



## PLACE OF DEATH AND ACCESS TO HOME CARE SERVICES: ARE CERTAIN PATIENT GROUPS AT A DISADVANTAGE?

G. E. GRANDE,<sup>1\*</sup> J. M. ADDINGTON-HALL<sup>2</sup> and C. J. TODD<sup>1</sup>

<sup>1</sup>Department of Community Medicine, GPPCRU, Institute of Public Health, University of Cambridge, University Forvie Site, Robinson Way, Cambridge CB2 2SR, U.K. and <sup>2</sup>Department of Palliative Care and Policy, King's College School of Medicine and Dentistry/St. Christopher's Hospice, London SE5 9PJ, U.K.

**Abstract**—Research indicates that fewer people are able to die at home than would wish to do so. Furthermore the ability to die at home is unequally distributed depending on patient characteristics. Unless factors associated with home deaths are identified and interventions are targeted accordingly, further general improvements in care support may only help those already at an advantage. This paper reviews research investigating the relation between patient characteristics and home deaths and considers whether these variables influence place of death because they are associated with differential access to services, focusing on access to palliative home care. Patients with informal carer support were both more likely to die at home and to access palliative home care. Provision of home care did not remove the dependence on informal carers in achieving home death, however. An important target in improving home death rates is therefore better support for informal carers overall. Older patients were both less likely to die at home and to access home care. Once in home care they no longer were less likely to die at home. Although age related needs require consideration, improved access to home care is therefore likely to increase home deaths for older people. Women were less likely to die at home than men, yet younger women may be more likely to access home care. There is some evidence to suggest that men were less efficient as carers, which may help explain why women were less likely to achieve home deaths, while making their referral to home care more likely. While home care may help redress the gender imbalance, men may also need to be encouraged and enabled to take on the carer role. Cancer patients in higher socioeconomic groups were both more likely to die at home and to access home care. Hence home deaths may increase by improving access for lower socioeconomic groups to the services available. © 1998 Elsevier Science Ltd. All rights reserved

**Key words**—place of death, palliative care, home care, terminal care

### INTRODUCTION

Approximately 25% of people in the U.K. currently die at home (Seale and Cartwright, 1994) and lower percentages have been cited for cancer deaths in U.S.A. and Australia (Hunt and McCaul, 1996). However, research suggests that death at home is preferred by one half or more of terminally ill patients (Dunlop *et al.*, 1989; Townsend *et al.*, 1990), by a majority of the general public (Charlton, 1991; Toscani *et al.*, 1991; Ashby and Wakefield, 1993) and primary care professionals (Cartwright, 1991). Bereaved informal carers are also more likely to state that the place of death was right (Ward, 1987; Addington-Hall *et al.*, 1991) and suffer less distress (Catalan-Fernandez *et al.*, 1991) if the patient died at home rather than in hospital. There is therefore an imbalance between what primary care support is able to provide and what patients, carers, health professionals and the public want. However, access to palliative home care ser-

vices and ability to die at home is unequally distributed and further general increases in palliative care support may mainly help those who are already at an advantage. This paper summarises what is known about differences in death at home and access to palliative home care in order to identify target groups for further research and intervention.

The paper reviews research relating to home deaths and access to palliative home care for adults. Studies were identified through the databases Medline Express 1968–1997 and SERLINE on SilverPlatter 1997 and by manually following up references cited in identified papers. The search terms used were “place” or “location of death” and “terminal” or “palliative” “home care” or “domiliary care”. The review was limited to English language papers and therefore mainly contains research conducted in the U.K., the U.S.A. and Australia. However, papers from Canada, Italy, Sweden, Israel and Switzerland are included. The results are therefore restricted to the historico-cultural context of Europe, North America and Australia in recent decades. Aries (1981) paints

\*Author for correspondence.

Table 1. Studies of variables associated with death at home, all diagnoses (positive relationship +, negative relationship -, no significant relationship found 0)

Study	Subjects	Method	Variables
Cartwright <i>et al.</i> (1973)	random sample of 960 adult (> = 15) deaths from twelve registration districts in England and Wales in 1969; 785 (82%) bereaved carers interviewed	retrospective interviews with informal carer or official; mainly $\chi^2$ tests	Informal support: living alone -, married +, children +, daughters +; Diagnosis: cerebrovascular disease -, respiratory disease -, ischaemic heart disease and other circulatory disease +; ADL: patient restrictions -, bedridden -; Symptoms: pain -, confusion -, vomiting +, loss of appetite +, bedsores +, dyspnoea +; Time period: length of need for self care and night care -; Age: below 45 -, 45-54 years of age +; Sex: female -; Social class: 0; Other: district nurse support +, awareness of condition or outcome 0
Bowling and Cartwright (1982)	random sample of 1600 deaths from eight representative areas in England; all married women > = 60 and all married men > = 65 were identified; 361 (74%) bereaved spouses interviewed	retrospective interviews with bereaved spouse; mainly $\chi^2$ tests	Informal support: carer is wife rather than husband +; Diagnosis: bronchitis +; ischaemic heart disease +, pneumonia -, influenza -; Sex: female -; Other: spent time in hospital during last year of life-
Rosenberg and Short (1983)	all deaths age > = 65 in Whatcom county in 1971, 1975 and 1978 ( <i>n</i> = 543-807), in King County in 1971 ( <i>n</i> = 10,213), Detroit 1971 ( <i>n</i> = 20,203) and Springfield, Illinois in 1975 ( <i>n</i> = 777)	mortality and death certificate data; $\chi^2$	Sex: female -; Other: white versus non-white-
Polissar <i>et al.</i> (1987)	all 426115 deaths of residents in a U.S. state 1968-1981 inclusive	data from death certificates; cross-tabulation of results	Informal support: divorced +; Diagnosis: heart and vascular disease +, cerebrovascular disease (including stroke) -, pneumonia and influenza -; Age: 75 or above -; Sex: female -; Social class: percentage of high school graduates in area of residence 0; Other: white -, urban residence 0
Hunt <i>et al.</i> (1989)	all cancer deaths in specific Australian city suburbs in 1981 ( <i>n</i> = 432) and 1986 ( <i>n</i> = 609), selection of next registered cancer death for resident in other suburb ( <i>n</i> = 2082), random sample of 2643 non-cancer deaths	data from death certificates; $\chi^2$ and unconditional logistic regression	Sex: female -
Hunt <i>et al.</i> (1991)	records from funeral directors representing half the deaths in an Australian city; 20 % of deaths randomly sampled every 10th year from 1910 to 1980 inclusive, and 1987; <i>n</i> = 2566 deaths	data from funeral director records; $\chi^2$ and logistic regression	Informal support: partner +, number of children + <sup>†</sup> ; Diagnosis: non-cancer +; Age: over 65 0; Sex: female -; Social class: unskilled + <sup>†</sup> ; Other: urban residence + <sup>†</sup> <sup>a</sup>
Clifford <i>et al.</i> (1991)	all deaths registered during a 3 month period in 1988 in Victoria, Australia ( <i>n</i> = 7697)	retrospective data from the office of the Registrar of Births, Deaths and Marriages; descriptive percentages and logistic regression	Informal support: married +; Diagnosis: circulatory disease versus cancer + stomach cancer versus other cancers +; Age: > 65 -, Sex: female -; Social class: socioeconomic area of residence 0
Seale and Cartwright (1994)	random sample of 800 adult (> = 15) deaths from ten local authority areas in England in October and November 1987; 639 (80%) bereaved carers interviewed	retrospective interviews with informal carer or official; tests of differences in proportions or $\chi^2$ tests	Informal support: living alone -; Age: 75 or above -; Sex: female -; Social class: 0

<sup>a</sup>Paper considers different inpatient settings separately. For some variables  $\chi^2$  can be recalculated, comparing home deaths with inpatient deaths overall. Otherwise significance of variable's relationship to home death is unclear.

