Study characteristics							Patients' characteristics at baseline						Informal caregivers' (CG) characteristics at baseline				Needs assessment			Needs complexity		Intervention characteristics (structure and process quality criteria)																		Outcomes		Results for each outcome	Results for outcomes related to informal CG	Comments
Author, Journal, Year	Title	Type of study / Design	Aim of study	Inclusion criteria	Centre (single - multicentric)	Country	Level of Evidence (HLoE) (SIGN) / Justification	Number of patients / Dropouts (DO) / Dropouts through death (DOd)	Female / Male (n/n)	Age (mean, SD)	% of patients with cancer	1. Diagnosis 2. stage/grade 3. phase of illness	Perform-ance status (ECOG, ...)	Patients' needs (psychosocial, spiritual, etc...)	Others	Number of CG / Drop outs	Female / Male (n/n)	Age (mean, SD)	CG's needs (psychosocial, spiritual, etc...)	Others	Who assesses	When	How (tool)	Categories	Process of categorisation (needs > complexity)	Overall description	Setting	Health care providers: Total, n/profession or qualification	Number of places/ beds	Equipment (incl. drugs, EDV, setting/ room/housing)	Funding		Organisation / Management related to structures		Referral criteria / allocation of place	Description of **intervention**		Description of **bereavement intervention**		Description of **control** intervention	Coordination of intervention	Discharge criteria	Integration of oncological and palliative structures		Primary outcomes (1.O) - Secondary outcomes (2.O) (tool, when, how long) / Measure	Costs			
																										Intervention	Control				Who (source)	How much	Who	How		Schedule/Frequency	Content (clinical/non-clinical)	Schedule/Frequency	Content		Who	How		Who	How					
PALLIATIVSTATION																																														
Greer, J. Chron Dis 1986 [163]	An alternative in terminal care: Results of the national hospice study	quasi experimental study	1. What is the difference between hospice and conventional care? 2. What is the differential impact of hospice and conventional care on the quality of life of patients and their families? 3. What is the impact of hospice on the health care costs incurred by terminal cancer patients?	cancer patients served in HC or HB hospices or in CC settings; cancer; remote metastasis (except for lung, brain, and pancreatic cancer); patients for a primary care person (PCP); generally a family member in the household (this excluded all nursing home patients); age 18 or older; KarnoSky Performance Status (KPS) of 50 or less	multicentric (60 hospices) and 14 conventional oncological care settings; 28 hospices received special Medicare demonstration in waivers allowing reimbursing for normally non-covered services))	USA	2v (some evidence because only outpatients with cancer and with a primary care person were included, i.e. patients living alone excluded)	n=1754 (820 HC, 297 CC, 624 HB, 20? DO (drop out: 4.4% with no differences across settings ; n.d.*	% female (HC vs. CC) 51.3 vs. 51.6 vs. 52.7	mears n.d.; HC: n. HB: vs. CC: n 21-54 years 10.3 vs. 8.3 vs. 26.6, 55-64y: 21.0 vs. 14.3 vs. 20.6, 65-74y: 23.1 vs. 19.4 vs. 26.3, ≥75y: 25.8 vs. 31.6 vs. 14.5	100%	1. lung, breast, prostate, colorectal cancer; 2. metastatic at diagnosis: HC: 49.6 vs. HB: 50.4 vs. CC: 39.3; 3. "terminally ill"/"terminal cancer"	HC vs. HB vs. CC: least functional (10-30): 45.8 vs. 49.8 vs. 47.7 % most functional (60 and over): 32.2 vs. 30.2 vs. 32.3%	Patient awareness at initial interview comparable (full mental capacity: HC vs. HB vs. CC): 48.9 vs. 43.9 vs. 54.3%	n.d.			PCP was the patient's spouse or child in 4 out of 5 cases; In HC hospices the PCPs were significantly less likely than in HB or employed at the time of hospice entry. At the onset of the disease, a higher percentage (48%) of all PCPs were employed; those with patients entering hospice were only slightly less likely to be employed at this juncture (42 vs 48% and 51% for HB and CC respectively).	**Patient assessments:** Primary care person assessed patients' and social needs (HB and CC) and pain and symptoms; patients themselfs rated satisfaction with care; **PCP outcomes**	**patients needs:** Personal interviews with the patient and PCP were conducted at study entry; first interview occurred 7 days later and then repeated every 14 days thereafter until the patient's death; **PCP outcomes:** Personal interviews with bereavement interview 90-120 days after the patient's death		Functional performance least functional (10-30) vs. most functional (40 and over); aggressive treatment (no/yes); severe pain reported (no/yes)		hospice programm (hospices classified as those with beds (hospital based; HB) and those without beds (home care, HC); conventional (oncological) care	home care and inpatient facilities (hospices with beds (hospital based; HB) and without beds (home care, HC); conventional oncological care)		home care hospices: 14 demonstration, 6 non-demonstration facilities; hospital based hospices: 11 demonstration, 8 non-demonstration utilities	n.d.	