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SYSTEMATIC REVIEW

The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review

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Abstract

Objective: to investigate variations in the use of specialist palliative care (SPC) services for adult cancer patients, in relation to age.
Design: systematic review of studies examining use of or referral to SPC services in adult cancer patients.
Search strategy and selection criteria: six electronic databases (Medline, Embase, Web of Science, HMIC, SIGLE and AgeInfo) were searched for studies published between 1966 and March 2005, and references in the articles identified were also examined. Inclusion criteria were all studies which provided data on age in relation to use of or referral to SPC. Two reviewers independently selected studies, extracted data and assessed methodological quality according to defined criteria.
Main outcome measures: use of or referral to SPC services, determined from all sources of report (patient, informal carer, health care professional, health care records).
Results: 14 studies were identified. All reported a statistically significant lower use of SPC among older cancer patients (65 and above or older) at a univariate level [crude odds ratios ranged from 0.33 (0.15–0.72) to 0.82 (0.80–0.82)]. However, there were important methodological weaknesses in all of the studies identified; most crucially, studies failed to consider variations in use in relation to need for SPC.
Conclusions: there is some evidence that older people are less likely to be referred to, or to use, SPC. These findings require confirmation in studies using prospectively collected data which control for patient's need for SPC.

Keywords: *palliative care, utilisation, age factors, review, systematic review, elderly, cancer, oncology*

Introduction

As populations age and disease patterns change, the need for access to high quality palliative care at the end of life is becoming of increasing public health concern [1]. For the growing numbers of older people with advanced, progressive illnesses, poor access to effective symptom control and psychosocial support as they near the end of life can lead to an increased risk of hospital admission and death in hospital [2]. Older people frequently present with complex needs as a result of co-morbidities, social isolation, frail older caregivers, and economic hardship. They may respond well to the expertise offered by specialist palliative care (SPC) providers across all settings [2]. However, recent UK policy documents including the NHS Cancer Plan and the National Service Framework for Older People report that older people have poorer access to palliative care compared with younger people [3, 4].

The debate about the appropriateness of rationing health care provision by age has been fuelled recently by a National Institute for Clinical Excellence (NICE) consultation document on social value judgements, which concluded that 'where age is an indicator of benefit or risk, age discrimination is appropriate' [5]. The concept of a 'fair innings' has also been used to justify the prioritisation of health care resources to younger people [6]. However, these arguments refer to health care aimed at prolonging life, and are not applicable to palliative care, an intervention which improves the quality rather than the length of life [7].

Two previous reviews have investigated variations in access to SPC [8, 9]. On the basis of seven studies published between 1997 and 2003, Ahmed *et al.* concluded that there was some evidence that patients aged 65 and over have a reduced likelihood of referral to SPC [8]. Grande *et al.* reviewed 14 studies and found that older patients were less likely to receive home SPC [9]. However, neither review quantified the difference in use by younger and older patients to enable estimation of the scale of the problem. In addition, neither review applied a quality assessment to the included studies, which limits the confidence that can be placed in the conclusions.

This review is the first to critically appraise published quantitative research on the effect of age on referral to and use of SPC for patients with cancer, and to quantify the impact of age on use. Cancer patients were chosen because they represent 95% of SPC users in the UK [10].

Review methods

Search strategy and selection criteria

We searched Medline, Embase, Web of Science, HMIC, SIGLE and AgeInfo from 1966 to March 2005 for all studies which included quantitative data on referral to and/or use of SPC by adult cancer patients (at any site and stage of disease), across all clinical settings. Settings included inpatient care in a designated palliative care unit (e.g. hospice), day care in a designated palliative care unit, home care received from an SPC team and hospital care received from an SPC team. Studies of care not provided by a dedicated SPC team, including generalist palliative care provided by, for example, family doctors and palliative radiotherapy, were excluded. Retrospective or prospective cohort studies, case-control studies and cross-sectional surveys were eligible for inclusion if they provided data on and included age within their analysis, even if age was not their primary predictor variable. All sources of report of referral or use (patient, informal carer, health care professional, health care records) were eligible for inclusion. There were no restrictions on the country of research, but the language of publication was restricted to English.