Table 2. Studies of variables associated with death at home, cancer patients (positive relationship +, negative relationship -, no significant relationship found 0)

Study	Subjects	Method	Variables
Parkes (1978)	276 of 435 spouses, aged <65, of cancer patients aged <65 who died in two London boroughs 1967-1971; analysis of 100 patients who died in hospital and 65 patients who died at home or spent all but last week at home; patients without identifiable terminal period or who died in hospice excluded	post bereavement interview with carers; $\chi^2$	Informal support: age of carer 0; ADL: mobile +; Symptoms: initial pain -, pain in final phase +, confusion -; Sex: 0; Social class: 0
McCusker (1983)	all 2989 adult (> = 15) residents who died in a U.S. County 1976-1978, whose cancers had been diagnosed before death and with known place of death and socioeconomic area (unknown for 9.7% of initial sample)	data from regional tumour registry and census data; odds ratios estimated from logit model analysis	Diagnosis: leukaemia -, lymphoma -, colorectal +, genitourinary +; Time period: survival (mainly >1 month) +; Age: 0; Sex: 0; Social class: high socioeconomic area of residence +; Other: ethnic background 0
Polissar <i>et al.</i> (1987)	further analysis of Polissar <i>et al.</i> , Table 1; all cancers newly diagnosed in 13 U.S. counties 1974-1981 which could be linked with death certificate information; $N = 33865$	data from Cancer Surveillance System; cross-tabulation of results	Diagnosis: non-Hodgkins lymphoma -, Time period: survival <1 month-
Roder <i>et al.</i> (1987)	random stratified samples of cancer patients from Australian death records for 1981 ( $n = 795$ ) and 1985 ( $n = 787$ )	data from death certificates; $\chi^2$	Informal support: married men vs unmarried +; Diagnosis: haematological cancer -; Age: 0; Sex: female -; Social class: resident in affluent suburb +
Moinpour and Polissar (1989)	all 28828 residents of 13 Washington state counties who died 1980-1985 with cancer as primary cause and diagnosis made prior to death; values for all variables obtained for 26500 (92%) patients for logistic regression analysis	data from existing population, cancer surveillance and service provider records; calculation of relative risk and logistic regression	Informal support: married +; Time period: survival <1 month -; Age: 85 or above -; Other: non-urban residence +
Hunt <i>et al.</i> (1989)	further analysis of Hunt <i>et al.</i> , Table 1, cancer patients only	data from death certificates; $\chi^2$ and unconditional logistic regression	Informal support: number of children +, married men vs unmarried +; Age: -; Sex: female -; Other: Australian-born female-
Johnson and Oliver (1991)	all cancer deaths 1977-1988 in U.K. health district, ranging from 444 to 712 deaths per year; similar data obtained for surrounding health districts for 1977, 1982 and 1987	Cancer Registry data; $\chi^2$	Diagnosis: primary cerebral tumour -, ovarian cancer +; Social class: disadvantaged health district +?
Hunt <i>et al.</i> (1993)	all deaths attributed to cancer in South Australia for whom place of death was known ( $n = 2715$ )	retrospective data from the Central Cancer Registry and the Registrar General of Births, Deaths and Marriages; unconditional multiple logistic regression	Diagnosis: haematological malignancy -, upper gastrointestinal malignancy +; Time period: survival 0; Age: 70 or above -; Sex: male +; Social class: high or middle socioeconomic area of residence +; Other: country of birth 0, Aboriginal +
Costantini <i>et al.</i> (1993)	all 12343 adult (> 17) cancer deaths in Genoa 1986-1990	linkage of data from death certificates, general registry office and home care service records; univariate odds ratio and multivariate logistic regression	Informal care: married +; Diagnosis: leukaemia/lymphoma -, head/neck -, lung -, prostate +; Age: +; Sex: female +; Social class: education level +
Higginson <i>et al.</i> (1994)	all cancer deaths in 44 electoral wards in London during 1988-1992	OPCS data, Underprivileged Area (UPA) score calculated with 1991 census data. Spearman's correlation between proportion of home deaths and UPA score	Social class: high underprivileged area score -
Axelsson and Christensen (1996)	all 203 patients who died in a Swedish county of cancer of the G1 tract, urogenital organs, the breast, the skin or the thyroid	data from death certificates, medical records and parish registries; $\chi^2$	Informal support: married 0; Diagnosis: 0; Time period: survival <1 month -; Age: 0; Sex: 0; Other: distance to hospital 0
Sims <i>et al.</i> (1997)	all cancer deaths among Doncaster (U.K.) residents in 1995 for whom former occupation was known (99%, $n = 820$ )	retrospective data from the Office of National Statistics; $\chi^2$	Social class: skilled workers (III) vs highest (I and II) and lowest social class (IV and V) +

Table 3. Variables associated with referral to home care, cancer patients (positive relationship +, negative relationship -, no significant relationship found 0)