Medicare; Twenty-six (28) of the hospices received special Medicare demonstration waivers allowing them to care for normally non-covered care (home care hospices: 14 demonstration, 6 non-demonstration facilities; hospital based hospices: 11 demonstration, 8 non-demonstration utilities)	small volunteer-dominated community programs caring for a handful of patients to large institutions and organizations with major commitments to hospice care.								conducted to assess PCP outcomes and to summarize records of utilization of hospital, physician, and home health services that the PCP had maintained during the patient's wake. In addition to the patient interviews, at each contact the PCP provided data on his own condition and attitudes, presented a list of the medical services utilized by the patient, and reported on the patient's condition.	"conventional care" = all health care received by terminal cancer patients not enrolled in hospice. "Access patients" were located and used to identify a control group of patients not receiving hospice care. The NHO selected conventional care (CC) settings representing, in the opinion of knowledgeable area physicians, "good" oncological care. Fourteen such access points ultimately participated in referring patients who, although receiving care in outpatient setting, may have used a different inpatient service and vice versa.	US hospices?							impact in 4 areas: **- pattern of care: % of patients receiving medical and social service interventions in the last weeks of life (data obtained from PCP and Medicare/reimbursement records whenever feasible)** Intensive medical services (= Radiation therapy, surgery, chemo or hormonal therapy, hospital admission, transfusion, blood tests, X-rays, or scans), Oxygen or respiratory therapy, Social services at last week of life (= Counseling, financial or legal assistance, paperwork, service referrals, training in patient self-care) **- patient outcomes** overall and social QoL* (QL-Index, Karnofsky Performance Index, Duke-UNC Functional Social Support Questionnaire, California pain assessment profile), satisfaction with care (medical interview satisfaction scale); * = assessed by primary care person. More details on QoL see Morris et al 1986a; more details on pain see Morris et al 1986b). **- family outcomes** (PCP): perceived acute strain (Stress Measurement Questionnaire), chronic strain (Moos Stress), emotional distress following patient death (Manual for the Grief Experience Inventory); mortality during the bereavement period **- utilization** data (obtained from the PCP and linked with Medicare and other reimbursement records whenever feasible) **- total costs** (only direct health care costs;	Hospice inpatient and home care unit cost coefficients were developed using 1982 cost report data compiled either by HCFA or evaluation staff from hospices that reports separately allocated all patient agency costs to a hospice cost center. All inpatient costs were nationally adjusted using Medicare hospital reporting data; hospice home care costs were not nationally adjusted since national standards did not exist. (See Birnbaum and Kelly 1984 for a description of the approach to calculating the cost of utilization episodes.)	QoL similar in hospice and CC settings with the exception of pain and symptom control, which may be better in the inpatient hospice setting [HB]. Hospice patients are less likely to receive diagnostic tests, X-rays, and aggressive anti-tumor therapy in the terminal period, and they are more likely to receive social service support than CC patients. **- pattern of care:** **- satisfaction with care:** HB PCPs higher satisfaction with care than HC PCPs; **- quality of life - Hours of direct care** provided to the patient sig. higher for HC patients than HB or CC patients (p=n.s.), **hours of social visiting (rather than PCP) 3 weeks prior to death:** HC sign. higher than CC, difference between HC and HB n.s.; **pain and other symptoms:** for pain see Morris et al. 1986; **other symptoms (nausea, vomiting, constipation, dyspnea, anorexia, dysphagia):** 3 weeks before death: HB fewer symptoms than HC or CC; 1 week prior to death: same but stat. sign. in the HB-CC comparison, only for details on pain see Morris et al. 1986b **- satisfaction with care:** No sig. differences, "uniformly high in all settings" **- Quality of life in last ninety days:** substantially lower in CC than in HB or CC (8.01 (SE=0.1) vs. 8.148 (SE=0.2) vs. 8.149 (SE=11.7) pm.d.). These differences were related to utilization patterns. **Inpatient and physician costs per ninety day:** sign. higher in CC than in either HC or HB settings, more details see Birnbaum et al. 1984 **- aggressiveness of care:** see Mor and Masterson-Allen, Cancer 1986																																													
Greer, J. Chron Dis 1983 [164]	National hospice study analysis plan	Analyses Plan	(1) What is the differential impact of hospice on the QoL of terminal patients and their families, as compared to "conventional" care? (2) What are the differential costs of caring for comparable terminally ill patients? (3) What are the differences in the services provided? (4) What is the likely impact of Medicare reimbursement on the organizational structure? (5) What are the likely national cost implications of reimbursed hospice care?"			