A combination of text words and thesaurus terms were used for two major search concepts and their synonyms—*referral/use* and *specialist palliative care* (Appendix 1 for full strategy, available online at www.ageing.oxfordjournals.org). The search strategy was developed in Medline and then adapted for other databases. Bibliographies of full-text articles identified through database searching and included in the review were scrutinised for further relevant studies. The lists of titles, abstracts and then full texts were scrutinised independently by two reviewers (JB and RR) to determine whether they met the inclusion criteria.

Data extraction, appraisal and synthesis

Extraction of data from each paper was performed by one reviewer (JB) and checked by a second (RR). Discrepancies were resolved by referral to the original studies. A checklist was used to extract data on the methods (including design, completeness of outcome ascertainment, analysis); size of study; study population (region, subjects and inclusion/exclusion criteria); outcomes of interest; and proportions of users/non-users by age. Components for quality assessment were adapted from the methodology checklists developed by the Scottish Intercollegiate Guidelines Network (SIGN) and used by organisations including the NICE [11]. These series of questions, published for study designs including cohort and case-control studies, guide assessment of the internal validity of a study. Each study-design specific checklist covers details on the selection of subjects, the assessment of outcome, confounding, and statistical analysis. Criteria are answered on a scale from 'Not reported' to 'Well covered', and an overall assessment of the study is then made based on how many of the criteria are met. Cross-sectional studies were appraised using a modified version of the cohort study checklist.

Because of the diverse nature of the included study populations and of the outcomes, statistical synthesis of study findings was inappropriate. Where data allowed, crude odds ratios and 95% confidence intervals for the use of SPC in older versus younger cancer patients were calculated. We used an age cut-off of over and under 75 where original age categories allowed. Extracted data are presented in tabular form and a narrative synthesis conducted.

Results

Description of studies

Of 2,652 citations initially identified, 14 articles (which related to 13 studies) met the inclusion criteria [12–25] (Figure 1).

Nine of the thirteen studies were retrospective cohort studies which used administrative data and ranged in size from 521 [18] to 170,136 participants [23]. Two studies were cross-sectional surveys using retrospective reports of service use from proxy respondents (usually carers). They included 96 [24] and 2,074 [12, 13] participants respectively. One study used a retrospective case-control design [17] and one was a retrospective review of a palliative care service records, with comparisons to the wider population of cancer deaths [16]. Studies covered deaths occurring from 1979 to 1999. Two studies restricted participants to patients aged 65 years and above at death, and one to 67 years and above; the remaining restricted participants to adults, or had no stated age restrictions (Table 1).

Four articles focused specifically on the receipt of SPC at home [13, 15, 17, 24]. The remaining included one or more services providing SPC across a range of settings (e.g. home, hospital and hospice). Studies based their outcome ascertainment on records kept or provided by the SPC service of interest, except the two surveys of proxy respondents, which relied on participant's reports of the deceased's use of services.

Use of specialist palliative care in relation to age

All of the studies reported a statistically significant lower use of SPC among older cancer patients at a univariate level. Crude odds ratios for the use of SPC in older versus younger cancer patients ranged from 0.37 (0.23–0.60) to 0.82 (0.80–0.84) (Table 2).

Eight studies included a multivariate regression analysis to investigate the effect of age on referral to or use of SPC, after controlling for potential confounding factors [12–14, 17, 19–21, 23]. Of these, six reported older adults were significantly less likely to use SPC services [12–14, 19–21].

