een dienst middellang verblijf (Meerdere antwoorden mogelijk)

- ☐ Revalidatie
- ☐ In afwachting van een plaatsing in een rusthuis
- ☐ Andere reden _____

6.3. Is de patiënt opgenomen via de spoedopname van het ziekenhuis ? ☐ Ja
☐ Neen

6.4. Is de patiënt opgenomen via een andere dienst van het ziekenhuis ? ☐ Ja
☐ Neen

6.5. Was deze patiënt, voor de ziekenhuisopname, reeds gekend op deze afdeling?

- ☐ Ja
☐ Neen

INLICHTINGEN BETREFFENDE DE UITKOMST VAN DE TOEKOMSTIGE VERWACHTINGEN VAN DE BEHANDELING EN DE ORIËNTATIE VAN DE PATIËNT

7.1. Wat zijn de wensen van de verschillende partijen voor deze patiënt?

	Verblijf in de dienst tot overlijden	Terugkeer naar huis	Overdracht naar ROB of RVT	Overdracht naar een dienst palliatieve zorg	Overdracht naar dienst met chronische bedden (middellange)	Overdracht naar een andere dienst voor een korte periode	Overdracht naar een andere verblijfplaats	Heeft geen enkele specifieke wens geuit	Ik beschik niet over deze informatie
Patient	☐	☐	☐	☐	☐	☐	☐	☐	☐
Naaste(n)	☐	☐	☐	☐	☐	☐	☐	☐	☐
De geneeskundige ploeg	☐	☐	☐	☐	☐	☐	☐	☐	☐
De verpleegkundigen	☐	☐	☐	☐	☐	☐	☐	☐	☐

☐ is niet in de mogelijkheid om een wens uit te drukken
☐ geen naasten aanwezig of niet in de mogelijkheid een wens uit te drukken

7.2. Welk verloop verwacht u voor deze patiënt ?

- ☐ De patiënt zal in het ziekenhuis verblijven tot het moment van overlijden
☐ De patiënt zal naar eigen woning terug kunnen
☐ Dat patiënt zal overgebracht worden naar een rust(en verzorgings)tehuis
☐ Dat patiënt zal overgebracht worden naar een palliatieve afdeling
☐ Dat patiënt zal overgebracht worden naar een afdeling voor opnames van middellange duur (revalidatie)
☐ Dat patiënt zal overgebracht worden naar een andere dienst voor een korte periode (kortverblijf)
☐ Dat patiënt zal overgebracht worden naar een andere plaats _____
☐ Dit aspect van de zorg is nog niet overwogen
☐ Ik beschik niet over deze informatie

**VRAGENLIJST AAN VERZORGINGSTEAM BETREFFENDE HET ZORGTRAJECT
VAN PALLIATIEVE PATIËNTEN (D₁₄ OF 42)****1 PATIËNTGEGEVENS****Identificatienummer van de patiënt** _____**1.1. De patiënt (een antwoord mogelijk)**

- | | |
|--|---|
| ☐ is overleden op de afdeling | Overlijdensdatum: _____ / _____ / 2008 |
| ☐ is ontslagen op de afdeling | Datum van ontslag: _____ / _____ / 2008 |
| ☐ verblijft nog steeds op de afdeling | |

2 INLICHTINGEN BETREFFENDE DE INTERVENTIE VAN HET MOBIELE PALLIATIEVE TEAM

Op het ogenblik van overlijden van de patiënt, het ogenblik van zijn ontslag of tot op heden (als de patiënt nog steeds gehospitaliseerd is)

2.1. Een interventie van het mobiele palliatieve team :

- ☐ heeft plaatsgevonden en is afgerond
- ☐ wordt verleend
- ☐ is/was voorzien maar heeft niet plaatsgevonden
- ☐ wordt/werd overwogen, maar niet gepland
- ☐ is/was uitgesloten (*ga naar deel 3*)
- ☐ is/was niet besproken (*ga naar deel 3*)
- ☐ ik beschik niet over deze informatie (*ga naar deel 3*)

2.2. Het mobiele palliatieve team wordt/werd ingezet voor (*Meerdere antwoorden mogelijk*)

- ☐ hulp bij symptoomcontrole
- ☐ psychologische ondersteuning van de patiënt
- ☐ psychologische ondersteuning van de naaste(n)
- ☐ hulp bij de organisatie naar terugkeer eigen woning
 - ☐ met de hulp van een palliatief team-2de lijn
 - ☐ zonder hulp van een palliatief team-2de lijn
 - ☐ ik beschik niet over deze informatie
- ☐ hulp bij een overdracht naar een ROB/RVT
 - ☐ met de hulp van een palliatief team-2de lijn
 - ☐ zonder hulp van een palliatief team-2de lijn
 - ☐ ik beschik niet over deze informatie
- ☐ Hulp bij de organisatie van de overdracht naar een palliatieve eenheid
- ☐ Hulp bij het ontslag van de patiënt in functie van een overdracht naar een andere plaats _____
- ☐ Hulp aan het zorgteam ter ondersteuning van het therapeutisch project
- ☐ Andere reden _____
- ☐ Ik beschik niet over deze informatie

3 INLICHTINGEN BETREFFENDE DE ZORG EN DE MATE WAARIN VOLGENDE ZORGEN EN/OF BEHANDELINGEN VERSTREKT ZIJN / WORDEN

De dagen voor het overlijden van de patiënt, de dag van zijn vertrek of op heden (indien de patiënt nog steeds gehospitaliseerd is).

3.1. Wat zijn (waren) de wensen van de verschillende partijen ten opzichte van dit therapeutisch project?

	Levensduur verlengen	Comfortverhogende zorgen	Heeft geen enkele specifieke wens geuit	Ik beschik niet over deze informatie	
Patiënt	☐	☐	☐	☐	☐ is niet in de mogelijkheid om een wens uit te drukken
Naasten	☐	☐	☐	☐	☐ geen naasten aanwezig of niet in de mogelijkheid een wens uit te drukken
De geneeskundige ploeg	☐	☐	☐	☐	
Verpleegkundigen	☐	☐	☐	☐	

3.2. Welke zorgen en/of behandelingen zijn (waren) voor deze patiënt voorzien?

	uitgesloten	Kan overwogen worden	Is opgenomen in planning	Wordt gegeven	Niet bepaald
Cardiopulmonaire resuscitatie	☐	☐	-	-	☐
Opname op intensieve zorgen	☐	☐	☐	-	☐
Curatieve behandeling t.o.v. de palliatieve pathologie	☐	☐	☐	☐	☐
Kunstmatige voeding (oraal of parenteraal)	☐	☐	☐	☐	☐
Toediening van antibiotica	☐	☐	☐	☐	☐
Bloedtransfusie	☐	☐	☐	☐	☐

Beantwoord vraag 3.3 indien de behandeling overwogen kan worden, opgenomen is in de planning of opgestart is.

3.3. Met welk doel is/was deze behandeling opgestart?

	Levensduur verlengen	Louter symptoomcontrole	Louter psychologische ondersteuning van de patiënt	Andere doelstelling	Zonder specifieke doelstelling
Verwijzing naar een intensieve eenheid	☐	☐	☐	☐	☐
Specifieke behandeling van de pathologie	☐	☐	☐	☐	☐
Kunstmatige voeding (oraal of parenteraal)	☐	☐	☐	☐	☐
Toediening van antibiotica	☐	☐	☐	☐	☐
Bloedtransfusie	☐	☐	☐	☐	☐

- 3.4. De therapeutische behandeling
- ☐ is besproken met het multidisciplinaire team
 - ☐ is enkel besproken binnen het betrokken medische team
 - ☐ is niet besproken

- Het therapeutisch project
- ☐ is schriftelijk vastgelegd
 - ☐ is mondeling afgesproken met het volledige verzorgingsteam
 - ☐ is niet doorgegeven aan het volledige verzorgingsteam

4 INLICHTINGEN BETREFFENDE HET TRAJECT EN DE ORIËNTATIE VAN PATIËNTEN

Vraag 4.1 handelt enkel over patiënten die overleden zijn op de ziekenhuisafdeling

4.1 Was er een ontslagregeling voorzien voordat de patiënt overleden is?

- ☐ Neen, het overlijden in het ziekenhuis was te voorzien
- ☐ Ja (specificeer wat was voorzien)
 - ☐ De patiënt was in afwachting om naar huis terug te keren
 - ☐ met de hulp van een palliatief team-2de lijn
 - ☐ zonder hulp van een palliatief team-2de lijn
 - ☐ ik beschik niet over deze informatie
 - ☐ De patiënt was in afwachting van een overdracht naar een RVT/ROB
 - ☐ met de hulp van een palliatief team-2de lijn
 - ☐ zonder hulp van een palliatief team-2de lijn
 - ☐ ik beschik niet over deze informatie
 - ☐ De patiënt was in afwachting van een overdracht naar de afdeling 'palliatieve zorg'
 - ☐ De patiënt was in afwachting van een overdracht naar een afdeling voor opnames van middellange duur (revalidatie)
 - ☐ De patiënt was in afwachting van een overdracht naar een afdeling voor een korte periode (kortverblijf)
 - ☐ De patiënt was in afwachting van een overdracht naar een andere plaats
- ☐ Ik beschik niet over deze gegevens

Vraag 4.2 handelt enkel over patiënten die de afdeling verlaten hebben

4.2. Wat is de evolutie van de patiënt na zijn ontslag op de afdeling?

- ☐ De patiënt is naar huis terug gekeerd
 - ☐ met de hulp van een palliatief team-2de lijn
 - ☐ zonder hulp van een palliatief team-2de lijn
 - ☐ ik beschik niet over deze informatie
- ☐ De patiënt is verhuisd naar een RVT/ROB
 - ☐ met de hulp van een palliatief team-2de lijn
 - ☐ zonder hulp van een palliatief team-2de lijn
 - ☐ ik beschik niet over deze informatie
- ☐ De patiënt is overgebracht naar de afdeling 'palliatieve zorg'
- ☐ De patiënt is overgebracht naar een afdeling voor opnames van middellange duur (revalidatie)
- ☐ De patiënt is overgebracht naar een afdeling voor een korte periode (kortverblijf)
- ☐ De patiënt is overgebracht naar een andere plaats _____
- ☐ Ik beschik niet over deze gegevens

Vraag 4.3 handelt enkel over patiënten die tot op heden nog steeds gehospitaliseerd zijn