Study	Subjects	Method	Variables
Mor and Hiris (1983)	National Hospice Study data; 3257 adult patients who died in 26 hospices Aug. 1981–Nov. 1982 and were admitted before July 1982; hospices were home based, hospital based or free-standing	retrospective, hospice records; univariate analysis and discriminant function analysis	Informal support: living alone -, carer employed -, carer lives elsewhere -, carer is old -, ADL: functionally dependent -; Social class: education level +, income > \$10000 +, private insurance - Diagnosis: oropharyngeal +, lung +, gastrointestinal -, breast -, haematological cancer -; Age: -, Sex: 0
Evans and McCarthy (1984)	125 patients referred to a London terminal support team compared with all local cancer deaths; support team worked both in community and hospital and had no designated beds	research record system for admitted patients; OPCS deaths and 1981 census data; $\chi^2$	Diagnosis: oropharyngeal +, lung +, gastrointestinal -, breast -, haematological cancer -; Age: -, Sex: 0
McCusker (1985)	54 home care users and 68 non-users, aged > 18, who were diagnosed > 2 weeks before death and not permanently institutionalised; randomly selected from all 220 cancer deaths in U.S. county December 1979 and January 1980	interviews with patients' physician and closest surviving relative; $\chi^2$ , <i>t</i> -tests and analysis of variance	Informal support: married +, spouse as primary caregiver +; Symptoms: pain severity at onset of TCP: 0; Time period: TCP > 45 days +; Functional status during TCP: 0; Age: over 65 -; Sex: 0; Other: spending main part of TCP at home +
Mor <i>et al.</i> (1985)	National Hospice Study data Oct. 1980–Sept. 1982; all 5912 cancer patients referred to 8 home based ( <i>n</i> = 2466) or 9 hospital based hospices ( <i>n</i> = 3446) for whom both modes of care existed within 30 miles; 3500 patients from demonstration hospices for analysis of inpatient stays	retrospective, patient records; logistic regression; <i>t</i> -tests for comparison of pre-hospice inpatient stays	Informal support: living alone -, carer is male -, carer is employed -, ADL: 0; Symptoms: required intravenous care -, required bowel or bladder care -; Age: 0; Sex: female +; Other: length of pre-hospice hospital stays -, white-
Greer <i>et al.</i> (1986)	National Hospice Study data Aug. 1981–March 1983; random selection or census of patients from 20 hospices with home care only ( <i>n</i> = 833), 19 hospices with beds ( <i>n</i> = 624) and 14 conventional care sites ( <i>n</i> = 297); patients had metastases, an adult primary carer and, for conventional care patients, a Karnofsky score < = 50 and poor prognosis	interviews with patient and primary carer on entry, 7 day follow up, 2 weekly follow up, bereavement interview 3–6 months after a death; logistic, linear and weighted least square regression	Informal support: living alone -, carer employed -, married 0; ADL: poor Karnofsky score (10–30) -, functionally impaired -; Time period: survival 0, length of stay +; Age: 65 or above +; Social class: income < \$10000 -; Other: hospitalisation in the two months previous to study-
Gray <i>et al.</i> (1987)	98 Australian home care patients on cancer registry in 1983 and 98 other cancer registry patients matched on age, sex and site of primary cancer, both diagnosed after August 1981	Cancer Registry, Health Department and hospital records; analysis of variance	Informal support: married 0; Time period: survival +; Social Class: socioeconomic area of residence 0; Other: length of time in hospital during last month-
Powers and Burger (1987)	National Hospice Study data 1981–1982; sample as for Greer <i>et al.</i> (1986) with patient prognosis < 6 months; hospices with home care only ( <i>n</i> = 827), hospices with beds ( <i>n</i> = 612) and conventional care sites ( <i>n</i> = 293)	data collection as for Greer <i>et al.</i> ; univariate and discriminant function analysis	Informal support: living alone -, married +, number of people helping +, family closeness +; ADL: disabled -; Symptoms: required intravenous support -, required catheter -, weight loss +, appetite change +, cold sweats +, calm +, happy +, lonely -, frightened -, apathetic -; Time period: length of stay +; Age: +; Carer problems: carer stress +, time commitment +, loss of income +, carer happy +, burdensome patient +
McCusker and Stoddard (1987)	cancer patients aged < 65 who died in U.S. county 1975–1982; health insurance members who had made claims in the 6 months before death and died at least one month after diagnosis; insurance members represented 74% of all cancer deaths; 857 had used home care (hospice or conventional) and 1017 had not	quasi-experimental time series evaluation of expanding home care program; $\chi^2$ ; means ANOVA tested, logarithmic transformation of cost variables, square root of utilisation	Informal support: married 0; Diagnosis: breast +, genitourinary +, leukaemia -, lymphoma -; Time period: survival +; Age: 0; Sex: female +

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Komesaroff <i>et al.</i> (1989)	243 patients allocated to hospice inpatient care ( $n = 108$ ) or home care ( $n = 135$ ) in an Australian city, by doctor or social worker independent of study; patients had three month prognosis and, for home care, residence within 20 km of care base	prospective, data recorded on admission; statistical method not stated	Informal support: married +; Diagnosis: 0; Time period: survival from referral +; Age: 70 or above -; Sex: 0; Social class: professional or non-manual occupation +, private insurance +, pensioner -; Other: specific cancer therapy not appropriate -
Dunphy and Amesbury (1990)	547 patients of a London hospice referred to the hospice's inpatient ( $n = 404$ ) or home care service ( $n = 143$ ) during six months	retrospective review; $\chi^2$	Informal support: married +; Diagnosis: lung +, CNS tumours -; Symptoms: dyspnoea +, anxiety/depression at presentation +; Time period: survival from admission +; Age: young female +
Bradshaw (1993)	random sample of patients referred over 6 months to a home care service, free-standing hospice or palliative care unit in a teaching hospital in an Australian city, who died within a 6 month period; $n = 60$ from each site, total $n = 176$	retrospective study of patient records; ANOVA with Student-Newman-Keuls multiple range test, $\chi^2$	Informal care: has primary carer +; Diagnosis: 0; ADL: needing help with ADL -; Symptoms: bowel and bladder problems, confusion, seizures, wound dressings and pressure area care -; Age: -; Sex: 0; Social class: health insurance 0
Costantini <i>et al.</i> (1993)	further analysis by Costantini <i>et al.</i> , Table 2, of 541 patients who received support from a palliative home care service and 11802 who did not	linkage of data from death certificates, general registry office and home care service records; $\chi^2$	Informal care: married +; Diagnosis: lung +, breast +, prostate +; Age: -; Sex: 0; Social class: education level +
Sessa <i>et al.</i> (1996)	993 of 1223 cancer patients who died in Swiss region between January 1991 and July 1993, who were resident in the area and for whom the region's referral centre for medical oncology was in charge of treatment; 317 participated in home care program	retrospective review of clinical records, enquiry to patient's last address for missing data; $\chi^2$ and Kruskal-Wallis tests	Diagnosis: haematological malignancy -, breast -; Age: 0, Sex: 0, Other: number of hospitalisations -, median length of hospital stay in last 3 months -, median months contact with the medical oncology centre +
Hunt and McCaul (1996)	all 2800 cancer deaths in South Australia in 1990, of which 1561 had hospice involvement (home or inpatient)	Central Cancer Registry data and state death records logistic regression	(referral to hospice whether home or inpatient) Informal support: married +; Diagnosis: haematological cancer -; Time period: survival > 6 months +, Age: -; Sex: 0; Other: born in U.K. or Europe +, rural residence -
Talmi <i>et al.</i> (1997)	all patients with terminal head and neck cancer admitted to inpatient hospice program in Israel between 1988-1994 ( $n = 102$ ) or home hospice program 1990-1994 ( $n = 24$ )	retrospective survey of patient charts; statistical method not stated, means, frequencies and percentages reported	Diagnosis: oral cavity tumours -, Symptoms: pain severity on admission -, oral candidiasis -, weight loss -; Time period: survival from diagnosis: 0, survival from admission; +; Age: -; Sex: 0
Eve <i>et al.</i> (1997)	all services known to the U.K. Hospice Information Service 1995 approached, responses from 138 (75%) of 186 inpatient services and 235 (68%) of 347 home care services analysed; patient details obtained from 31-52% of all inpatient and 27-43% of all home care services	questionnaire about services provided and patient details; tables of percentages	Diagnosis: cancer 0; Age: above 65 -; Sex: 0; Other: ethnicity 0

<sup>a</sup>Terminal care period (TCP): progressive malignancy, therapy would no longer prolong survival, care directed towards symptom control.