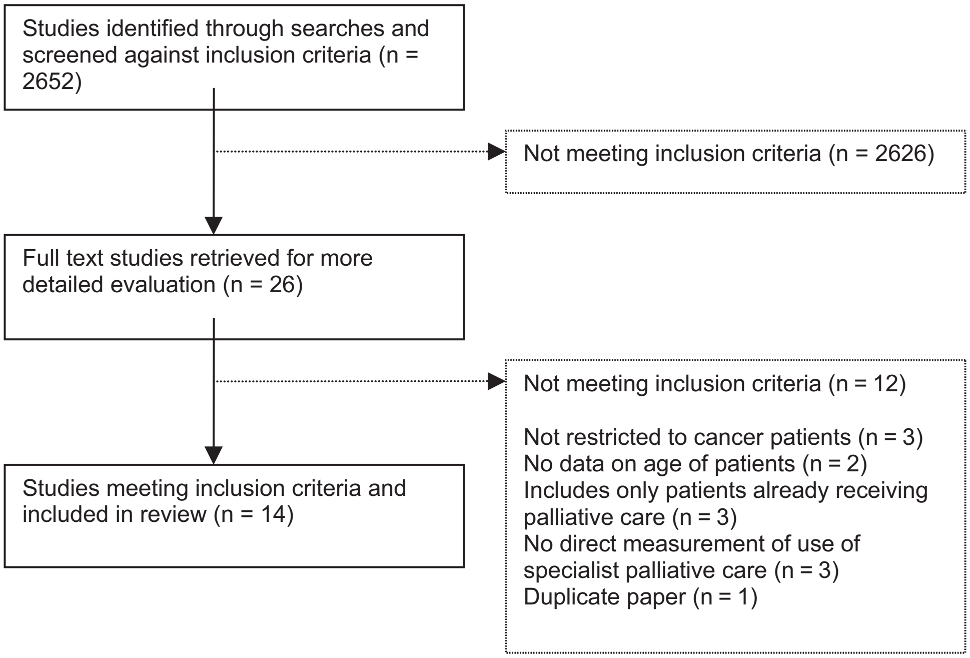

Figure 1. Flowchart of literature search and study selection.

However, age group cut-offs and variables included in regression models varied between studies, making direct comparison between them difficult. In Grande *et al.* (2002) case control study, the effect of age disappeared after controlling for other variables, including use of cancer and district nursing services [17]. As the author's acknowledged, if age is related to use of other health care services, its relationship with hospice use may have been disguised in their analysis. The final study reported that, following multiple regression analysis, the effect of age (as a continuous variable) on the use of hospice care increased over the period of their study, 1991–1999 [23].

Discussion

Our findings suggest that patients' age may be an influential factor in use of or referral to SPC, with older patients less likely to receive these services than younger patients. However, important weaknesses in the studies reviewed limit the certainty of the findings.

Crucially, these studies did not explicitly explore the issue of *inequality* versus *inequity* of use. Inequality and inequity are related, but not equivalent, concepts. Inequities in the use of health care are inequalities (differences) in use which are considered to be unfair or unjust [26]. The judgement as to what is unfair or unjust is usually based on consideration of the need for health care and the extent to which health care inequalities are avoidable. An equitable health care system is one in which there is equal use of health care for equal need. Therefore, the measurement of need is fundamental to studies of the fair use of health care [27]. This concept of fairness, rather than simply of equality, is widely recognised when the distribution of NHS care is considered. For example, standard one of the National Service Framework (NSF) for Older People states that 'NHS services will be provided, regardless of age, on the basis of clinical need alone' [4]. SPC is designed to meet only the most complex or persistent needs of cancer patients—and therefore not all patients require this care [28].

Unequal use of health care between particular population groups is not inequitable if it reflects an unequal need for care. These findings may therefore reflect a reduced need for SPC amongst older people. It is not yet clear whether this is indeed the case, for two reasons. First, although it has been agreed that SPC should be reserved for those with 'complex and persistent' needs, there has been little examination on how this definition of need should be operationalised, resulting in a lack of agreement between medical and nursing staff as to which hospital inpatients require such care [29]. Second, the evidence on variations in the need for care by age, based upon the presence and impact of symptoms, is limited and conflicting. For example, one post-bereavement survey of carers found that patients over 85 years had a greater number of symptoms than patient under 65, but symptoms in the older group were less likely to be 'very distressing' [30]. By contrast, a secondary analysis of a retrospective survey of cancer patient carers suggested that both the number of symptoms and the proportion perceived to be 'very distressing' declined with age, whilst the level of functional dependency did not vary [31].