USA											caregivers: levels (PCP); family secondary morbidity (psycho-social distress, role loss, and interpersonal symptoms); Family satisfaction with care received; Subjectively reported grief reaction	dem	dem plus decribed: level detailed in Tab.6, p.754				Hospices classified into 3 types: (a) Hospital-based; (b) Home health agency-based; (c) Freestanding **hospices** may have beds in hospital, home care or inpatient facility. **Home health agency based** hospices are affiliated with existing home care agencies,	DC **group:** Customary care sites were selected using the following criteria: (i) Appropriate representation of major categories (a) University medical center, supervised by academic oncologists or (b) Community-based oncological care. (ii) Ease of access to patients (e.g. cancer clinics or hospices). (iii) Conditions conducive to follow-up (e.g. integrated records). (iv) Willingness of key providers to participate. (v) Proximity to regional management centers.							dem, see diagramm page 746 for additional information	characteristic of hospice programs: (a) Health care and services are provided to terminally ill. (b) The patient, family, and other persons essential to the patient's care comprise the unit of care. The "hospice patient's family" refers to the patient's immediate relatives, individuals with significant ties to the patient, and persons who constitute the "family" by mutual agreement among the patient, the individual, and the hospice organization. (c) Inpatient and home care services are closely integrated to ensure continuity and coordination of care. (d) Care is available 7 days a week, 24 hours a day. (e) Care is planned and provided by a medically supervised interdisciplinary team composed of several individuals with appropriate skills. The team members work together to plan and provide services that will secure the physical, emotional and spiritual welfare of the patient and his/her family. (f) Palliative and supportive care is directed at relieving the pain and physical and emotional discomfort associated with terminal illness. (g) Bereavement services are provided which may include follow-up visits and supports of the family after the patient dies. (h) An education program is available which has two components: (i) Educating the patient, family and community about the nature of terminal illness and dying. (ii) Teaching the family to care for the patient in the home. (i) Volunteers play an important role in the provision of care.																																													
Morris JN, J Chron Dis, 1986a [165]	The effect of treatment setting and patient characteristics on pain in terminal cancer patients: a report from the National Hospice Study	subanalysis	Relationship between measures of pain, Comparison of prevalence and severity of pain among TCPs served in different settings. Description of pain and the prevalence and severity of pain as a therapeutic approach death	dem	dem	dem		dem	dem	dem	dem	dem plus additional information: MC vs. HB vs. CC: Primary breast cancer: 13.4 vs. 11.1 vs. 3.0 %, Primary lung cancer: 25.1 vs. 22.6 vs. 25.2%, brain metastases: 18.6 vs. 14.8 vs. 18.5%, bone metastases: 35.5 vs. 34.1 vs. 36.0%	dem	at study entry - 12.1% of patients reported "horrible" or "excruciating" pain (PCP reported "frequent" or "persistent" pain in 12.1% of patients); 37% of patients reported that pain was "not present"; 8.8% of patients were "free of pain" according to the PCP)	dem	n.a.	n.a.	n.a.		Pain was reported by the patient when able to respond and by the patients' primary care person (PCP) during scheduled interviews until death.	dem; retrospective interview stream (see text); control retrospectively into fixed periods prior to death; **Pain:** PCP measure (T2) included interviews that occurred within 14 days of death and averaged 7 days. The penultimate (T2) and pre-penultimate (T3) interviews averaged approximately 21 and 35 days before death, respectively)	**Patient:** Pain was measured via a direct self-reported question; **PCP:** was asked to characterize the patient's pain on a scale of 4 to 1	categories "pain free" and "persistent pain"	categories "pain free" and "persistent pain" because these are felt to be clinically the most ambiguous categories																																											
Morris JN, J Chron Dis, 1986b [166]	Last days: a study of the quality of life of terminally ill cancer patients	repository analysis	Behavior of a number of Quality of Life measures gathered from two samples of terminal cancer patients over the last weeks of their lives are reported.	dem plus additional study (only results or NHS study participants reported in the following):	dem	USA and Canada (only results or NHS study participant is reported in the following)															dem	dem	a. outcomes	3 x 1% of patients whose QL data are improving/deteriorating/beeing stable over a 6-week time period, means at each of successive time periods as death is approached, and 2.) the proportion of patients in the "worst" and "best" quartiles of the measures over the 9-week time period																																											
Strickland HD, AJPH 1984 [167]	What Does Hospice Cost?	observatyon (cost analysis)	To address the question: What is the cost of hospice? (...) a second question: Does hospice care provided to Medicare beneficiaries cost less than conventional methods of caring for terminally ill cancer patients?	dem		dem																					hospital based hospice (HB): "either as part of a hospital or freestanding organizations with their own inpatient beds"																		

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