Table 4. Studies of variables associated with home death for home care patients, cancer (positive relationship +, negative relationship -, no significant relationship found 0)

Study	Subjects	Method	Variables
Groth-Juncker and McCusker (1983)	100 U.S. county residents admitted to home care 1977 to 1982 who died under the care of the service, from a total sample of 183 admissions; admission criteria included having at least one informal carer significantly involved in the care; non-cancer patients included in sample	retrospective review of medical records; statistical method not stated, medians and percentages reported	Informal support: living alone 0, married 0; Diagnosis: cancer vs non-cancer 0; Symptoms: pain 0; Time period: length of period under home care -; Age: 0; Sex: 0; Social class: Medicaid recipient 0; Other: patient planned to remain at home until death +
Hays (1986)	288 U.S. hospice home care clients, 137 requiring home care only (HC) and 151 requiring both home and inpatient care (HC/IP); random selection of 50 patients from HC group and 50 from HC/IP group	demographic data for total sample, retrospective chart audit of last 10 days of life for $n = 100$ subsample; <i>t</i> -tests	Informal care: married 0, living alone 0; Diagnosis: 0; Symptoms: pain -, nausea/vomiting -, respiratory distress (last 6 days) +; Sex: 0; Carer problems: anxiety and fatigue during last 6 days -; Other: race 0
McCusker and Stoddard (1987)	further analysis by McCusker and Stoddard, Table 3, of 857 home care users, 107 stopped using home care a month before death and 750 still received home care in last month	Regional Tumour Registry data; $\chi^2$	Informal support: married +; Diagnosis: 0; Time period: 0; Age: -; Sex: female -
Dunphy and Amesbury (1990)	further analysis by Dunphy and Amesbury, Table 3, of 140 patients referred to a London hospice home care service who died	retrospective review; $\chi^2$	Informal support: married +, has primary carer +, identity of carer 0; Symptoms: pain -; Time period: admission to death 0; Age: 0; Sex: 0
Loven <i>et al.</i> (1990)	58 patients admitted to Israeli home care programme similar to hospice movement, house-bound with debilitating condition	retrospective review; Fisher exact tests	Informal support: primary carer is first degree relative +; ADL: mobility on admission 0; Symptoms: frequency of symptoms 0; Time period: home care > = 6 months 0; Age: 0; Sex: 0
Hinton (1994)	415 patients referred to London hospice home care service during two years, 304 died as inpatients and 111 at home; 77 patients from a randomly selected one in three sample of the 232 adults who were still alive one week after referral, able to converse and at home with carer	demographic and diagnostic information for total sample; weekly interviews with subsample; $\chi^2$ ; percentage and mean differences with confidence intervals	Informal care: living alone -, no competent adult carer -, carer unfit -; Diagnosis: breast -, stomach/bowel +; ADL: low Spitzer QoL score overall or decrease over time -; Symptoms: depression -, psychological symptom -, weakness overall or increase over time -, peak of any symptom -, worsened concentration -; Time period: length of care period -; Age: 0; Sex: 0; Carer problems: carer strain -, overall anxiety or increase in anxiety over time -, overall depression or increase in depression over time -, increase in fatigue over time -, carer likely to show emotions -; Other: initial optimism -, initial intention to fight illness -, denial of diagnosis and prognosis -, awareness of dying +, patient increase in acceptance over time -, patient and carer rate support as satisfactory +
McWhinney <i>et al.</i> (1995)	all 75 patients of a Canadian palliative home care team who died at home and 75 randomly selected patients of the team who died in hospital	retrospective chart review, $\chi^2$ and <i>t</i> -tests	Informal care: family member in addition to spouse involved in care +, married 0; Diagnosis: 0; Age: 0; Sex: 0; Other: patient preferred home death +, private nursing care +
De Conno <i>et al.</i> (1996)	all patients referred to a Milan cancer home care service from 1989 to 1991 ( $n = 348$ ); criteria for admission included prognosis < = 2 months and availability of family support	prospective data collected from family; Fisher exact probability test and loglinear models with binomial error	Informal support: family support +, married 0; Age: > 61 0; Sex: female -; Social class: poor financial conditions -, housing conditions 0, educational level 0
Hinton (1996)	patients referred to London hospice home care team 1984 to 1992; same sample of 77 patients as Hinton (1994)	weekly interviews; percentages with confidence intervals	Symptoms: weakness -, pain -; Carer problems: carer strain -

quite different pictures of death during the development of western civilisation, and death in other cultures today may also be quite different in form and meaning to the "hidden death" of the late twentieth century "European" model. The review excluded studies conducted on patients identified through hospital specialist oncology services as these patients probably represent a selective subset of the cancer population, the particular characteristics of which were difficult to determine. For instance, only 38% of lung cancer patients in a U.K. region had been in contact with oncology services (Sanderson *et al.*, 1992). All other studies which consider patient or carer variables associated with death at home or access to palliative home care were included, regardless of study methodology.

The paper first identifies characteristics of patients dying at home for the population in general and cancer patients in particular. It then considers characteristics of cancer patients referred to palliative home care teams and place of death for cancer patients under home care, with the aim of assessing whether cancer patients with certain characteristics tend to die at home because they have better access to palliative home care, rather than because of their characteristics per se. Similar literature on home care for non-cancer patients was not found using our search strategy. The home setting is compared to other care settings overall, but data relating to differences in proportions of deaths in different inpatient settings are not considered. Tables 1-4 include all variables investigated in the studies relating to palliative home care access and home deaths.

#### STUDIES INVESTIGATING PLACE OF DEATH BOTH FOR CANCER AND NON-CANCER PATIENTS

Studies identified (Table 1) suggest the importance of informal carer support in facilitating home deaths. Patients who lived with someone, were married or had a partner were more likely to die at home than those who did not (Cartwright *et al.*, 1973; Clifford *et al.*, 1991; Hunt *et al.*, 1991; Seale and Cartwright, 1994). Only one study found that divorced patients were more likely to die at home than others (Polissar *et al.*, 1987). The identity of the informal carer mattered. If the wife was the carer, death at home was more likely than if the husband was the carer (Bowling and Cartwright, 1982). The availability of children for support appeared more important than the presence of a spouse and the presence of daughters more important than that of sons (Cartwright *et al.*, 1973).

Men were more likely to die at home than women (Cartwright *et al.*, 1973; Bowling and Cartwright, 1982; Rosenberg and Short, 1983; Polissar *et al.*, 1987; Hunt *et al.*, 1989, 1991; Clifford *et al.*, 1991; Seale and Cartwright, 1994). As women tend to live longer than men, they are

more likely to be frail and widowed by the time they die. This is reflected in women's greater likelihood of dying in nursing or residential homes than men (Cartwright *et al.*, 1973; Polissar *et al.*, 1987; Hunt *et al.*, 1989, 1991; Clifford *et al.*, 1991; Seale and Cartwright, 1994). However, as seen above, home death was more likely when wives and daughters were the carers rather than husbands and sons, which suggest that gender roles also play a part.

According to data from the 1960s, patients with fewer restrictions and a shorter care period were more likely to die at home than their counterparts, while length of incontinence rather than incontinence per se was associated with hospital deaths (Cartwright *et al.*, 1973). Patients who died in hospital were more likely to have suffered pain and confusion, while home death was associated with vomiting, loss of appetite, bedsores and dyspnoea (Cartwright *et al.*, 1973).

Home deaths were least likely for patients who died from cerebrovascular disease (Cartwright *et al.*, 1973; Polissar *et al.*, 1987), pneumonia and influenza (Bowling and Cartwright, 1982; Polissar *et al.*, 1987), all three of which are often associated with old age. Home deaths were most likely for those with heart and other vascular disease (Cartwright *et al.*, 1973; Bowling and Cartwright, 1982; Polissar *et al.*, 1987; Clifford *et al.*, 1991), which often imply a sudden death. Cartwright *et al.*'s (1973) data suggest that patients with respiratory disease were among those least likely to die at home, while Bowling and Cartwright's (1982) report that patients with bronchitis were among those most likely. Although these two disease categories overlap they are not the same. Hunt *et al.*'s (1991) findings indicate that home death was less likely for cancer patients than for non-cancer patients in Australia during this century.