4.3. Wat verwacht u in de nabije toekomst voor deze patiënt ?

- ☐ De patiënt zal op deze afdeling blijven tot het overlijden
- ☐ De patiënt zal terug naar huis gaan
 - ☐ met de hulp van een palliatief team-2de lijn
 - ☐ zonder hulp van een palliatief team-2de lijn
 - ☐ dit is niet in overweging genomen
 - ☐ ik beschik niet over deze informatie
- ☐ De patiënt zal overgebracht worden naar een RVT/ROB
 - ☐ met de hulp van een palliatief team-2de lijn
 - ☐ zonder hulp van een palliatief team-2de lijn
- ☐ dit is niet in overweging genomen
- ☐ ik beschik niet over deze informatie
- ☐ De patiënt zal overgebracht worden naar een afdeling 'palliatieve zorg'
- ☐ De patiënt zal overgebracht worden naar een afdeling voor opnames van middellange duur (revalidatie)
- ☐ De patiënt zal overgebracht worden naar een afdeling voor een korte periode (kortverblijf)
- ☐ De patiënt zal overgebracht worden naar een andere plaats _____
- ☐ Dit is nog niet in overweging genomen
- ☐ Ik beschik niet over deze informatie

VRAGENLIJST BESTEMD VOOR DE DIRECTIE VAN HET ZIEKENHUIS, VOOR DE VERANTWOORDELIJKE VAN HET MOBIELE PALLIATIEVE TEAM EN VAN DE AFDELING 'PALLIATIEVE ZORG'. (OP VOORWAARDE DAT DERGELIJKE STRUCTUUR BESTAAT BINNEN HET BETREFFENDE ZIEKENHUIS)

Identificatienummer van de instelling _____

Dank om dit formulier ingevuld terug te zenden in bijgevoegde omslag.

I. INLICHTINGEN BETREFFENDE DE STRUCTUUR VAN DE INSTELLING

Soort bedden op 1 januari 2008			Aantal bedden op 1 januari 2008
Acute bedden (kortverblijf)	C	C	
		C i	
		C U	
	D	D	
		D i	
		D U	
	G	G	
		G U	
	C+D	C + D	
		C + D U	
H			
L			
Andere :			
Middellang verblijf	S1		
	S2		
	S3		
	S5		
	S6		
	Andere		
Totaal			

Zie keerzijde aub.

2. INLICHTINGEN BETREFFENDE HET FORMALISEREN VAN HET BEHANDELPLAN IN DE INSTELLING

2.1. Beschikken de betrokken verzorgenden op 1 januari 2008 over een document waarin het therapeutisch project van de gehospitaliseerde patiënt is beschreven ?

☐ Neen (Ga naar deel 3)

☐ Ja

2.2. Het gebruik van formulieren die het therapeutisch project van de gehospitaliseerde patiënten vastlegt is

☐ verplicht

☐ sterk aangeraden

☐ een keuze van het verzorgende team

2.3. Sinds hoeveel tijd is het gebruik van dergelijke formulier ingevoerd ?

☐ < 5 jaar

☐ > 5 jaar en < 10 jaar

☐ > 10 jaar

3. GEGEVENS OVER DE AANWEZIGHEID VAN PALLIATIEVE ZORG STRUCTUREN BINNEN DE INSTELLING

3.1.1. Is er een mobiel palliatief team in het ziekenhuis ?

☐ Neen (ga naar vraag 3.2)

☐ Ja

3.1.2. Welke medewerkers maken op 1 januari 2008 deel uit van dit team?

☐ Arts(en) _____ personen _____ VTE

☐ Verpleegkundige(n) _____ personen _____ VTE

☐ Psycholo(o)g(en) _____ personen _____ VTE

☐ Sociaal of verpleegassistent(en) _____ personen _____ VTE

☐ Administratief personeel _____ personen _____ VTE

☐ Andere _____ personen _____ VTE

3.1.3. Hoe lang is dit team operatief in de instelling ?

☐ < 5 jaar

☐ > 5 jaar en < 10 jaar

☐ > 10 jaar

3.2.1. Is er een gespecialiseerde palliatieve unit in uw instelling ?

☐ Neen (Hartelijk dank om deze vragenlijst te beantwoorden)

☐ Ja Preciseer het aantal eenheid: _____

Hoeveel bedden telt deze eenheid(heden) op 1 januari 2008 ? _____ bedden

3.2.2. Tot welke categorie behoren deze bedden?

☐ S 4 (palliatieve zorgen)

☐ C

☐ Andere _____

3.2.3. Sinds hoe lang is de palliatieve eenheid werkzaam ?

☐ < 5 jaar

☐ > 5 jaar en < 10 jaar

☐ > 10 jaar

Hartelijk dank om deze vragenlijst te beantwoorden.

De volgende vragenlijsten zijn bestemd voor de verantwoordelijken van het 'mobiele support team' en van de eenheid 'palliatieve zorgen' binnen uw instelling. Is het mogelijk deze aan de bevoegde personen te overhandigen aub ? Waarvoor dank.

VRAGENLIJST BESTEMD VOOR DE VERANTWOORDELIJKE VAN DE MOBIELE
SUPPORT TEAM.

Identificatienummer van de instelling _____

Hebt u de activiteiten van de mobiele palliatieve eenheid systematisch geregistreerd gedurende het jaar 2007:

- ☐ Indien niet, hartelijk dank om deze vragenlijst ingevuld te hebben
- ☐ Indien wel, wilt U zo vriendelijk zijn te antwoorden op onderstaande vragen

VOOR DE PERIODE VAN 1 JANUARI TOT 31 DECEMBER 2007

5. INLICHTINGEN BETREFFENDE HET AANTAL PATIËNTEN DIE DOOR HET MOBIELE TEAM GEVOLGD WERDEN

Totaal aantal patiënten gevolgd door het mobile team : _____ patiënten

6. INLICHTINGEN BETREFFENDE HET PROFIEL VAN PATIËNTEN DIE GEVOLGD WERDEN DOOR HET MOBIELE TEAM

Aantal patiënten getroffen door kanker : _____ patiënten
 een andere pathologie dan kanker : _____ patiënten

Aantal mannelijke patiënten : _____ patiënten
 vrouwelijke patiënten : _____ patiënten

Gemiddelde leeftijd van de patiënten, gevolgd door het mobiele palliatieve team
 _____ jaar

7. INLICHTINGEN BETREFFENDE DE ZIEKENHUISAFDELINGEN

In welke diensten is deze equipe het meest tussengekomen?

1. _____
2. _____
3. _____

8. INLICHTINGEN BETREFFENDE HET SOORT INTERVENTIE TOT STAND GEBRACHT DOOR HET MOBIELE TEAM

Aantal patiënten dat gevolgd wordt met het oog op :

Controlebeheersing van één of meerdere symptomen _____ patiënten
 Psychologische ondersteuning van de patiënt _____ patiënten
 Psychologische ondersteuning van de naasten _____ patiënten

Het verzorgende team helpen om een therapeutisch

project uit te werken _____ patiënten
 Organiseren van het ontslag van de patiënt _____ patiënten
 Ander soort interventie _____ patiënten

9. GEGEVENS BETREFFENDE DE DOSSIERAFRONDING EN DE OPVOLGING VAN DE PATIËNT

Aantal opvolgingen beëindigd omwille van:

Overlijden van de patiënt binnen de afdeling _____ opvolgingen
 Overdracht van de patiënt naar de eenheid 'palliatieve zorg' _____ opvolgingen
 Terugkeer naar eigen huis of overplaatsing naar RVT/ROB _____ opvolgingen
 Met tussenkomst van een begeleidingsdienst _____ opvolgingen
 Zonder tussenkomst van een begeleidingsdienst _____ opvolgingen

Hartelijk dank om deze vragenlijst te beantwoorden.

**VRAGENLIJST BESTEM AAN DE VERANTWOORDELIJKE VAN DE AFDELING
'PALLIATIEVE ZORG'**

Identificatienummer van de instelling _____

Hebt u de activiteiten van de mobiele palliatieve eenheid systematisch geregistreerd gedurende het jaar 2007:

- ☐ Indien niet, hartelijk dank om deze vragenlijst ingevuld te hebben
- ☐ Indien wel, wilt U zo vriendelijk zijn te antwoorden op onderstaande vragen

VOOR DE PERIODE VAN 1 JANUARI TOT 31 DÉCEMBER 2007

10. INLICHTINGEN BETREFFENDE DE ACTIVITEITEN VAN DE EENHEID 'PALLIATIEVE ZORG'

Totaal aantal gehospitaliseerde patiënten _____ patiënten
 Gemiddelde verblijfsduur in de eenheid 'palliatieve zorg' _____ dagen
 Bezettingsgraad van de palliatieve eenheid _____ %
 Gemiddelde wachttijd voor opname van patiënt _____ dagen

11. INLICHTINGEN BETREFFENDE HET PROFIEL VAN DE GEHOSPITALISEERDE PATIËNTEN BINNEN DE PALLIATIEVE EENHEID

Aantal patiënten getroffen door kanker : _____ patiënten
 andere pathologie dan kanker : _____ patiënten
 Aantal mannelijke patiënten : _____ patiënten
 vrouwelijke patiënten : _____ patiënten
 Gemiddelde leeftijd van de patiënten, gevolgd door het mobiele palliatieve team
 _____ jaar

12. INLICHTINGEN BETREFFENDE DE ZORGSTRUCTUREN DIE PATIËNTEN VERWIJZEN

Aantal patiënten verwezen via :

Het ziekenhuis waar de eenheid toe behoort _____ patiënten
 Een ander ziekenhuis _____ patiënten
 Eigen woning _____ patiënten
 RVT/ROB _____ patiënten
 Een andere plaats _____ patiënten

Benoem drie diensten binnen de instelling die het grootste aantal patiënten verwezen:

1. _____
2. _____
3. _____

13. GEGEVENS BETREFFENDE DE REDEN VAN STOPZETTEN VAN DE ZORG AAN DE GEHOSPITALISEERDE PATIËNT (ONTSLAG VAN DE PATIËNT)

Aantal afgesloten ziekenhuisopnames voor :

het overlijden van de patiënt _____ ziekenhuisopname
 de terugkeer naar eigen woning _____ ziekenhuisopname
 de overdracht naar een RVT/ROB _____ ziekenhuisopname

Hartelijk dank om deze vragenlijst te beantwoorden.