It is argued that the need for SPC should be determined by social, emotional and spiritual concerns as well as by health status [1]. Across a life span, patients' health, social and economic status (including the presence of dependent children or partners, the likelihood of living alone and employment status) fluctuates. It is therefore possible that the need for SPC will vary with age. However, in the absence of explicit definitions of the needs that can be

Table 1. Characteristics and quality appraisal of studies

Study (location)	Age of patients	Participants	Outcome	SIGN score[1]
Retrospective cohort studies				
Burge 2002 (Canada) [14]	No stated restrictions	4,376 cancer deaths (1992–1997) identified from death certificates in one municipality. No stated age restrictions.	Referral to the municipality palliative care programme. Not stated how determined.	2–
Costantini 1993 (Italy) [15]	18+	12,343 cancer deaths (1986–1990) identified from local department of statistics in one city.	Use of the palliative home-care service. Determined from clinical records of the service.	2–
Evans 1984 (UK) [16]	No stated restrictions	125 patients (referred between May 1982 and June 1983) identified from the clinical records of the service and who received continuing care. 437 cancer deaths (1982) in one district identified from the death records of the Office of Population Censuses and Surveys.	Receipt of continuing care from the multidisciplinary terminal care support team.	2–
Gray 1997 (UK) [18]	16+	521 cancer deaths (1991) identified from death register held by the Director of Public Health. Participants included if postcode of residence within District Health Authority; cancer recorded as a causal or contributory factor in death. 16 years and over	Receipt of care from one or more SPC agencies, last 12 months of life. Determined from in-patient and day hospice records; Marie Curie and Macmillan nurse' case load diaries.	2–
Hunt 1996 (Australia) [19]	No stated restrictions	2,800 cancer deaths (1990) identified from Central Cancer Registry (CCR) database. Deaths attributable to a non-cancer cause—based on State death records—excluded. No stated age restrictions.	Use of one of South Australia's inpatient hospice or outreach palliative care services. Determined from lists provided by all hospice and palliative care services of their patients who died in 1990.	2–
Hunt 2002 (Australia) [20]	No stated restrictions	3,086 cancer deaths (1999) identified from State Cancer Registry database. No stated age restrictions.	Use of one of South Australia's inpatient hospice or outreach palliative care services. Determined from lists provided by all hospice and palliative care services of their patients who died in 1999.	2–
Johnston 1998 (Canada) [21]	20+	14,494 cancer deaths (1988–1994) identified from death certificate data included in the Cancer Registry in one region. 20 years and over.	Referral to a comprehensive Palliative Care Program (PCP) based in one Infirmary. Inpatient unit, hospital consultation, clinic follow-up, home consultation and bereavement support. Determined from clinical records of the service.	2–
Lackan 2003 (USA) [22]	65+	25,161 breast cancer deaths (1991–1996) identified from Surveillance, Epidemiology and End Result (SEER) Medicare databases—population-based registry for incident cancer cases. SEER areas represent about 14% of the US population. Diagnosed with breast cancer between 1986 and 1996. Aged 65 years and over.	Receipt of hospice care. Determined by existence of a hospice claim in the hospice standard analytic file [Medicare claims].	2–
Lackan 2004 (USA) [23]	67+	170,136 breast, colorectal, lung and prostate cancer deaths (1991–1999) identified from Surveillance, Epidemiology and End Result (SEER) Medicare databases—population-based registry for incident cancer cases. SEER areas represent about 14% of the US population. Diagnosed with cancer between 1991 and 1996. Aged 67 years and over.	Receipt of hospice care. Determined by existence of a hospice claim in the hospice standard analytic file [Medicare claims].	2–
Virnig 2002 (USA) [25]	65+	388,511 deaths from one of seven cancers (1996) identified from the National Center for Health Statistics' Report of Final Mortality Statistics. Aged 65 years and over.	Use of hospice care. Determined from 1996 hospice claims data submitted to the Health Care Financing Administration.	2–
Retrospective surveys of proxy respondents				
Addington-Hall 1998 (UK) [12]	No stated restrictions	2,074 of 2,915 (71% response rate) cancer deaths randomly sampled from 20 self-selected health authorities. Deaths occurring in last quarter of 1990. For each death, the best informant about the deceased's last 12 months of life sought, and interviewed using a structured questionnaire.	Receipt of hospice inpatient care. Determined by respondent's recollection of the names of hospitals and hospices to which the deceased was admitted. Names cross-checked with the 1990 Directory of Hospice Services.	2–
Addington-Hall 2000 (UK) [13]	No stated restrictions	2,074 of 2,915 (71% response rate) cancer deaths randomly sampled from 20 self-selected health authorities. Deaths occurring in last quarter of 1990. For each death, the best informant about the deceased's last 12 months of life sought, and interviewed using a structured questionnaire.	Receipt of CSPC nursing. Determined by respondent's reports of use of these services—no further details.	2–