Polissar *et al.* (1987), Clifford *et al.* (1991) and Seale and Cartwright (1994) found that patients aged 75 years and above were less likely to die at home than other adults. Cartwright *et al.*'s (1973) earlier study found home deaths to be least likely for patients under 45 years of age and patients aged 85 and above, while Hunt *et al.* (1991) found no relationship between age and home deaths in Australia in the time period 1910 to 1987. Social class did not appear to show a relationship with home deaths (Cartwright *et al.*, 1973; Polissar *et al.*, 1987; Hunt *et al.*, 1991; Clifford *et al.*, 1991; Seale and Cartwright, 1994). Patients who died in hospital were more likely to have spent time in hospital in the last year of life than patients dying at home (Bowling and Cartwright, 1982), while those who died at home had greater district nurse input (Cartwright *et al.*, 1973). However, level of primary or secondary care input may have been an effect of place of death itself.

#### STUDIES INVESTIGATING CANCER PATIENTS' PLACE OF DEATH

Seale (1991) notes that cancer patients are different from other disease groups. They tend to die younger and are therefore more likely to have a living spouse and other living relatives. Age related symptoms such as mental confusion and long term disability are less common. Furthermore, the incidence, duration, intensity and type of symptoms follow a different course and a terminal phase can be more easily distinguished. The variables related to place of death for cancer patients may therefore be different to those for the rest of the population.

Studies reviewed (Table 2) again indicate that being married is positively associated with death at home, either for both sexes (Moinpour and Polissar, 1989; Costantini *et al.*, 1993) or, as found in Australia, for males only (Roder *et al.*, 1987; Hunt *et al.*, 1989). Home death was positively related to number of children for both sexes (Hunt *et al.*, 1989). Axelsson and Christensen (1996) found no effect of marriage on home deaths. However, the number of home deaths in their study was small ( $n = 24$ ). Australian women were less likely to die at home than Australian men (Roder *et al.*, 1987; Hunt *et al.*, 1989). However, Costantini *et al.* (1993) found the reverse for Italian women.

Moinpour and Polissar (1989), Hunt *et al.* (1989) and Hunt *et al.* (1993) report that older patients were less likely to die at home than younger patients. However, Costantini *et al.* (1993) found that it was the older patients who were most likely to die at home. Parkes (1978), McCusker (1983) and Axelsson and Christensen (1996) found no effect of age on home deaths.

Patients who were diagnosed less than a month before death were less likely to die at home (McCusker, 1983; Polissar *et al.*, 1987; Moinpour and Polissar, 1989; Axelsson and Christensen, 1996). This may reflect a high incidence of hospital tests and attempts at treatment in the month following cancer diagnosis. Increase in interval between diagnosis and death beyond a month appeared to have little effect on home deaths.

Parkes (1978) data suggest that patients who died in hospital were less mobile, more likely to suffer confusion and more likely to suffer pain initially than patients remaining at home. However, in the final phase of illness, patients who remained at home were likely to experience more pain.

Diagnoses especially associated with home deaths were gastrointestinal and genitourinary cancer (McCusker, 1983; Clifford *et al.*, 1991; Johnson and Oliver, 1991; Costantini *et al.*, 1993; Hunt *et al.*, 1993). Patients with haematological cancers were more likely to die in acute care (McCusker, 1983; Polissar *et al.*, 1987; Roder *et al.*, 1987; Costantini *et al.*, 1993; Hunt *et al.*, 1993) presumably due to a greater amount of hospital treatment. Patients with

head/neck or lung cancer (Costantini *et al.*, 1993) and primary cerebral tumours (Johnson and Oliver, 1991) also tended to die in hospital. The latter would be associated with confusion, a variable which is associated with hospital death (Cartwright *et al.*, 1973), but it is less clear why the other sites may result in hospitalisation.

Several studies show that cancer patients who had higher education (Costantini *et al.*, 1993) or were living in a higher socioeconomic area of residence (McCusker, 1983; Roder *et al.*, 1987; Hunt *et al.*, 1993; Higginson *et al.*, 1994) had a greater likelihood of dying at home than their counterparts. McCusker's (1983) U.S. study showed this trend to be reversed only for people in areas sufficiently deprived to warrant reimbursement of home care services. While Higginson *et al.* (1994) investigated both patients with cancer and those with circulatory disorders, socioeconomic differences were found for cancer patients only. Data from one recent study (Sims *et al.*, 1997) suggests that those in skilled occupations were more likely to die at home compared both to higher and lower occupational groups. However, the lower occupational groups, representing 61% of the sample, were considerably more likely to die in hospital and less likely to die in a hospice compared with the other groups. Thus the lower occupational groups appear at a disadvantage both in terms of home death and access to cancer related services. Johnson and Oliver (1991) reported that the district in their investigation was more disadvantaged than surrounding districts, yet had a higher proportion of home deaths. However, they did not conduct a formal investigation of this relationship. Parkes (1978) found no effect of social class.

In summary the importance of having support from a partner, children or other primary carer is illustrated both for studies of the general population and those relating to cancer patients. The strain placed on primary carers in the form of patients' care requirements also has an impact on home deaths. This illustrates the dependency on the primary carer in achieving home deaths.

Overall males appeared more likely to die at home and older people less likely to do so. Patients who are female and old are therefore at a disadvantage if death at home is the desired aim. This may partly be related to availability of primary care support as females tend to die at a higher age than men, which means that presence of a primary carer is less likely (Seale and Cartwright, 1994). The one study which found females and old people to have greater likelihood of home death was Italian (Costantini *et al.*, 1993), which suggests that it is not simply gender or age per se which is important, but the cultural and family context in which patients live. Gender roles are also likely to play a part, as studies of the general population show that home death is more likely if the carer is female.



Females are probably more likely to be cast in the role as the provider rather than the recipient of care. By encouraging and helping males to take on the role as care providers one may tap a hitherto underused resource.

There were socioeconomic differences in place of death for cancer patients. In contrast, such differences were not found in the studies of deaths from all causes, reviewed in Section 2, or when considering patients with circulatory disease (Higginson *et al.*, 1994). Currently a greater range of support is possible for cancer than for other diseases, e.g. in the form of Marie Curie nursing care in the U.K. or hospice care. The greater range of support available may lead to greater differences between those who are effective in gaining access to support and those who are not, compared to other common, long term diseases. Only Parkes (1978) found no effect of socioeconomic status. However, this was an early study before cancer care services in the U.K. were that well developed. Access may be related to ability to pay for care, at least in the U.S.A., as McCusker's (1983) study showed the effect to be removed if home care service use was reimbursed. Individuals from higher socioeconomic groups may also be more articulate and resourceful in accessing the range of support available locally. Furthermore they may be better able to ensure that they live in a setting with a good level of services available, because they can afford to live in affluent areas, and they may also be more effective in ensuring that support services are established locally. As the socioeconomic differences found mainly relate to socioeconomic area of residence, one needs to establish whether it is the socioeconomic level of the individual or that of their area of residence which is most closely related to place of death, as this would require totally different approaches to amending inequality.