4.4.3 Sample Size in hospitals

Objectives: to estimate the population of palliative patients (total & prevalence) staying in short-stay and medium-stay hospitals, and to describe the distribution of these patients according to medical and demographic characteristics and ward category.

Other objectives are to describe the care such patients receive, use of resources, and the agreement on patients' status between physicians and nurses.

The study is interested in hospital level characteristics (care, use of palliative resources) as well as population parameters (prevalence of palliative patients).

Using prevalence to compute sample size:

Estimates from the literature show that 5 to 15% hospitalised patients are palliative patients, i.e. 10% on the average.

- With the hypothesis that the prevalence of palliative patients is 0.10 (on a total of 50000 inpatients), and using the following formula:
- $ne = n * DE = N z^2 p (1-p) / [d^2(N-1) + z^2 p(1-p)]$ where
 - o ne = effective sample
 - o DE = design effect, or cluster effect^{mm}
 - o N = population size (number of acute hospital beds)
 - o z = z score corresponding to confidence level (i.e. 0.95 or 0.99)
 - o p = prevalence
 - o d = accuracy (in %).
- We compute sample size estimate for:

o A moderate confidence	$z = 0.95$	
Accuracy (%)		$d = 5.0$
Design effect		$DE = 2.0$
o Prevalence	$p = 0.10$	

^{mm} Variance of a cluster sample is partitioned into between-cluster variance and within-cluster variance. Data from literature (8 studies) show that between-cluster variance $p_{CL-UW} = 0.002$ and within-cluster var $p_{SRS} = pq/n = 0.000009$. Design effect = var p_{CL} / var p_{SRS} .

4.4.4 Hospitals' Sample and characteristics

HOSPITAL	Total beds	Included beds	C+D+H+L	C	D	H	L	G	Sp	SI	S2	S3	S5
1	964	774	702	345	357	0	0	48	24	0	24	0	0
2	1062	825	775	401	374	0	0	30	20	0	20	0	0
3	258	186	162	97	38	27	0	24	0	0	0	0	0
4	197	153	95	59	36	0	0	58	0	0	0	0	0
5	141	80	80	0	0	80	0	0	0	0	0	0	0
6	365	274	246	112	122	12	0	28	0	0	0	0	0
7	334	259	205	94	111	0	0	24	30	0	30	0	0
8	330	249	143	60	74	9	0	40	66	20	26	20	0
9	569	386	284	143	111	0	30	50	52	32	20	0	0
10	912	719	535	271	264	0	0	144	40	0	20	20	0
11	717	615	473	205	131	137	0	102	40	0	40	0	0
12	78	78	0	0	0	0	0	30	48	0	48	0	0
13	54	54	0	0	0	0	0	30	24	24	0	0	0
14	219	129	0	0	0	0	0	0	129	45	56	0	28
Total beds	6200	4781	3700	1787	1618	265	30	608	473	121	284	40	28

	Hospitals' number	Included beds' number
TYPE OF INSTITUTION		
- University hospital	2	1599
- General hospital	10	2921
- Specific hospital	3	261
GEOGRAPHICAL POSITION		
- Brussels	5	1698
- Flanders	5	2010
- Wallonia	4	1073
TOTAL NUMBER OF BEDS		
- < 300 beds	6	680
- 300 à 500 beds	3	782
- > 500 et < 750 beds	5	3319
PROPRIETARY STATUS		
- Public hospital	4	2179
- Private hospital	10	2602
NUMBER OF HOSPITAL'S SITES		
- 1 site	11	2812
- > 1 site	4	1969
APPROVED PALLIATIVE CARE SERVICES		
Palliative care support team	13	4649
Palliative care unit	4	2100

Sample	Perspective	Interventions	Data collection	Design	Scope of costs	Time horizon	Year of costing	Costs	Ref
204 patients with hepatocellular carcinoma	Society	Palliative care services	Prospective analysis of interview data	Case series	Health care costs (hospital and outpatient care), costs of informal services, indirect costs	From first hospitalization until death	1998	Mean cost for formal health services per patient amounted to 3,546 €. Severity and chemotherapy increased formal service costs per day, but patient age, number of days of observation and survivorship decreased formal service costs per day.	Chan et al. (2001) ²³¹
119 patients	Hospital	Palliative care in two hospitals providing general medicine, surgical and obstetric care; and in two hospitals offering extended care and rehabilitation.	Prospective analysis of survey data	Cohort study	Hospital costs	From hospitalization until death	2000	Total costs per day amounted to 493 € for all patients, 547 € for patients admitted to hospitals providing general medicine, and 440 € for patients admitted to hospitals providing extended care. Degree of anxiety of patients and their family; proximity of death; extreme dependence; ear, nose and throat cancer; young patient age; and the provision of certain procedures increased costs.	Tiby-Lévy et al. (2006) ²³²
76 patients	Hospital	Care in palliative unit; care outside palliative unit provided by other medical or surgical teams.	Retrospective analysis of claims data	Matched case-control study	Hospital costs	Patients who died in first 6 months after palliative unit opened	2000	The palliative unit generated lower daily charges (-59%) and lower daily costs (-57%).	Smith et al. (2003) ²³³

Sample	Perspective	Interventions	Data collection	Design	Scope of costs	Time horizon	Year of costing	Costs	Ref
1,744 patients	Hospital	Care in palliative unit; care in any unit other than palliative unit.	Retrospective analysis of claims data	Cohort study	Hospital costs	Last 20 days of life	2004	The cost per day was lower on the palliative care unit than on any other unit. Admitting patients to the palliative care unit at the right time is important to contain costs. Palliative care unit costs diminished due to better coordination of care and elimination of unnecessary tests.	White et al. (2006) ²³⁴
314 veterans	Hospital	Palliative care or usual care	Retrospective analysis of claims data	Cohort study	Hospital costs	Terminal hospitalization	2003	Hospital palliative care was associated with lower inpatient costs per day (-245 €) and lower ancillary costs per day (-100 €). There was no difference in pharmacy costs between palliative care and usual care.	Penrod et al. (2006) ²³⁵
25,459 patients	Hospital	Consultative palliative care programme versus usual care	Retrospective analysis of claims data	Matched case-control study	Hospital costs	30 days	2004	Palliative care patients discharged alive had net savings of 1,684 € in costs per admission and 277 € in costs per day compared with usual care patients. Palliative care patients who died had net savings of 4,872 € in costs per admission and 371 € in costs per day compared with usual care patients.	Morrison et al. (2008) ²³⁶

Sample	Perspective	Interventions	Data collection	Design	Scope of costs	Time horizon	Year of costing	Costs	Ref
316 patients	Hospital	Consultative palliative care programme versus usual care	Retrospective analysis of claims data	Case-control study	Hospital costs	Hospitalisation episode	2001	Mean daily charges amounted to 4,043 € for cases and 4,358 € for control patients. Patients who received a consultation because of non-physical symptoms (e.g. care planning, personal concerns, spiritual concerns) had higher charges.	Cowan (2004) ²³⁷
<i>Palliative care costs at home</i>									
256 patients	National Health Service	Home care service consisted of telephone hotline and team of oncologists and nurses.	Prospective analysis	Case series	Health care costs	Last 2 months of life	2002	Costs of the home care service amounted to 39.9 € per patient per day. This figure covered costs of support and coordination team (8.3 €), medicines (14.4 €), general practice fees (5.7 €), medical examinations (5.0 €), nursing (4.2 €), supplies (1.6 €) and specialist consultations (0.5 €).	Di Cosimo et al. (2003) ²³⁸

Sample	Perspective	Interventions	Data collection	Design	Scope of costs	Time horizon	Year of costing	Costs	Ref
144 patients with haematologic malignancies	National Health Service	Home care service according to disease status: terminal phase requiring palliative care; advanced phase requiring palliative care; chronic phase requiring supportive therapy; curable phase requiring supportive therapy. Home care was provided by multi-professional team.	Retrospective analysis of clinical records and claims data	Cohort study	Health care costs	2 years	2005	Mean monthly costs of health care providers, materials and medicines, transfusional support, laboratory and diagnostic procedures amounted to 4,533 € for the terminal phase; 2,468 € for the advanced phase; 1,594 € for the chronic phase; and 4,270 € for the curable phase.	Cartoni et al. (2007) ²³⁹
155 patients with cancer	National Health Service	Standard care management or home care support by specialized team.	Retrospective analysis of claims data	Cohort study	Health care costs	1 month	1998	Mean costs per patient were lower for patients receiving home support than for patients receiving standard care management (-683 €). This cost advantage originated from lower costs of hospitalisation, outpatient care use, emergency department visits, and days of stay in palliative care units in nursing homes.	Serra-Prat et al. (2001) ²⁴⁰
635 patients	Health maintenance organization	Home-specialised palliative care services or usual care.	Retrospective analysis of claims data	Cohort study	Health care costs	Last year of life	2000	Health care costs of home-specialised services were 30% lower than those of usual care. The cost difference increased nearer time of death. Lower costs of home-specialised services were due to lower costs of hospitalisations and of oncology treatments.	Tamir et al. (2007) ²⁴¹

Sample	Perspective	Interventions	Data collection	Design	Scope of costs	Time horizon	Year of costing	Costs	Ref
80 patients	National Health Service	Rapid response team or discharge community link nurses.	Retrospective analysis of claims data	Before-and-after study	Health care costs	From access to service until death	2006	The mean cost of acute and community services amounted to 8,888 € for patients who accessed programme services and 8,760 € for patients who did not.	Addicott and Dewar (2008) ²⁴²
226 patients	National Health Service	Palliative day care centre or support from specialist palliative home care team.	Prospective analysis of survey data	Cohort study	Health and social care costs	4 weeks	1999	Costs of palliative day care amounted to 106 € per person per day, increasing to 146 € if unpaid resources (e.g. volunteers) were included.	Douglas et al. (2003) ²⁴³