Table 1. *continued*

Study (location)	Age of patients	Participants	Outcome	SIGN score[1]
McCusker 1985 (USA) [24]	No stated restrictions	133 cancer deaths randomly selected from deaths in one county, December 1979 to January 1980. Surviving relatives contacted and interviewed (96/133—72% response rate).	Use of the county home-hospice programme.	2−
Retrospective case-control study				
Grande 2002 (UK) [17]	No stated restrictions	121 cancer patients referred to HAH from June 1994 to June 1995 (cases) and 206 cancer deaths randomly sampled from the area Cancer Registry who were not referred to HAH (control).	Referral to the Hospital at Home palliative care service. Not stated how determined.	2+

[1] Based on the SIGN methodological quality checklists. Code 2 ++ (High quality case-control, cohort or cross-sectional studies with a very low risk of confounding, bias or chance and a high probability that the relationship is causal), 2+ (Well conducted case-control, cohort or cross-sectional studies with a low risk of confounding, bias or chance and a moderate probability that the relationship is causal), 2− (Case control, cohort or cross-sectional studies with a high risk of confounding, bias or chance and a significant risk that the relationship is not causal). NB: retrospective studies can only score + or −.

addressed by SPC, it is not possible to explore the extent to which they differ with age. Only one of the studies included in this review attempted to define patients' need for SPC, and this was limited to a consideration of symptoms [12, 3].

An alternative explanation for lower use of SPC by older patients is that their needs are being met elsewhere. Perhaps health or social care services 'fill the gap' for older cancer patients. It may be that a palliative care approach is used by generalist or care of the elderly services and that these meet the needs of older cancer patients [28]. The high proportion of older cancer patients dying in care homes may also reflect another effective approach to meeting the needs of these patients [32]. However, until a greater understanding of need is developed, it is difficult to judge how far SPC needs are met by alternative care sources.

Some further limitations of the studies included in this review should be pointed out. First, four studies gave an inadequate description of SPC services that were included, their setting and the care offered, limiting their generalisability [14, 20, 22, 23]. Second, the quality of the outcomes data was often poor. All the studies were based on retrospective investigations of service use, relying on routine administrative data or recall of service use by proxy respondents. It is understandable why such data sources are used in preference to prospectively collected data from patients themselves. In this field, prospective data collection is challenging, because of the terminal nature of illness and risk of loss of data because of participants' incapacity or death. However, the limitations of retrospective methods should be recognised. For example, referral to or use of SPC has been shown to be inconsistently recorded in patient records [33]; the validity of responses about service use and subjective symptoms from proxies such as carers is uncertain [34]; and questions asked of proxy respondents to determine use of SPC are often insufficiently comprehensive [24]. The sensitive nature of terminal illness research should not exclude the use of prospective studies. Instead, discerning methods of data collection should be designed, which may include, for example, flexibility in data collection intervals and settings. If retrospective methods continue to be used, validation methods should ascertain the accuracy of their outcomes data. These could include prospective investigation of the completeness and accuracy of medical records, or cross-validation of respondent reports with data from SPC services.