#### THE EFFECT OF SERVICES ON PLACE OF DEATH

Referral to palliative home care services is likely to be a contributory factor towards home death. Indeed, users of home care services are more likely to die at home than other patients (Zimmer *et al.*, 1984; Greer *et al.*, 1986; Gray *et al.*, 1987; Komesaroff *et al.*, 1989; Moinpour and Polissar, 1989; Dunphy and Amesbury, 1990; Costantini *et al.*, 1993; Sessa *et al.*, 1996). However, the type of home care matters. Patients receiving home care attached to an inpatient service are considerably less likely to die at home than patients receiving home care not thus attached (Ward, 1987; Smith *et al.*, 1992). Integration with inpatient care may therefore facilitate inpatient admission. It is not clear, however, whether home care with bed attachment may in fact at times be associated with fewer deaths at home than no home care.

Studies suggest that it is the particular support service per se which facilitates home death rather than the characteristics of the patients referred. A discriminant function analysis of place of death for U.S. hospice patients showed that the variable best able to predict place of death was the type of hospice, i.e. whether it was home care based only or had beds (Mor and Hiris, 1983). Once type of hospice was considered, knowledge of patients' demographic characteristics and support-network added only 1% to the ability to predict site of death. The case-mix between hospices was found to be less able to predict place of death than the type of hospice. A logistic regression analysis of cancer patients in South Australia (Hunt and McCaul, 1996) showed that place of death was largely determined by whether or not the patient was admitted to a hospice (providing either home or inpatient support). While there were demographic and clinical differences between admitted and non-admitted patients, multivariate analysis showed that these differences had very little effect on the odds of dying in different settings. Finally, a randomised controlled trial of a home care team found that patients assigned to the team had a greater likelihood of dying at home (Zimmer *et al.*, 1984).

Patients with certain characteristics may therefore be more likely to die at home by virtue of being more likely to access services which improve their chances of dying at home. Inequalities in referral to services may therefore account for inequalities in place of death. Two approaches are used to assess this further. First, by considering which patients are referred to palliative home care and checking if the patterns are identical to those relating to place of death. Second, by reviewing place of death of home care patients to ascertain whether the previously observed relationships between patient characteristics and place of death still remain, or appear to be cancelled out by the home care setting.

#### STUDIES INVESTIGATING CANCER PATIENTS' LIKELIHOOD OF BEING REFERRED TO PALLIATIVE HOME CARE

The studies reviewed make one of three types of comparison (Table 3): patients referred to hospices which provide home care only are compared with patients referred to hospices with beds (which may also provide some home care), patients referred to the home care branch of a hospice are compared with those referred to its inpatient branch, or patients referred to home care are compared with some or all of the remaining terminal cancer population. Results from these comparisons will all be reported in the form of patients' likelihood of being referred to home care and it will be assumed that being referred to the home care "arm" in each comparison represents an advantage in achieving home death.

Studies involving patients both with and without a primary carer found that having a primary carer, being married or living with someone increased the likelihood of being referred to palliative home care (McCusker, 1985; Komesaroff *et al.*, 1989; Dunphy and Amesbury, 1990; Costantini *et al.*, 1993; Bradshaw, 1993). Having a spouse as the primary caregiver also increased likelihood of referral to home care compared to other caregivers (McCusker, 1985). Studies which considered only patients with a primary carer, found that referral to home care was less likely if the carer did not live with the patient or was employed (Mor and Hiris, 1983; Mor *et al.*, 1985; Greer *et al.*, 1986; Powers and Burger, 1987) or old (Mor and Hiris, 1983). Referral to home care was less likely if the carer was male, even when carer employment was considered in the analysis (Mor *et al.*, 1985).

Most studies involving patients both with and without a primary carer indicate that older patients are less likely to be referred to home care (Evans and McCarthy, 1984; McCusker, 1985; Komesaroff *et al.*, 1989; Dunphy and Amesbury, 1990; Costantini *et al.*, 1993; Eve *et al.*, 1997; Talmi *et al.*, 1997) or to hospice care in general (Hunt and McCaul, 1996). Only Sessa *et al.* (1996) found no age effect. Addington-Hall *et al.* (1998) have found that patients over age 85 are also less likely to be referred to hospice inpatient care than younger patients. Therefore older patients may fail to access services overall, as suggested by Cartwright (1993). For studies involving only patients with a primary carer, age effects were less clear (Mor *et al.*, 1985; Greer *et al.*, 1986; Powers and Burger, 1987). Mor *et al.* (1985) found no effects of age. Greer *et al.* (1986) and Powers and Burger's (1987) results suggest that patients under 65 years of age were more likely to be referred to conventional care compared to older patients. However, conventional care patients had the highest study refusal rates and those who refused were significantly more likely to be old. Therefore the conventional care sample may be younger as an artefact of sample recruitment.

Studies which found a gender effect paradoxically found that females were more likely to be referred to home care than men (Mor *et al.*, 1985; McCusker and Stoddard, 1987; Dunphy and Amesbury, 1990) while men, as shown above, are more likely to die at home. However, most studies report no effect of gender (Evans and McCarthy, 1984; McCusker, 1985; Costantini *et al.*, 1993; Sessa *et al.*, 1996; Eve *et al.*, 1997; Talmi *et al.*, 1997).

Patients referred to home care tended to have a better level of function and fewer nursing care requirements than those referred to inpatient care (Mor and Hiris, 1983; Mor *et al.*, 1985; Greer *et al.*, 1986; Powers and Burger, 1987; Bradshaw, 1993). Home care patients also had longer survival from admission or greater length of stay within the service than patient admitted to inpatient care

(Greer *et al.*, 1986; Powers and Burger, 1987; Komesaroff *et al.*, 1989; Dunphy and Amesbury, 1990; Talmi *et al.*, 1997). This may relate to level of function upon admission. Patients referred to home care (Gray *et al.*, 1987; McCusker and Stoddard, 1987) and to hospice care in general (Hunt and McCaul, 1996) tended to have longer survival from diagnosis compared with other patients. Similarly, longer contact with the local oncology centre was positively related to referral to home care (Sessa *et al.*, 1996). McCusker (1985) found that patients who used home care compared with those who did not, had a longer terminal care period (over 45 days), as reflected by evidence of progressive malignancy and a switch towards palliative rather than curative treatment.

Patients with haematological malignancy were less likely to receive home care (Evans and McCarthy, 1984; McCusker and Stoddard, 1987; Sessa *et al.*, 1996) or hospice care in general (Hunt and McCaul, 1996). Likewise home care was less likely for patients with cancers of the central nervous system (CNS) (Dunphy and Amesbury, 1990). Lung cancer patients tended to be referred to home care (Evans and McCarthy, 1984; Dunphy and Amesbury, 1990; Costantini *et al.*, 1993) and this care location was also associated with a greater incidence of dyspnoea and anxiety or depression upon presentation (Dunphy and Amesbury, 1990). An American study (McCusker and Stoddard, 1987) and an Italian study (Costantini *et al.*, 1993) found that breast cancer tended to be associated with home care, while a U.K. study (Evans and McCarthy, 1984) and a Swiss study (Sessa *et al.*, 1996) suggest the opposite trend. Patients with genitourinary (McCusker and Stoddard, 1987; Costantini *et al.*, 1993) and oropharyngeal cancers (Evans and McCarthy, 1984) were more likely to be referred to home care, while patients with gastrointestinal cancers were less likely (Evans and McCarthy, 1984). Among patients with head and neck cancer oral cavity tumours were negatively associated with home care (Talmi *et al.*, 1997).

Referral to home care was positively related to professional and non-manual occupations (Komesaroff *et al.*, 1989), higher income (Greer *et al.*, 1986) and higher education (Costantini *et al.*, 1993). Tables presented by Mor and Hiris (1983) also suggest that home care patients were more likely to be college educated and have higher family incomes compared to inpatients. Greer *et al.* (1986) found that patients with income below \$10,000 were less likely both to be referred to home care and conventional care compared to care in hospice with beds.