6 REFERENCES

1. Ahmedzai SH, Costa A, Blengini C, Bosch A, Sanz-Ortiz J, Ventafridda V, et al. A new international framework for palliative care. *Eur J Cancer*. 2004;40(15):2192-200.
2. Hanratty B, Hibbert D, Mair F, May C, Ward C, Corcoran G, et al. Doctor's understanding of palliative care. *Palliative Medicine*. 2006;20(5):493-7.
3. Mathew A, Cowley S, Bliss J, Thistlewood G. The development of palliative care in national government policy in England, 1986-2000. *Palliative Medicine*. 2003;17(3):270-82.
4. van Kleffens T, van Baarsen B, Hoekman K, van Leeuwen E. Clarifying the term 'palliative' in clinical oncology. *European Journal of Cancer Care*. 2004;13(3):263-71.
5. Zwerdling T, Hamann K, Meyers F. Extending palliative care is there a role for preventive medicine? *Journal of Palliative Medicine*. 2005;8(3):486-9.
6. Aabom B, Kragstrup J, Vondeling H, Bakketeig LS, Stovring H. Defining cancer patients as being in the terminal phase: Who receives a formal diagnosis, and what are the effects? *Journal of Clinical Oncology*. 2005;23(30):7411-6.
7. Addington-Hall J. Research sensitivities to palliative care patients. *European Journal of Cancer Care*. 2002;11(3):220-4.
8. Auret K, Bulsara C, Joske D. Australasian haematologist referral patterns to palliative care: lack of consensus on when and why.[see comment]. *Intern Med J*. 2003;33(12):566-71.
9. Baka S, Lorigan P, Thatcher N. Palliative treatment. *Hematology/Oncology Clinics of North America*. 2004;18(2):417-32.
10. Billings JA, Gardner M, Putnam AT. A one-day, hospital-wide survey of dying inpatients. *J Palliative Medicine*. 2002;5(3):363-74.
11. Borgsteede SD, Deliens L, Francke AL, Stalman WAB, Willems DL, van Eijk JTM, et al. Defining the patient population: One of the problems for palliative care research. *Palliative Medicine*. 2006;20(2):63-8.
12. Boute C, Millot I, Ferre P, Devilliers E, Piegay C, Lemery B, et al. Comment estimer les besoins en soins palliatifs dans les établissements de court séjour? A propos d'une expérience en Côte d'Or. *Santé Publique*. 1999;11(1):29-39.
13. Casarett D, Kassner CT, Kutner JS. Recruiting for research in hospice: Feasibility of a research screening protocol. *Journal of Palliative Medicine*. 2004;7(6):854-60.
14. Casarett D. Ethical considerations in end-of-life care and research. *Journal of Palliative Medicine*. 2005;160(82 ref).
15. Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *BMJ*. 2000;320(7233):469-72.
16. Claxton-Oldfield S, Claxton-Oldfield J, Rishchynski G. Understanding of the term "palliative care": a Canadian survey. *Am J Hosp Palliat Care*. 2004;21(2):105-10.
17. Currow DC, Nightingale EM. "A planning guide": Developing a consensus document for palliative care service provision. *Medical Journal of Australia*. 2003;179(6 SUPPL.):S23-S5.
18. Dinat N, Russell A. Palliative care - A clinical approach for adults with HIV/AIDS. *Southern African Journal of HIV Medicine*. 2003;12(12):40-5.
19. Edmonds P, Karlsen S, Addington-Hall J. Palliative care needs of hospital inpatients. *Palliative Medicine*. 2000;14(3):227-8.
20. El Osta B, Palmer J, Paraskevopoulos T, Pei B-L, Roberts LE, Poulter VA, et al. Interval between first palliative care consult and death in patients diagnosed with advanced cancer at a comprehensive cancer center. *Journal of Palliative Medicine*. 2008;11(1):51-7.
21. Farquhar M, Grande G, Todd C, Barclay S. Defining patients as palliative: Hospital doctors' versus general practitioners' perceptions. *Palliative Medicine*. 2002;16(3):247-50.
22. Fox E, Landrum-McNiff K, Zhong Z, Dawson NV, Wu AW, Lynn J. Evaluation of prognostic criteria for determining hospice eligibility in patients with advanced lung, heart, or liver disease. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *JAMA*. 1999;282(17):1638-45.

23. Gillick MR. Rethinking the central dogma of palliative care. *Journal of Palliative Medicine*. 2005;8(5):909-13.
24. Glazer JP, Hilden JM, Poltorak DY. Pediatric Palliative Medicine. *Child and Adolescent Psychiatric Clinics of North America*. 2006;15(3):xvii-xx.
25. Gott MC, Ahmedzai SH, Wood C. How many inpatients at an acute hospital have palliative care needs? Comparing the perspectives of medical and nursing staff. *Palliative Medicine*. 2001;15(6):451-60.
26. Haddad P, Wilson P, Wong R, Williams D, Sharma N, Soban F, et al. The success of data collection in the palliative setting--telephone or clinic follow-up? *Support Care Cancer*. 2003;11(9):555-9.
27. Higginson I, Costantini M. Accuracy of prognosis estimates by four palliative care teams: a prospective cohort study. *BMC Palliat Care*. 2002;1(1):1.
28. Jaulin L. Enquête de prévalence régionale PACA des patients relevant de soins palliatifs spécifiques. *Médecine Palliative*. 2006; 5(4):184 -9.
29. Kim A, Fall P, Wang D. Palliative care: optimizing quality of life. *J Am Osteopath Assoc*. 2005;105(11 Suppl 5):S9-14.
30. Desai MJ, Kim A, Fall PC, Wang D. Optimizing quality of life through palliative care. *J Am Osteopath Assoc*. 2007;107(12 Suppl 7):ES9-14.
31. Kuebler KK, Lynn J, Von Rohen J. Perspectives in palliative care. *Seminars in Oncology Nursing*. 2005;21(1):2-10.
32. Lamers WM, Jr. Defining hospice and palliative care: some further thoughts. *Journal of Pain & Palliative Care Pharmacotherapy*. 2002;16(3):65-71.
33. Lamers WM, Jr. Defining palliative care, cancer without pain, when to contact hospice, when to treat multiple myeloma, meaning of physical signs, pneumonia at end-of-life. *Journal of Pain & Palliative Care Pharmacotherapy*. 2007;21(1):85-90.
34. Lorenz K, Lynn J. End-of-Life Care and Outcomes. Rockville: Agency for Healthcare Research and Quality; 2004. Evidence Report/Technology Assessment (110) Available from: <http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcare/eolcare.pdf>
35. Martin CM. Understanding palliative care. *Consultant Pharmacist*. 2006;21(9):698-713.
36. Meier DE. Palliative Care in Hospitals. *J Hosp Med*. 2006;1(1):21-8.
37. Milicevic N. The hospice movement: History and current worldwide situation. *Archive of Oncology*. 2002;10(1):29-31.
38. Morize V, Salomon L, Nguyen DT, Rosenheim M, Desfosses G. Palliative care: are we talking about the same patients? *Palliative Medicine*. 2002;16(1):65-6.
39. Morize V, Bois A. Accompagnement et soins aux personnes âgées en fin de vie à l'hôpital, vécu des soignants. *Soins*. 2006(708):44-8.
40. Nguyen DT, Frank-Soltysiak M, Bisson M. Etude des besoins des patients en phase avancée d'une maladie évolutive dans un CHU. *Santé Publique*. 2001;13(4):339-47.
41. Payne S, Sheldon F, Jarrett N, Large S, Smith P, Davis CL, et al. Differences in understanding of specialist palliative care amongst service providers and commissioners in South London. *Palliative Medicine*. 2002;16(5):395-402.
42. Steihauser KE, Clipp EC, Hays JC, Olsen M, Arnold R, Christakis NA, et al. Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research. *Palliative Medicine*. 2006;20(8):745-54.
43. Todd J, Baldwin CM. Palliative care and culture: an optimistic view. *Journal of Multicultural Nursing & Health*. 2006;12(2):28-32.
44. Vejlgaard T, Addington-Hall JM. Attitudes of Danish doctors and nurses to palliative and terminal care. *Palliative Medicine*. 2005;19(2):119-27.
45. Villard ML, Carlin N, Laval G, Schaerer R. Patients hospitalisés en phase avancée ou terminale d'une maladie grave engageant le pronostic vital. Enquête de prévalence un jour donné, au Centre hospitalier de Grenoble. *Presse Med*. 2003;32(5):203-11.
46. Widder J, Glawischnig-Goschnig M. The concept of disease in palliative medicine. *Medicine, Health Care & Philosophy*. 2002;5(2):191-7.

47. Davies B, Brenner P, Orloff S, Sumner L, Worden W. Addressing spirituality in pediatric hospice and palliative care. *Journal of Palliative Care*. 2002;18(1):59-67.
48. Kuuppelomaki M. Spiritual support for terminally ill patients: nursing staff assessments. *Journal of Clinical Nursing*. 2001;10(5):660-70 (27 ref).
49. Taylor EJ. Prevalence and associated factors of spiritual needs among patients with cancer and family caregivers. *Oncology Nursing Forum Online*. 2006;33(4):729-35.
50. Sand L, Strang P. Existential loneliness in a palliative home care setting. *Journal of Palliative Medicine*. 2006;9(6):1376-87.
51. Stephenson PL, Draucker CB, Martsof DS. The experience of spirituality in the lives of hospice patients. *Journal of Hospice and Palliative Nursing*. 2003;5(1):51-8.
52. Byrne M. Spirituality in palliative care: what language do we need? Learning from pastoral care. *International Journal of Palliative Nursing*. 2007;13(3):118-24.
53. Kellehear A. Spirituality and palliative care: A model of needs. *Palliative Medicine*. 2000;14:149-55.
54. Miller DK, Chibnall JT, Videen SD, Duckro PN. Supportive-affective group experience for persons with life-threatening illness: reducing spiritual, psychological, and death-related distress in dying patients. *Journal of Palliative Medicine*. 2005;8(2):333-43.
55. Kernohan WG, Waldron M, McAfee C, Cochrane B, Hasson F. An evidence base for a palliative care chaplaincy service in Northern Ireland. *Palliative Medicine*. 2007;21(6):519-25.
56. Hampton DM, Hollis DE, Lloyd DA, Taylor J, McMillan SC. Spiritual needs of persons with advanced cancer. *American Journal of Hospice & Palliative Care*. 2007;24(1):42-8.
57. Kuin A, Deliens L, van Zuylen L, Courtens AM, Vernooij-Dassen MJFJ, van der Linden B, et al. Spiritual issues in palliative care consultations in the Netherlands. *Palliative Medicine*. 2006;20(6):585-92.
58. Holmes SM, Rabow MW, Dibble SL. Screening the soul: communication regarding spiritual concerns among primary care physicians and seriously ill patients approaching the end of life. *American Journal of Hospice & Palliative Care*. 2006;23(1):25-33.
59. Hermann CP. The degree to which spiritual needs of patients near the end of life are met. *Oncology Nursing Forum*. 2007;34(1):70-8.
60. Murray SA, Kendall M, Boyd K, Worth A, Benton TF. Exploring the spiritual needs of people dying of lung cancer or heart failure: a prospective qualitative interview study of patients and their carers. *Palliative Medicine*. 2004;18(1):39-45.
61. Strang S, Strang P. Questions posed to hospital chaplains by palliative care patients. *Journal of Palliative Medicine*. 2002;5(6):857-64.
62. Hermann CP. Spiritual needs of dying patients: a qualitative study. *Oncology Nursing Forum*. 2001;28(1):67-72.
63. Sulmasy DP. Spiritual issues in the care of dying patients: ". . . it's okay between me and god". [see comment]. *JAMA*. 2006;296(11):1385-92.
64. Galek K, Flannelly KJ, Vane A, Galek RM. Assessing a patient's spiritual needs: a comprehensive instrument. *Holistic Nursing Practice*. 2005;19(2):62-9.
65. McDermott E, Bingley AF, Thomas C, Payne S, Seymour J, Clark D. Viewing patient need through professional writings: A systematic 'ethnographic' review of palliative care professionals' experiences of caring for people with cancer at the end of life. *Progress in Palliative Care*. 2006;14(1):9-18.
66. Grocott P, Browne N, Cowley S. Psychosocial aspects in wound care. Quality of life: assessing the impact and benefits of care to patients with fungating wounds. *Wounds: A Compendium of Clinical Research and Practice*. 2005;17(1):8-15 (8 ref).
67. Casarett D, Abrahm JL. Patients with cancer referred to hospice versus a bridge program: patient characteristics, needs for care, and survival. *Journal of Clinical Oncology*. 2001;19(7):2057-63.
68. Pollock K, Wilson E, Porock D, Cox K. Evaluating the impact of a cancer supportive care project in the community: patient and professional configurations of need. *Health & Social Care in the Community*. 2007;15(6):520-9.