Implications

This review highlights the requirement to investigate the use of SPC in relation to the need for such care in order to understand whether the objectives of the NHS Cancer Plan and the NSF for Older People are being fulfilled in line with the principles of the NHS. Sensitive and flexible prospective methods should be developed to examine the extent to which the use of SPC is fair. This review also highlights wider issues about how need for SPC may be defined. Although this paper is restricted to cancer patients, the ongoing debate about SPC for non-cancer patients may present an opportunity to focus on and clarify what SPC actually is and offers, and who has a need for such care.

Funding

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Key points

- This is the first systematic review to explicitly quantify reported differences in use of SPC between older and younger cancer patients.
- There is some evidence that older cancer patients are less likely to be referred to or to use SPC services than younger patients.
- However, there were important methodological weaknesses in all of the studies identified; most crucially, studies failed to consider variations in use in relation to need for SPC.

Conflicts of interest

None declared.

Ethical approval

Not required.

Table 2. Estimates of use of SPC by age group

			Extracted results: Crude (unadjusted) odds ratios			
Study	Results: Use of SPC by age		Comparison group	Odds ratio	95% CI	Multivariate analysis
Retrospective cohort studies						
Burge 2002 [14]	<65 = 75% 65–74 = 70% 75–84 = 53% ≥85 = 38%[1]		—	—	—	Patients older than 65 less likely to receive SPC than patients under 65. Controlled for sex, cancer type, year of death and receipt of palliative radiotherapy. Odds ratios (OR): <65 = 1.00 65–74 = 0.72 (0.60, 0.85) 75–84 = 0.44 (0.37, 0.53) ≥85 = 0.21 (0.17, 0.27)
Costantini 1993 [15]	<55 = 8.1% 55–64 = 6.1% 65–74 = 5.0% 75–84 = 2.8% ≥85 = 1.6%	(92/1,142) (139/2,287) (179/3,590) (110/4,005) (21/1,319)	Over/under 75	0.41	0.33 to 0.50	Multivariate analysis not conducted to investigate use of SPC (investigated predictors of home death for patients receiving care from SPC home care service)
Evans 1984 [16]	<44 = 75.0% 45–54 = 66.7% 55–64 = 30.9% 65–74 = 28.7% 75–84 = 19.3% ≥85 = 9.5%	(9/12) (18/27) (29/94) (41/143) (23/119) (4/42)	Over/under 75	0.37	0.23 to 0.60	Multivariate analysis not conducted
Gray 1997 [18]	Mean age at death: Use SPC: 66.6 (SD 11.9) No use SPC: 73.0 (SD 10.6)		—	—	—	Multivariate analysis not conducted
Hunt 1996 [19]	<40 = 56.7% 40–59 = 66.3% 60–79 = 58.1% ≥80 = 41.2%	(51/90) (299/451) (963/1,657) (248/602)	Over/under 80	0.47	0.39 to 0.57	Patients older than 80 less likely to receive SPC compared withpatients under 40. Controlled for area of residence, site, survival, place of birth, other variables uncertain/not stated. ORs: <40 = 1.00 40–59 = 1.26 (0.78, 2.03) 60–79 = 0.89 (0.57, 1.39) ≥80 = 0.41 (0.26, 0.65)
Hunt 2002 [20]	<60 = 73.3% 60–69 = 73.6% ≥0–79 = 70.9% (80 = 58.3%	(356/486) (457/621) (778/1,097) (514/882)	Over/under 80	0.54	0.46 to 0.63	Patients older than 80 less likely to receive SPC compared withpatients under 60. Controlled for area of residence, country of birth, primary cancer site, survival from diagnosis. ORs: <60 = 1.00 60–69 = 0.96 (0.72, 1.27) 70–79 = 0.83 (0.64, 1.07) ≥80 = 0.50 (0.39, 0.65)
Johnston 1998 [21]	20–74 = 50.1% ≥75 = 35.0%	(409/817) (182/520)	Over/under 75	0.54	0.43 to 0.67	Older patients less likely to receive SPC compared with younger patients. Controlled for sex, cancer cause of death, provision of palliative radiation, year of death, time between diagnosis and death, place of residence. ORs:

Table 2. *continued*

						20–54 = 4.9 (3.2, 7.6) 55–64 = 3.4 (2.2, 5.1) 65–74 = 3.1 (2.1, 4.5) 75–84 = 2.1 (1.4, 3.1) ≥85 = 1.0
Lackan 2003 [22]	67–74 = 25.4% 75–84 = 22.8% 85–89 = 18.1% ≥90 = 12.3%	(1,383/5,443) (2,432/10,666) (861/4,756) (528/4,293)	Over/under 75	0.71	0.66 to 0.76	Effect of age in multivariate analysis not reported
Lackan 2004 [23]	67–74 = 33.1% 75–84 = 31.2% ≥85 = 24.3%	(18,377/55,520) (23,411/75,035) (9,557/39,329)	Over/under 75	0.82	0.80 to 0.84	Multivariate analysis showed the effect of age (as a continuous variable) on use of hospice increased between 1991 and 1999—adjusted odds ratios for use of hospice in 1991 were 0.99 (0.99–1.00), and in 1999 0.98 (0.97–0.98)
Virnig 2002 [25]	65–69 = 41.8 70–74 = 45.0 75–79 = 45.3 80–84 = 45.0 85–89 = 43.1 90–94 = 41.0 ≥95 = 38.2	Rate per 100 deaths, standardised for sex and race	—	—	—	Multivariate analysis not conducted (rates standardised for sex and race)
Proxy surveys						
Addington-Hall 1998 [12]	<55 = 17.9% 55–64 = 20.9% 65–74 = 19.5% 75–84 = 15.3% ≥85 = 7.9%	(37/207) (67/321) (111/570) (105/686) (22/277)	Over/under 75	0.62	0.49 to 0.79	Being under the age of 85 years was significantly associated with an increased likelihood of receiving inpatient hospice care. Under 85 odds ratio 2.82 (1.59–5.00). Variables included in model not explicitly stated.
Addington-Hall 2000 [13]	<55 = 43.0% 55–64 = 39.3% 65–74 = 31.1% 75–84 = 21.1% ≥85 = 13.4%	(89/207) (126/321) (177/570) (145/686) (37/277)	Over/under 75	0.42	0.34 to 0.51	Being under the age of 75 years was significantly associated with an increased likelihood of receiving community SPC nursing. Under 75 odds ratio 1.77 (1.4–2.3). Variables in model 23, including type of respondent, marital status, whether had living children and symptoms.
McCusker 1985 [24]	<65 = 61.9% 65–74 = 35.9% (75 = 34.1%	(26/42) (14/39) (14/41)	Over/under 75	0.53	0.25 to 1.15	Multivariate analysis not conducted
Retrospective case-control study						
Grande 2002 [17]	Users mean age Non-users mean age	70.5 (SD 13.8) 74.7 (SD 12.0)	—	—	—	Effect of age significant at a univariate level (difference in mean age between Hospice at Home and control groups $P = .006$); disappeared in multivariate logistic regression analysis. Variables in the final model predicting membership of the Hospice at Home group included noncancer causes of death, cancer diagnosis, contact with oncologist, late start for acute hospital care, late start for district nursing input, and receipt of Marie Curie nursing care.

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[1] NB: No numerator or denominator data shown.

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