Talmi *et al.* (1997) found that pain severity at the onset of care was negatively associated with home care. Powers and Burger (1987) report that patient appetite change, cold sweats, calmness and happiness and carer stress, time commitment, loss of

income, perceived patient burden and happiness were associated with home care, while the patient being lonely and frightened was associated with other care. However, these factors may have been measured subsequent to admission to care. Powers and Burger (1987) report that patient weight loss was associated with home care while Talmi *et al.* (1997) report the opposite.

Perhaps not surprisingly the patient's care location towards the end was related to home care use. McCusker (1985) found that patients who spent most of their terminal care period at home were more likely to be home care users. Those not referred to home care tended to have spent more time in hospital towards the end of life (Gray *et al.*, 1987; Sessa *et al.*, 1996). However, one cannot assess whether patients' location was affected by home care or whether use of home care was affected by patients' location.

In summary, many of the factors increasing likelihood of referral to palliative home care are similar to the factors increasing likelihood of place of death. Presence of a primary carer, preferably not male, old or employed, and membership of a high socioeconomic group overall increase likelihood of referral to home care. Being old, having high care requirements or having a haematological malignancy appear to reduce the likelihood.

However, studies in which gender was found to have an effect, report that females tended to be referred to home care, while men tend to die at home. Two of these three studies considered females under the age of 65 (McCusker and Stoddard, 1987) or found a significant effect for young women (Dunphy and Amesbury, 1990). This may reflect a support service bias towards wanting to keep women in a family care setting for as long as possible, perhaps particularly if there are young children present. However, it is not necessarily seen as equally desirable that the death itself should occur at home.

For survival and place of death it appeared that the important difference was whether the diagnosis had been made more or less than 1 month before death. For referral to palliative home care it appeared to be survival from diagnosis in the longer term which was of importance. Survival from diagnosis is not equivalent to length of care period. Longer survival may mean that patients have longer time to establish a relationship with local health care professionals and adjust to the disease. Thus longer survival may make access to home care more likely, while the eventual place of death may be determined by factors other than survival, such as eventual nursing care requirements and length of terminal phase.

#### STUDIES INVESTIGATING PLACE OF DEATH FOR CANCER PATIENTS UNDER PALLIATIVE HOME CARE

As the same variables often predict referral to home care and dying at home, it may be admission to palliative home care rather than these variables per se which affects place of death. This section considers place of death of patients who have been admitted to home care, to investigate whether these variables still have an impact on place of death or appear to be cancelled out by home care. Gender showed no relationship or an opposite relationship with home care admission compared with place of death. Therefore, the behaviour of this variable for home care patients will be of particular interest. Unfortunately survival was not reported in the studies below and socioeconomic variables rarely considered.

Studies reviewed (Table 4) again show that patients with a primary carer (McCusker and Stoddard, 1987; Dunphy and Amesbury, 1990; Loven *et al.*, 1990; Hinton, 1994; De Conno *et al.*, 1996) and additional home support (McWhinney *et al.*, 1995) were more likely to die at home. Hays (1986), however, found no differences between patients requiring both home and inpatient care and those requiring home care only and Groth-Juncker and McCusker (1983) found no effect of being married or living alone. Likelihood of home death depended on the primary carer's fitness (Hinton, 1994). Carer fatigue, strain, anxiety and depression were negatively associated with home death (Hays, 1986; Hinton, 1994, 1996). Patients who eventually died as inpatients were likely to spend longer time in care (Groth-Juncker and McCusker, 1983; Hinton, 1994) and experience lower quality of life (Hinton, 1994) while reported satisfaction with support was associated with home death (Hinton, 1994). These variables are likely to be associated with the strain placed on the carer during the care period.

Once in home care, age was generally not found to be related to place of death. Only McCusker and Stoddard (1987) report that home care patients who stopped using home care in the last month of life were older than those who remained in home care. Their sample was limited to patients under 65 and not all of their home care patients would eventually die at home.

Likewise once in home care, most studies found no evidence that gender had an effect on place of death. Only McCusker and Stoddard (1987) found that females were more likely to stop receiving home care in the last month of life compared with males and De Conno *et al.* (1996) found that females were less likely to die at home. The only study which considered socioeconomic factors for home care patients, report that poor financial conditions were negatively associated with death at

home, while housing conditions and education had no effect (De Conno *et al.*, 1996).

Unrelieved pain was often associated with inpatient admission (Hays, 1986; Dunphy and Amesbury, 1990; Hinton, 1996), likewise psychological symptoms, weakness, peak of any symptom (Hinton, 1994, 1996), nausea/vomiting and respiratory distress (Hays, 1986). The only effects of diagnosis were reported by Hinton (1994) who found that breast cancer patients were more likely to die in inpatient care, while patients with stomach or bowel cancer were more likely to die at home. While the patient's denial of illness was negatively associated with home death (Hinton, 1994), the patient's preference for dying at home was positively associated with death at home (Groth-Juncker and McCusker, 1983; McWhinney *et al.*, 1995).

Age and sex may have less impact on home deaths once under home care. However, the presence of a primary carer, the carer's fitness and the strain placed on him or her remained important. The need for symptom control clearly emerged as a key variable in inpatient admissions. Other research investigating reasons for final inpatient admissions, without comparison with non-admitted patients, have also identified symptom control as a major reason for admission (Herd, 1990) alongside insufficient care resources in the home (Doyle, 1980; Wilkes, 1984; Herd, 1990).

#### SUMMARY AND DISCUSSION

Research reviewed in this paper shows that both the likelihood of dying at home and of being admitted to palliative home care depend on patient characteristics. Some of these characteristics relate to clinical variables and support requirements and may justify differential treatment. However, other variables suggest that the opportunity to access home care and achieving home death are unevenly distributed.

During this century there has been a decrease in the proportion of deaths occurring at home, at least in the developed world. This occurred in parallel with an increased belief in and availability of hospital interventions and a decrease in family unit size and increase in life expectancy. This meant that there was a decrease in family support available and an increase in the proportion of older people in need of care and that patients more often tended to die in a technical, hospital environment. Increasing recognition of the inadequacy of acute hospital care in meeting the needs of the dying, led to the rise of the modern hospice movement, beginning with St Christopher's Hospice in the U.K. in 1967. Similar developments of hospice care occurred in U.S.A. in the 1970s (Siebold, 1992) and Australia in the 1980s (Hunt *et al.*, 1991). A natural extension of this approach was to support patients in their own

home environment, and there was a rapid expansion of home care teams in the U.K. in the early 1980s (Boyd, 1994), while home care developed more in parallel with inpatient care in U.S.A. and Australia. Furthermore, there was increased focus on improved palliation of symptoms. The proportion of deaths in inpatient hospices have risen in accord with service developments (Seale and Cartwright, 1994). Similarly, as we have seen, home care services appear to increase the number of deaths at home, although it is more difficult to establish a direct link. However, although these services may improve the care of cancer patients, this group still display similar patterns of inequality in terms of age and sex as other groups and in addition appear to display differences in access and place of death based on socioeconomic factors. Therefore where improvements in palliative care occur, these may not reach everybody in the same diagnostic group equally and may in fact exacerbate differences between patients.