69. Carter H, MacLeod R, Brander P, McPherson K. Living with a terminal illness: patients' priorities. *Journal of Advanced Nursing*. 2004;45(6):611-20.
70. Goldsteen M, Houtepen R, Proot IM, Abu-Saad HH, Spreeuwenberg C, Widdershoven G. What is a good death? Terminally ill patients dealing with normative expectations around death and dying. *Patient Education & Counseling*. 2006;64(1-3):378-86.
71. Murray SA, Grant E, Grant A, Kendall M. Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their carers.[see comment]. *BMJ*. 2003;326(7385):368.
72. Proot IM, Abu-Saad HH, ter Meulen RHJ, Goldsteen M, Spreeuwenberg C, Widdershoven GAM. The needs of terminally ill patients at home: directing one's life, health and things related to beloved others. *Palliative Medicine*. 2004;18(1):53-61.
73. Jarrett N, Payne S, Turner P, Hillier R. 'Someone to talk to' and 'pain control': What people expect from a specialist palliative care team. *Palliative Medicine*. 1999;13(2):139-44.
74. Astradsson E, Granath L, Heedman PA, Starkhammar H. Cancer patients hospitalised for palliative reasons. Symptoms and needs presented at a university hospital. *Supportive Care in Cancer*. 2001;9(2):97-102.
75. Voogt E, van Leeuwen AF, Visser AP, van der Heide A, van der Maas PJ. Information needs of patients with incurable cancer. *Supportive Care in Cancer*. 2005;13(11):943-8.
76. Sharpe L, Butow P, Smith C, McConnell D, Clarke S. The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer and their carers. *Psycho-Oncology*. 2005;14(2):102-14.
77. Wong RKS, Franssen E, Szumacher E, Connolly R, Evans M, Page B, et al. What do patients living with advanced cancer and their carers want to know? - A needs assessment. *Supportive Care in Cancer*. 2002;10(5):408-15.
78. Goncalves F, Marques A, Rocha S, Leitao P, Mesquita T, Moutinho S. Breaking bad news: experiences and preferences of advanced cancer patients at a Portuguese oncology centre. *Palliative Medicine*. 2005;19(7):526-31 (31 ref).
79. Axelsson B, Sjoden PO. Quality of life of cancer patients and their spouses in palliative home care. *Palliative Medicine*. 1998;12(1):29-39.
80. de Vogel-Voogt E, van der Heide A, van Leeuwen AF, Visser A, van der Rijt CC, van der Maas PJ. Patient evaluation of end-of-life care. *Palliative Medicine*. 2007;21(3):243-8.
81. Spruyt O. Community-based palliative care for Bangladeshi patients in east London. Accounts of bereaved carers. *Palliative Medicine*. 1999;13(2):119-29.
82. Beaver K, Luker K, Woods S. The views of terminally ill people and lay carers on primary care services. *International Journal of Palliative Nursing*. 1999;5(6):266.
83. Beaver K, Luker KA, Woods S. Primary care services received during terminal illness. *International Journal of Palliative Nursing*. 2000;6(5):220-7.
84. Kristjanson LJ, Cousins K, White K, Andrews L, Lewin G, Tinnelly C, et al. Evaluation of a night respite community palliative care service. *International Journal of Palliative Nursing*. 2004;10(2):84-90.
85. Aoun S, Kristjanson LJ, Currow D, Skett K, Oldham L, Yates P. Terminally-ill people living alone without a caregiver: an Australian national scoping study of palliative care needs. *Palliative Medicine*. 2007;21(1):29-34.
86. Kirk P, Kirk I, Kristjanson LJ. What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *BMJ*. 2004;328(7452):1343.
87. Osse BHP, Vernooij-Dassen MJFJ, Schade E, Grol RPTM. The problems experienced by patients with cancer and their needs for palliative care. *Supportive Care in Cancer*. 2005;13(9):722-32.
88. Maguire P, Walsh S, Jeacock J, Kingston R. Physical and psychological needs of patients dying from colo-rectal cancer. *Palliative Medicine*. 1999;13(1):45-50.
89. Aspinall F, Hughes R, Dunckley M, Addington-Hall J. What is important to measure in the last months and weeks of life?: A modified nominal group study. *International Journal of Nursing Studies*. 2006;43(4):393-403.

90. Lopez-Candales AL, Carron C, Schwartz J. Need for hospice and palliative care services in patients with end-stage heart failure treated with intermittent infusion of inotropes. *Clinical Cardiology*. 2004;27(1):23-8.
91. Aldred H, Gott M, Gariballa S. Advanced heart failure: impact on older patients and informal carers. *Journal of Advanced Nursing*. 2005;49(2):116-24 (32 ref).
92. Oates L. Providing spiritual care in end-stage cardiac failure. *International Journal of Palliative Nursing*. 2004;10(10):485-90.
93. Anderson H, Ward C, Eardley A, Gomm SA, Connolly M, Coppinger T, et al. The concerns of patients under palliative care and a heart failure clinic are not being met. *Palliative Medicine*. 2001;15(4):279-86 (11 ref).
94. Cortis JD, Williams A. Palliative and supportive needs of older adults with heart failure. *International Nursing Review*. 2007;54(3):263-70.
95. Horne G, Payne S. Removing the boundaries: palliative care for patients with heart failure. *Palliative Medicine*. 2004;18(4):291-6.
96. Rushby I, Scullion J. Continuing professional development. Managing dyspnoea in end-stage chronic obstructive pulmonary disease (COPD). *Primary Health Care*. 2004;14(1):43-50 (31 ref).
97. Finset A. Health care needs of patients with obstructive lung diseases [Editorial]. *Patient education and Counseling*. 2007;68:111-2.
98. Habraken JM, Willems DL, de Kort SJ, Bindels PJE. Health care needs in end-stage COPD: a structured literature review.[see comment]. *Patient Education & Counseling*. 2007;68(2):121-30.
99. Jefferson M, Davies C. Clinical management. Adults with cystic fibrosis. *European Journal of Palliative Care*. 1998;5(4):107-11 (12 ref).
100. Elkington H, White P, Addington-Hall J, Higgs R, Edmonds P. The healthcare needs of Chronic obstructive pulmonary disease patients in the last year of life. *Palliative Medicine*. 2005;19(6):485-91.
101. Gore JM, Brophy CJ, Greenstone MA. How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer.[see comment]. *Thorax*. 2000;55(12):1000-6.
102. Edmonds P, Karlsen S, Khan S, Addington-Hall J. A comparison of the palliative care needs of patients dying from chronic respiratory diseases and lung cancer. *Palliative Medicine*. 2001;15(4):287-95.
103. Skilbeck J, Mott L, Page H, Smith D, Hjelmeland-Ahmedzai S, Clark D. Palliative care in chronic obstructive airways disease: a needs assessment. *Palliative Medicine*. 1998;12(4):245-54.
104. Jones I, Kirby A, Ormiston P, Loomba Y, Chan KK, Rout J, et al. The needs of patients dying of chronic obstructive pulmonary disease in the community. *Family Practice*. 2004;21(3):310-3.
105. Ganzini L, Johnston WS, Silveira MJ. The final month of life in patients with ALS. *Neurology*. 2002;59(3):428-31.
106. Bolmsjo I, Hermeren G. Interviews with patients, family, and caregivers in amyotrophic lateral sclerosis: comparing needs. *Journal of Palliative Care*. 2001;17(4):236-40.
107. Dawson S, Kristjanson LJ, Toye CM, Flett P. Living with Huntington's disease: need for supportive care. *Nursing & Health Sciences*. 2004;6(2):123-30.
108. Travers E, Jones K, Nichol J. Palliative care provision in Huntington's disease. *International Journal of Palliative Nursing*. 2007;13(3):125-30.
109. Wollin JA, Yates PM, Kristjanson LJ. Supportive and palliative care needs identified by multiple sclerosis patients and their families. *International Journal of Palliative Nursing*. 2006;12(1):20-6.
110. Natterlund B, Sjoden PO, Ahlstrom G. The illness experience of adult persons with muscular dystrophy. *Disability & Rehabilitation*. 2001;23(17):788-98.
111. Parker D, Maddocks I, Stern LM. The role of palliative care in advanced muscular dystrophy and spinal muscular atrophy. *Journal of Paediatrics & Child Health*. 1999;35(3):245-50.
112. Hudson PL, Toye C, Kristjanson LJ. Would people with Parkinson's disease benefit from palliative care? *Palliative Medicine*. 2006;20(2):87-94.