The literature on place of death has mainly emerged subsequent to the rise of the hospice movement. All but two studies reviewed in this paper were published from 1980 onwards. The studies reviewed here consider different settings and focus on different variables and as such the conclusions drawn must be viewed with some caution. Furthermore the review has focused on studies from North America, Europe and Australia and especially Anglo-Saxon countries. Thus its findings are restricted to these cultures over the last, few decades. The situation during earlier periods and in developing countries is bound to be very different. The patterns emerging within the scope of the review, however, seem quite consistent, particularly in relation to informal support, age, sex and socioeconomic variables.

Significant relationships were found for a number of clinical variables. Symptom control needs were an important factor in inpatient admission. This highlights the need for improved symptom control in the community. Survival from diagnosis of less than 1 month was negatively associated with home death. Longer term survival was positively associated with referral to home care. Longer survival may give more time to establish links with community support and come to terms with illness. This may indicate the value of early, rather than late, referral to home care services. Haematological and CNS cancers were both negatively associated with home death and home care. Haematological cancers presumably require more hospital intervention and both patients and staff may want to continue the relationship they have developed over many months. The changes associated with CNS cancers may place more strain on carers. Gastrointestinal and genitourinary cancers were positively related to home death. The latter was also positively related to home care while the former was negatively re-

lated. Lung and head/neck cancer patients were less likely to die at home but more likely to be referred to home care. Although lung cancer is to date typically a male cancer (because of smoking behaviour) it shows an opposite relationship to home death and home care to that otherwise observed for men. The relationship between breast cancer and referral to home care is unclear, but it appears negatively associated with place of death for home care patients. Being predominantly a female cancer, gender may contribute to the patterns observed. Different cancers are associated with different courses of illness, survival and gender distributions. An understanding of the interaction between these variables and place of death would require research in greater detail on a larger patient sample than has hitherto been attempted.

Four non-clinical variables showed a relationship with home deaths and access to home care: presence of primary carer, age, gender and socioeconomic status. The presence of a primary carer and the strain placed on him/her were key variables in relation to home deaths. Home care support did not remove this relationship. Health professionals may be more likely to refer patients to home care when there are more care resources in the home. However, even from this position of strength, in which professional home care is added to informal care resources, death at home is still highly dependent on the carers' ability to stay the course. Although the patient is defined as the client, there may need to be a substantial shift in focus towards the needs of the patient's carer, if there is to be an improvement in proportion of home deaths.

Older people are less likely to die at home. This may be because they are less likely to have a suitable primary carer and more likely to have additional care needs and to reside in nursing homes. However, it may also relate to their poorer access to home care, as well as to services in general (Cartwright, 1993; Addington-Hall *et al.*, 1998). The review suggests that once in home care older people do not tend to be less likely to die at home. Although more information is required on the characteristics of older patients referred to home care, it is possible that better access to home care services would help towards removing the bias against home death in old age.

Women were less likely to die at home than men. However, they were not less likely to access home care and younger women may even be more likely to receive home care support than men. Thus women are not disadvantaged in their access to home care and causes for their disadvantage in achieving home death need to be sought elsewhere. Gender roles may explain the patterns observed, although effects of age need to be considered. In relation to home care there may be a greater tendency to call in help when males are the carers, while female carers may more often be left to cope. There

may also be a greater urgency to maintain the female patient in the family context, particularly when the family has young children. In relation to home deaths, the studies reviewed suggest that men are less effective as carers and past research shows that the greater burden of care typically falls on women (Anderson, 1987). As home deaths are greatly dependent on carers' ability to cope, any differences in ability to fulfil the carer role are likely to have considerable impact. While home care may redress the gender imbalance for those under such care, improvements in home death for women overall may require helping men to take on and cope with the carer role to a larger extent.

While primary carer support, age and sex showed a similar relationship to home death both for cancer and non-cancer patients, socioeconomic factors were associated with home death for cancer patients only. Higher socioeconomic groups were more likely to die at home. This is likely to be related to better access to support as these groups also appeared more likely to be referred to home care. However, present data do not allow us to assess directly whether being in home care helped redress the imbalance in home deaths for lower socioeconomic groups. Higher socioeconomic groups are better able to pay for additional care and may be more effective at gaining access to the services available to cancer patients, e.g. through skills associated with higher education. As the range of support available for cancer is greater, the difference between those who are effective at gaining access and those who are not may also be greater. This suggests the need to improve cancer service access for lower socioeconomic groups by a targeted approach. It similarly suggests that any expansion of cancer services to other patient groups needs to take care not to extend socioeconomic inequalities in place of death among cancer patients to other patient groups.

The studies reviewed were conducted alongside rising interest in care for the dying. Place of death is commonly included in palliative care research as it is one of its few measurable outcomes, with home death typically considered to be a positive outcome. Patient morbidity is arguably less applicable in this field and patients' own assessments of symptoms and quality of life are often difficult to obtain in the terminal phase. However, whilst factors relating to place of death therefore have been routinely analysed in numerous studies, researchers have not been particularly concerned with the inequalities to which these studies point, nor with designing further research to understand why these patterns emerge.

More work is required to understand the access to home care and its role in place of death. Most studies of access to home care consider patients already referred to hospice or specialist care, who therefore may already be subject to the biases of

interest in this review (Mor and Hiris, 1983; Mor *et al.*, 1985; Greer *et al.*, 1986; Powers and Burger, 1987; Komesaroff *et al.*, 1989; Dunphy and Amesbury, 1990; Bradshaw, 1993; Eve *et al.*, 1997). Geographical distance to services also needs to be taken into account. For instance, in some studies utilising National Hospice Study data patients did not have equal geographical access to home or inpatient hospice care (Mor and Hiris, 1983; Greer *et al.*, 1986; Powers and Burger, 1987). Furthermore a proper assessment of the impact of home care on home deaths requires carefully controlled studies which take into account the type of home care and the proportion of patients in the population accessing home care.

The retrospective, quantitative data collected from patient records and official statistics often used in this area of research are necessary to establish what the overall patterns are. Such routinely collected data can be further utilised to investigate how variables such as age and sex, marital and socioeconomic status may interrelate. However, to understand why a variable affects home care access and place of death, a more detailed and labour intensive approach is now required. For instance, we need to establish whether it is socioeconomic area of residence or an individual's education, income or occupation which affects outcomes. The former would suggest that more services simply should be provided in deprived areas, the latter that we need to understand the mechanisms whereby individuals acquire help. We need to establish how behaviour and perceptions of roles may differ depending on sex and how patients' age may affect attitudes and decision making. We need to investigate the circumstances under which informal carer support breaks down and when it does not. This requires more labour intensive research methods, including prospective observation and semi-structured interviews. The longitudinal research conducted by Hinton (1994, 1996) is a step in the right direction.

Until we understand the mechanisms behind differences in access to home care and deaths at home, further general improvements in home care support may only help those who are already at an advantage, in accord with the inverse care law (Tudor-Hart, 1971). Increased support may therefore not have an impact on home deaths which corresponds to resources invested. If more deaths at home is the aim, real progress may only be achieved by identifying why certain groups currently are at a disadvantage and targeting interventions towards removing these disadvantages. Until such time we will be no more equal in death than we have been in life.

*Acknowledgements*—The work undertaken for this review was made possible through funding from the Elizabeth Clark Charitable Trust and the NHS R&D Programme

Primary/Secondary Care Interface, although the views expressed are the authors' and may not be those of either organisation.

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