113. Reay N. An exploration of the NHS end of life care programme and its potential use for patients with end-stage systemic sclerosis. *Musculoskeletal Care*. 2007;5(3):130-8.
114. Kristjanson LJ, Aoun SM, Oldham L. Palliative care and support for people with neurodegenerative conditions and their carers. *International Journal of Palliative Nursing*. 2006;12(8):368-77.
115. Kristjanson LJ, Aoun SM, Yates P. Are supportive services meeting the needs of Australians with neurodegenerative conditions and their families? *Journal of Palliative Care*. 2006;22(3):151-7.
116. Burgess L. Addressing the palliative care needs of people with dementia. *Nursing Times*. 2004;100(19):36-9.
117. de Vries K, Sque M, Bryan K, Abu-Saad H. Variant Creutzfeldt-Jakob disease: need for mental health and palliative care team collaboration. *International Journal of Palliative Nursing*. 2003;9(12):512-20.
118. Harris D. Forget me not: palliative care for people with dementia. *Postgraduate Medical Journal*. 2007;83(980):362-6.
119. Stevens T, Payne SA, Burton C, Addington-Hall J, Jones A. Palliative care in stroke: a critical review of the literature. *Palliative Medicine*. 2007;21(4):323-31.
120. Tuffrey-Wijne I. The palliative care needs of people with intellectual disabilities: a literature review. *Palliative Medicine*. 2003;17(1):55-62.
121. Ryan KR, McQuillan R. Palliative care for disadvantaged groups: People with intellectual disabilities. *Progress in Palliative Care*. 2005;13(2):70-4.
122. Bailey B, Aranda S, Quinn K, Kean H. Creutzfeldt-Jakob disease: extending palliative care nursing knowledge. *International Journal of Palliative Nursing*. 2000;6(3):131-9.
123. Browning DM, Solomon MZ, for the Initiative for Pediatric Palliative Care Investigator T. The initiative for pediatric palliative care: an interdisciplinary educational approach for healthcare professionals. *Journal of Pediatric Nursing*. 2005;20(5):326-34.
124. Stillion J-M, Papadatou D. Suffer the children: An examination of psychosocial issues in children and adolescents with terminal illness. *American Behavioral Scientist*. 2002;46(2):299-315.
125. Schrijvers D, Meijnders P. Palliative care in adolescents. *Cancer Treatment Reviews*. 2007;33(7):616-21.
126. George R, Hutton S. Palliative care in adolescents. *European Journal of Cancer*. 2003;39:2662-8.
127. McSherry M, Kehoe K, Carroll JM, Kang TI, Rourke MT. Psychosocial and Spiritual Needs of Children Living with a Life-Limiting Illness. *Pediatric Clinics of North America*. 2007;54(5):609-29.
128. Kinsella E, Zeltzer P, Dignan T, Winter J, Breatnach F, Bouffet E. Safety of summer camp for children with chronic and/or life threatening illness. *European Journal of Oncology Nursing*. 2006;10(4):304-10.
129. DeCinque N, Monterosso L, Dadd G, Sidhu R, Macpherson R, Aoun S. Bereavement support for families following the death of a child from cancer: Experience of bereaved parents. *Journal of Psychosocial Oncology*. 2006;24(2):65-83.
130. Contro NA, Larson J, Scofield S, Sourkes B, Cohen HJ. Hospital staff and family perspectives regarding quality of pediatric palliative care. *Pediatrics*. 2004;114(5 (part 1)):1248-52 (19 ref).
131. Hannan J, Gibson F. Advanced cancer in children: how parents decide on final place of care for their dying child. *International Journal of Palliative Nursing*. 2005;11(6):284-91.
132. Donnelly JP, Huff SM, Lindsey ML, McMahon KA, Schumacher JD. The needs of children with life-limiting conditions: a healthcare-provider-based model. *American Journal of Hospice & Palliative Medicine* 2005;22(4):259-67.
133. Jones BL. Companionship, control, and compassion: A social work perspective on the needs of children with cancer and their families at the end of life. *Journal of Palliative Medicine*. 2006;9(3):774-88.
134. Monterosso L, Kristjanson LJ, Aoun S, Phillips MB. Supportive and palliative care needs of families of children with life-threatening illnesses in Western Australia: Evidence to guide the development of a palliative care service. *Palliative Medicine*. 2007;21(8):689-96.

135. Contro N, Larson J, Scofield S, Sourkes B, Cohen H. Family perspectives on the quality of pediatric palliative care.[see comment]. *Archives of Pediatrics & Adolescent Medicine*. 2002;156(1):14-9.
136. Field D, Addington-Hall J. Extending specialist palliative care to all? *Social Science & Medicine*. 1999;48(9):1271-80.
137. Luddington L, Cox S, Higginson I, Livesley B. The need for palliative care for patients with non-cancer diseases: a review of the evidence. *International Journal of Palliative Nursing*. 2001;7(5):221-6.
138. Seymour J. Needs and preferences of patients with diseases other than cancer: The UK experience. *Progress in Palliative Care*. 2007;15(3):108-12.
139. Fitzsimons D, Mullan D, Wilson JS, Conway B, Corcoran B, Dempster M, et al. The challenge of patients' unmet palliative care needs in the final stages of chronic illness. *Palliative Medicine*. 2007;21(4):313-22.
140. Nelson JE, Kinjo K, Meier DE, Ahmad K, Morrison RS. When critical illness becomes chronic: informational needs of patients and families. *Journal of Critical Care*. 2005;20(1):79-89.
141. Nelson JE, Mercado AF, Camhi SL, Tandon N, Wallenstein S, August GI, et al. Communication about chronic critical illness. *Archives of Internal Medicine*. 2007;167(22):2509-15.
142. Parker D, Grbich C, Brown M, Maddocks I, Willis E, Roe P. A palliative approach or specialist palliative care? What happens in aged care facilities for residents with a noncancer diagnosis? *Journal of Palliative Care*. 2005;21(2):80-7.
143. Tan A, Zimmermann C, Rodin G. Interpersonal processes in palliative care: An attachment perspective on the patient-clinician relationship. *Palliative Medicine*. 2005;19(2):143-50.
144. Baker LM. Information needs at the end of life: a content analysis of one person's story. *Journal of the Medical Library Association*. 2004;92(1):78-82 (37 ref).
145. Abrahm J. Pain management for dying patients. How to assess needs and provide pharmacologic relief. *Postgraduate Medicine*. 2001;110(2):99-100.
146. Gibson J, Grealish L. Relating palliative care principles to the promotion of undisturbed sleep in a hospice setting. *International Journal of Palliative Nursing*. 2001;7(3):140-5.
147. Coulter S, Gray R, Watson M. The need for dental involvement in palliative care. *European Journal of Palliative Care*. 2006;13(3):94-7.
148. Emanuel EJ, Fairclough DL, Slutsman J, Alpert H, Baldwin D, Emanuel LL. Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. *New England Journal of Medicine*. 1999;341(13):956-63.
149. Heyland DK, Dodek P, Rocker G, Groll D, Gafni A, Pichora D, et al. What matters most in end-of-life care: perceptions of seriously ill patients and their family members.[see comment]. *CMAJ Canadian Medical Association Journal*. 2006;174(5):627-33.
150. Casarett DJ, Hirschman KB, Henry MR. Does hospice have a role in nursing home care at the end of life?[see comment]. *Journal of the American Geriatrics Society*. 2001;49(11):1493-8.
151. Evers MM, Meier DE, Morrison RS. Assessing differences in care needs and service utilization in geriatric palliative care patients. *Journal of Pain & Symptom Management*. 2002;23(5):424-32.
152. McIlfratrick S. Assessing palliative care needs: views of patients, informal carers and healthcare professionals. *Journal of Advanced Nursing*. 2007;57(1):77-86.
153. Emanuel EJ, Fairclough DL, Slutsman J, Emanuel LL. Understanding economic and other burdens of terminal illness: the experience of patients and their caregivers. *Annals of Internal Medicine*. 2000;132(6):451-9.
154. Kutner JS, Steiner JF, Corbett KK, Jahnigen DW, Barton PL. Information needs in terminal illness. *Social Science & Medicine*. 1999;48(10):1341-52.
155. Shah S, Blanchard M, Tookman A, Jones L, Blizard R, King M. Estimating needs in life threatening illness: a feasibility study to assess the views of patients and doctors. *Palliative Medicine*. 2006;20(3):205-10.
156. Wenrich MD, Curtis R, Ambrozy DA, Carline JD, Shannon SE, Ramsey PG. Dying patients' need for emotional support and personalized care from physicians: perspectives of patients with terminal illness, families, and health care providers. *Journal of Pain and Symptom Management*. 2003;25(3):236-46 (29 ref).

157. Pevey C. Patient speaking: hospice patients discuss their care. *American Journal of Hospice & Palliative Care*. 2005;22(2):129-33.
158. Morasso G, Capelli M, Viterbori P, Di Leo S, Alberisio A, Costantini M, et al. Psychological and symptom distress in terminal cancer patients with met and unmet needs. *Journal of Pain & Symptom Management*. 1999;17(6):402-9.
159. Chan A, Woodruff RK. Comparison of palliative care needs of English- and non-English-speaking patients. *Journal of Palliative Care*. 1999;15(1):26-30.
160. Morrison LJ, Morrison RS. Palliative care and pain management. *Medical Clinics of North America*. 2006;90(5):983-1004.
161. Wong FKY, Liu CF, Szeto Y, Sham M, Chan T. Health problems encountered by dying patients receiving palliative home care until death. *Cancer Nursing*. 2004;27(3):244-51.
162. Reynolds K, Henderson M, Schulman A, Hanson LC. Needs of the dying in nursing homes. *Journal of Palliative Medicine*. 2002;5(6):895-901.
163. Teunissen SC, de Haes HC, Voest EE, de Graeff A. Does age matter in palliative care? *Critical Reviews in Oncology-Hematology*. 2006;60(2):152-8.
164. Wood FJ. The challenge of providing palliative care to terminally ill prison inmates in the UK. *International Journal of Palliative Nursing*. 2007;13(3):131-5.
165. Francke AL, Willems DL. Terminal patients' awareness of impending death: the impact upon requesting adequate care. *Cancer Nursing*. 2005;28(3):241-7.
166. Foley G. What are the care needs for people with motor neurone disease and how can occupational therapists respond to meet these needs? *British Journal of Occupational Therapy*. 2007;70(1):32-4.
167. Karus D, Raveis VH, Marconi K, Hanna B, Selwyn P, Alexander C, et al. Service needs of patients with advanced HIV disease: a comparison of client and staff reports at three palliative care projects. *AIDS Patient Care & Stds*. 2004;18(3):145-58.
168. Diver F, Molassiotis A, Weeks L. The palliative care needs of ethnic minority patients attending a day-care centre: a qualitative study. *International Journal of Palliative Nursing*. 2003;9(9):389-96.
169. Murray SA, Kendall M, Boyd K, Worth A, Benton TF. General practitioners and their possible role in providing spiritual care: a qualitative study. *British Journal of General Practice*. 2003;53(497):957-9.
170. Emanuel Linda L. Advance directives. *Annual Review of Medicine*. 2007;59:187-98.
171. Grimshaw J, McAuley LM, Bero LA, Grilli R, Oxman AD, Ramsay C, et al. Systematic reviews of the effectiveness of quality improvement strategies and programmes. *Qual Saf Health Care*. 2003;12(4):298-303.
172. Ahronheim JC, Morrison RS, Morris J, Baskin S, Meier DE. Palliative care in advanced dementia: a randomized controlled trial and descriptive analysis. *J Palliat Med*. 2000;3(3):265-73.
173. Aiken LS, Butner J, Lockhart CA, Volk-Craft BE, Hamilton G, Williams FG. Outcome evaluation of a randomized trial of the PhoenixCare intervention: program of case management and coordinated care for the seriously chronically ill. *J Palliat Med*. 2006;9(1):111-26.
174. Aristides M, Shiell A. The effects of hospital use and costs of a domiciliary palliative care nursing service. *Australian Health Review* 1993;16(4):405-13.
175. Baker R, Wu AW, Teno JM, Kreling B, Damiano AM, Rubin HR, et al. Family satisfaction with end-of-life care in seriously ill hospitalized adults. *J Am Geriatr Soc*. 2000;48(5 Suppl):S61-9.
176. Brumley R, Enguidanos S, Jamison P, Seitz R, Morgenstern N, Saito S, et al. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. *J Am Geriatr Soc*. 2007;55(7):993-1000.
177. Bunch E. AIDS in Norway: a post hoc evaluation of an AIDS home care project. *J Clin Nursing* 1998;7:183-7.
178. Butters E, Higginson I, George R, Smits A, McCarthy M. Assessing the symptoms, anxiety and practical needs of HIV/AIDS patients receiving palliative care. *Qual Life Res*. 1992;1(1):47-51.
179. Butters E, Higginson I, George R, McCarthy M. Palliative care for people with HIV/AIDS: views of patients, carers and providers. *AIDS Care*. 1993;5(1):105-16.

180. Butters E, Higginson I. Two HIV/AIDS community support teams: patient characteristics, problems at referral and during the last 6 weeks of life. *AIDS Care*. 1995;7(5):593-603.
181. Casarett D, Karlawish J, Morales K, Crowley R, Mirsch T, Asch D. Improving the use of hospice services in nursing homes: a randomized controlled trial. *JAMA*. 2005;294(2):211-7.
182. Cornbleet MA, Campbell P, Murray S, Stevenson M, Bond S, Joint Working Party of the Scottish Partnership Agency for Palliative and Cancer Care and National Council for Hospice and Specialist Palliative Care S. Patient-held records in cancer and palliative care: a randomized, prospective trial. *Palliat Med*. 2002;16(3):205-12.
183. Cummings JE, Hughes SL, Weaver FM, Manheim LM, Conrad KJ, Nash K, et al. Cost-effectiveness of Veterans Administration hospital-based home care. A randomized clinical trial. *Arch Intern Med*. 1990;150(6):1274-80.
184. Engelhardt JB, McClive-Reed KP, Toseland RW, Smith TL, Larson DG, Tobin DR. Effects of a program for coordinated care of advanced illness on patients, surrogates, and healthcare costs: a randomized trial. *Am J Manag Care*. 2006;12(2):93-100.
185. Field D, Dand P, Ahmedzai S, Biswas B. Care and information received by lay carers of terminally ill patients at the Leicestershire Hospice. *Palliat Med*. 1992;6:237-45.
186. Field D, McGaughey J. An evaluation of palliative care services for cancer patients in the Southern Health and Social Services Board of Northern Ireland. *Palliat Med*. 1998;12(2):83-97.
187. Foley ME, Fahs MC, Eisenhandler J, Hyer K. Satisfaction with home healthcare services for clients with HIV: preliminary findings. *J Assoc Nurses AIDS Care*. 1995;6(5):20-5.
188. Goodwin DM, Higginson IJ, Myers K, Douglas H-R, Normand CE. Effectiveness of palliative day care in improving pain, symptom control, and quality of life. *J Pain Symptom Manage*. 2003;25(3):202-12.
189. Grande G, Todd C, Barclay S, Farquhar M. Does hospital at home for palliative care facilitate death at home? Randomised controlled trial. *BMJ*. 1999;319(7223):1472-5.
190. Grande G, Todd C, Barclay S, Farquhar M. A randomized controlled trial of a hospital at home service for the terminally ill. *Palliat Med*. 2000;14:375-85.
191. Hanks GW, Robbins M, Sharp D, Forbes K, Done K, Peters TJ, et al. The imPaCT study: a randomised controlled trial to evaluate a hospital palliative care team. *Br J Cancer*. 2002;87(7):733-9.
192. Helgesen F, Andersson SO, Gustafsson O, Varenhorst E, Goben B, Carnock S, et al. Follow-up of prostate cancer patients by on-demand contacts with a specialist nurse: a randomized study. *Scand J Urol Nephrol*. 2000;34(1):55-61.
193. Higginson I, Wade A, McCarthy M. Palliative care: views of patients and their families. *BMJ*. 1990;301(6746):277-81.
194. Higginson IJ, Wade AM, McCarthy M. Effectiveness of two palliative support teams. *J Public Health Med*. 1992;14(1):50-6.
195. Higginson IJ, Hearn J. A multicenter evaluation of cancer pain control by palliative care teams. *J Pain Symptom Manage*. 1997;14(1):29-35.
196. Hughes SL, Cummings J, Weaver F, Manheim L, Braun B, Conrad K. A randomized trial of the cost effectiveness of VA hospital-based home care for the terminally ill. *Health Serv Res*. 1992;26(6):801-17.
197. Hughes SL, Weaver FM, Giobbie-Hurder A, Manheim L, Henderson W, Kubal JD, et al. Effectiveness of team-managed home-based primary care: a randomized multicenter trial. *JAMA*. 2000;284(22):2877-85.
198. Jordhoy M, Fayers P, Saltnes T, Ahlner-Elmqvist M, Jannert M, Kaasa S. A palliative-care intervention and death at home: a cluster randomised trial. *The Lancet*. 2000;356(9233):888-93.
199. Jordhoy MS, Fayers P, Loge JH, Ahlner-Elmqvist M, Kaasa S. Quality of life in palliative cancer care: results from a cluster randomized trial. *J Clin Oncol*. 2001;19(18):3884-94.
200. King MT, Hall J, Caleo S, Gurney HP, Harnett PR. Home or hospital? An evaluation of the costs, preferences, and outcomes of domiciliary chemotherapy. *Int J Health Serv*. 2000;30(3):557-79.

201. Koffman J, Higginson I, Naysmith A. Hospice at home—a new service for patients with advanced HIV/AIDS: a pilot evaluation of referrals and outcomes. *Br J Gen Pract* 1996;46:539-40.
202. Lucas C, Glare PA, Sykes JV. Contribution of a liaison clinical pharmacist to an inpatient palliative care unit. *Palliat Med*. 1997;11(3):209-16.
203. Lowenthal RM, Piasczyk A, Arthur GE, O'Malley S. Home chemotherapy for cancer patients: cost analysis and safety. *Med J Aust*. 1996;165(4):184-7.
204. Lloyd Williams M, Payne S. Can multidisciplinary guidelines improve the palliation of symptoms in the terminal phase of dementia? . *International Journal of Palliative Nursing*. 2002;8:370-5.
205. McCann K. The work of a specialist AIDS home support team: the views and experiences of patients using the service. *J Adv Nurs*. . 1991;16(7):832-6. .
206. McCarthy M, Lay M, Addington-Hall J. Dying from heart disease: symptoms and hospital care in the last year of life reported by informal carers *J R Coll Physicians*. 1996;30:325-8.
207. McCorkle R, Hughes L, Robinson L, Levine B, Nuamah I. Nursing interventions for newly diagnosed older cancer patients facing terminal illness. *J Palliat Care*. 1998;14(3):39-45.
208. McMillan S, Small B. Using the COPE intervention for family caregivers to improve symptoms of hospice homecare patients: a clinical trial. *Nurs Forum*. 2007;34(2):313-21.
209. McQuillan R, Finlay I, Roberts D, Branch C, Forbes K, Spencer M. The provision of a palliative care service in a teaching hospital and subsequent evaluation of that service. *Palliat Med*. 1996;10:231-39.
210. McWhinney IR, Bass MJ, Donner A. Evaluation of a palliative care service: problems and pitfalls. *BMJ*. 1994;309(6965):1340-2.
211. Micheels TA, Wheeler LM, Hays BJ. Linking quality and cost effectiveness: case management by an advanced practice nurse. *Clin Nurse Spec*. 1995;9(2):107-11.
212. Moons M, Kerkstra A, Biewenga T. Specialized home care for patients with AIDS: an experiment in Rotterdam, The Netherlands. *J Adv Nurs*. 1994;19(6):1132-40.
213. Moore S, Corner J, Haviland J, Wells M, Salmon E, Normand C, et al. Nurse led follow up and conventional medical follow up in management of patients with lung cancer: randomised trial. *BMJ*. 2002;325(7373):1145.
214. Nickel JT, Salsberry PJ, Caswell RJ, Keller MD, Long T, O'Connell M. Quality of life in nurse case management of persons with AIDS receiving home care. *Res Nurs Health*. 1996;19(2):91-9.
215. Rabow MW, Dibble SL, Pantilat SZ, McPhee SJ. The comprehensive care team: a controlled trial of outpatient palliative medicine consultation. *Arch Intern Med*. 2004;164(1):83-91.
216. Raftery JP, Addington-Hall JM, MacDonald LD, Anderson HR, Bland JM, Chamberlain J, et al. A randomized controlled trial of the cost-effectiveness of a district co-ordinating service for terminally ill cancer patients. *Palliat Med*. 1996;10(2):151-61.
217. Ringdal GI, Jordhoy MS, Kaasa S. Family satisfaction with end-of-life care for cancer patients in a cluster randomized trial. *J Pain Symptom Manage*. 2002;24(1):53-63.
218. Ritz LJ, Nissen MJ, Swenson KK, Farrell JB, Sperduto PW, Sladek ML, et al. Effects of advanced nursing care on quality of life and cost outcomes of women diagnosed with breast cancer. *Oncol Nurs Forum*. 2000;27(6):923-32.
219. Rummans TA, Clark MM, Sloan JA, Frost MH, Bostwick JM, Atherton PJ, et al. Impacting quality of life for patients with advanced cancer with a structured multidisciplinary intervention: a randomized controlled trial. *J Clin Oncol*. 2006;24(4):635-42.
220. Seale C, Kelly M. A comparison of hospice and hospital care for people who die: views of the surviving spouse. *Palliat Med*. 1997;11(2):93-100.
221. Schwartz CE, Wheeler HB, Hammes B, Basque N, Edmunds J, Reed G, et al. Early intervention in planning end-of-life care with ambulatory geriatric patients: results of a pilot trial. *Arch Intern Med*. 2002;162(14):1611-8.
222. Siegel K, Mesagno FP, Karus DG, Christ G. Reducing the prevalence of unmet needs for concrete services of patients with cancer. Evaluation of a computerized telephone outreach system. *Cancer*. 1992;69(7):1873-83.

223. Smeenk FW, Ament AJ, van Haastregt JC, de Witte LP, Crebolder HF. Cost analysis of transmural home care for terminal cancer patients. *Patient Educ Couns*. 1998;35(3):201-11.
224. Topp R, Tucker D, Weber C. Effect of a clinical case manager/clinical nurse specialist on patients hospitalized with congestive heart failure. *Nurs Case Manag*. 1998;3(4):140-5; quiz 6-7, 82.
225. Toseland RW, Blanchard CG, McCallion P. A problem solving intervention for caregivers of cancer patients. *Soc Sci Med*. 1995;40(4):517-28.
226. Tramarin A, Milocchi F, Tolley K, Vaglia A, Marcolini F, Manfrin V, et al. An economic evaluation of home-care assistance for AIDS patients: a pilot study in a town in northern Italy. *AIDS*. 1992;6(11):1377-83.
227. Viney LL, Walker BM, Robertson T, Lilley B, Ewan C. Dying in palliative care units and in hospital: a comparison of the quality of life of terminal cancer patients. *J Consult Clin Psychol*. 1994;62(1):157-64.
228. Volicer L, Collard A, Hurley A, Bishop C, Kern D, S. K. Impact of special care unit for patients with advanced Alzheimer's disease on patient's discomfort and costs. *Journal of the American Geriatrics Society*. 1994;42:597-603.
229. Gomez-Batiste X, Tuca A, Corrales E, Porta-Sales J, Amor M, Espinosa J, et al. Resource consumption and costs of palliative care services in Spain: a multicenter prospective study. *J Pain Symptom Manage*. 2006;31(6):522-32.
230. Guest JF, Ruiz FJ, Greener MJ, Trotman IF. Palliative care treatment patterns and associated costs of healthcare resource use for specific advanced cancer patients in the UK. *Eur J Cancer Care (Engl)*. 2006;15(1):65-73.
231. Chan AT, Jacobs P, Yeo W, Lai M, Hazlett CB, Mok TS, et al. The cost of palliative care for hepatocellular carcinoma in Hong Kong. *Pharmacoeconomics*. 2001;19(9):947-53.
232. Tibi-Levy Y, Le VM, de PG. Determinants of resource utilization in four palliative care units. *Palliat Med*. 2006;20(2):95-106.
233. Smith TJ, Coyne P, Cassel B, Penberthy L, Hopson A, Hager MA. A high-volume specialist palliative care unit and team may reduce in-hospital end-of-life care costs. *J Palliat Med*. 2003;6(5):699-705.
234. White K, Stove rKG, Cassel JB, Smith TJ. Nonclinical outcomes of hospital-based palliative care. *Journal of Healthcare Management*. 2006;51(4):260-73.
235. Penrod JD, Deb P, Luhrs C, Dellenbaugh C, Zhu CW, Hochman T, et al. Cost and utilization outcomes of patients receiving hospital-based palliative care consultation. *J Palliat Med*. 2006;9(4):855-60.
236. Morrison RS, Penrod JD, Cassel JB, Caust-Ellenbogen M, Litke A, Spragens L, et al. Cost savings associated with US hospital palliative care consultation programs. *Arch Intern Med*. 2008;168(16):1783-90.
237. Cowan J. Hospital charges for a community inpatient palliative care program. *American Journal of Hospice and Palliative Medicine*. 2004;21(3):177-90.
238. Di Cosimo S, Pistillucci G, Ferretti G, Cicchetti A, Leggio M, Silvestris N. Palliative home care and cost savings: encouraging results from Italy. *The New Zealand Medical Journal*. 2003;116(1170):1-4.
239. Cartoni C, Brunetti GA, D'Elia GM, Breccia M, Niscola P, Marini MG, et al. Cost analysis of a domiciliary program of supportive and palliative care for patients with hematologic malignancies. *Haematologica*. 2007;92(5):666-73.
240. Serra-Prat M, Gallo P, Picaza JM. Home palliative care as a cost-saving alternative: evidence from Catalonia. *Palliat Med*. 2001;15(4):271-8.
241. Tamir O, Singer Y, Shvartzman P. the economic perspective revisited. *Palliat Med*. 2007;21(6):537-41.
242. Addicott R, Dewar S. A descriptive analysis of the impact and costs of the Marie Curie delivering choice programme in Lincolnshire. London: King's Fund; 2008.
243. Douglas HR, Normand CE, Higginson IJ, Goodwin DM, Myers K. Palliative day care: what does it cost to run a centre and does attendance affect use of other services? *Palliat Med*. 2003;17(7):628-37.

This page is left intentionally blank.

KCE reports

- 33 Effects and costs of pneumococcal conjugate vaccination of Belgian children. D/2006/10.273/54.
- 34 Trastuzumab in Early Stage Breast Cancer. D/2006/10.273/25.
- 36 Pharmacological and surgical treatment of obesity. Residential care for severely obese children in Belgium. D/2006/10.273/30.
- 37 Magnetic Resonance Imaging. D/2006/10.273/34.
- 38 Cervical Cancer Screening and Human Papillomavirus (HPV) Testing D/2006/10.273/37.
- 40 Functional status of the patient: a potential tool for the reimbursement of physiotherapy in Belgium? D/2006/10.273/53.
- 47 Medication use in rest and nursing homes in Belgium. D/2006/10.273/70.
- 48 Chronic low back pain. D/2006/10.273/71.
- 49 Antiviral agents in seasonal and pandemic influenza. Literature study and development of practice guidelines. D/2006/10.273/67.
- 54 Cost-effectiveness analysis of rotavirus vaccination of Belgian infants D/2007/10.273/11.
- 59 Laboratory tests in general practice D/2007/10.273/26.
- 60 Pulmonary Function Tests in Adults D/2007/10.273/29.
- 64 HPV Vaccination for the Prevention of Cervical Cancer in Belgium: Health Technology Assessment. D/2007/10.273/43.
- 65 Organisation and financing of genetic testing in Belgium. D/2007/10.273/46.
- 66 Health Technology Assessment: Drug-Eluting Stents in Belgium. D/2007/10.273/49.
- 70 Comparative study of hospital accreditation programs in Europe. D/2008/10.273/03
- 71 Guidance for the use of ophthalmic tests in clinical practice. D/2008/10.273/06.
- 72 Physician workforce supply in Belgium. Current situation and challenges. D/2008/10.273/09.
- 74 Hyperbaric Oxygen Therapy: a Rapid Assessment. D/2008/10.273/15.
- 76 Quality improvement in general practice in Belgium: status quo or quo vadis? D/2008/10.273/20
- 82. 64-Slice computed tomography imaging of coronary arteries in patients suspected for coronary artery disease. D/2008/10.273/42
- 83. International comparison of reimbursement principles and legal aspects of plastic surgery. D/2008/10.273/45
- 87. Consumption of physiotherapy and physical and rehabilitation medicine in Belgium. D/2008/10.273/56
- 90. Making general practice attractive: encouraging GP attraction and retention D/2008/10.273/66.
- 91 Hearing aids in Belgium: health technology assessment. D/2008/10.273/69.
- 92. Nosocomial Infections in Belgium, part I: national prevalence study. D/2008/10.273/72.
- 93. Detection of adverse events in administrative databases. D/2008/10.273/75.
- 95. Percutaneous heart valve implantation in congenital and degenerative valve disease. A rapid Health Technology Assessment. D/2008/10.273/81
- 100. Threshold values for cost-effectiveness in health care. D/2008/10.273/96
- 102. Nosocomial Infections in Belgium: Part II, Impact on Mortality and Costs. D/2009/10.273/03
- 103 Mental health care reforms: evaluation research of 'therapeutic projects' - first intermediate report. D/2009/10.273/06.
- 104. Robot-assisted surgery: health technology assessment. D/2009/10.273/09
- 108. Tiotropium in the Treatment of Chronic Obstructive Pulmonary Disease: Health Technology Assessment. D/2009/10.273/20
- 109. The value of EEG and evoked potentials in clinical practice. D/2009/10.273/23
- 111. Pharmaceutical and non-pharmaceutical interventions for Alzheimer's Disease, a rapid assessment. D/2009/10.273/29
- 112. Policies for Orphan Diseases and Orphan Drugs. D/2009/10.273/32.
- 113. The volume of surgical interventions and its impact on the outcome: feasibility study based on Belgian data
- 114. Endobronchial valves in the treatment of severe pulmonary emphysema. A rapid Health Technology Assessment. D/2009/10.273/39
- 115. Organisation of palliative care in Belgium. D/2009/10.273/42

This list only includes those KCE reports for which a full English version is available. However, all KCE reports are available with a French or Dutch executive summary and often contain a scientific summary in English.

