

Manuscript title: **Financial stress and strain associated with terminal cancer – A systematic review of the evidence**

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Condensed abstract for Table of Contents

This review showed that financial stress and strain affect a significant minority of households of terminally ill cancer patients in different health systems. However, there are few data describing the consequences of financial circumstances for the health and wellbeing of the households of persons with terminal illness.

Abstract

Background

Financial circumstances are an important aspect of quality of life for older people, and may be a significant influence on health and wellbeing at the end of life. The aim of this study was to review the evidence for the existence and consequences of financial stress and strain at the end of life, for people dying with cancer

Methods: Systematic review of studies providing data on financial circumstances for people with terminal cancer. The databases Medline, Embase, CINAHL, Web of Science and Cancer Lit, were searched for studies published in English between 1966 and June 2006, providing data on illness related financial burden (stress), or perception of financial hardship (strain), from patient or caregiver.

Results: Twenty-four papers were identified from 20 studies, 13 of which were from the USA. A majority of studies (14) were of cross sectional design; four adopted a purely qualitative approach. Almost half were conducted with caregivers after the death of the patient. Depending on patient population, between 10 and 45% of households reported financial stress or strain. People with greater care needs, lower incomes, or of black racial origin were worst affected. One study found that financial stress was associated with different treatment choices, but no other consequences for patient or household were reported.

Conclusions: Financial stresses and strain affect a significant minority of households of people with terminal cancer in different health systems. Research into the consequences of this for the health and wellbeing of the household are needed to fill a gap in our understanding and improve holistic palliative care.

(258 words)

Key words (MeSH headings):Neoplasms; Terminally ill; Terminal care; Economics; Socioeconomic factors; Caregivers; Family

Introduction

Palliative and terminal care services aim to adopt a holistic approach to patients, where social, psychological and spiritual problems are addressed along with pain and other physical symptoms. Terminal illness may present particularly serious health and social and consequences for the whole household. Taking on the role of caregiver is associated with a wide range of increased physical and psychosocial risks, for example.^{1,2} Financial issues are also acknowledged as being important at the end of life^{1,3} and a need for more support and information for both caregivers and patients has been identified in a number of studies in Britain and the USA.⁴⁻⁶

It is widely accepted that quality of life and health status are separate constructs.⁷ People's perceptions of their financial circumstances are known to be an important contributor to quality of life in older age,⁸ and the perception of difficulties - or financial strain – has been linked with numerous adverse health outcomes across the life-course, both physical and mental.^{9,10} In this paper, our analysis uses a model of the potential impact of financial strain on quality of life and health shown in Figure 1. It proposes a circular relationship between money worries and health, mediated through health care costs. If financial strain reduces quality of life,¹¹ this is likely to have an adverse effect on health status and create greater need for health care. Increased use of services is associated with higher direct or indirect costs, which may lead on to increased financial stress and, for some people, strain.

Figure 1 here

The perception of financial hardship or stress may vary considerably with income level, outgoings and expectations, but there are many reasons to expect objectively measurable financial stress at the end of life. In countries without comprehensive welfare states, charges for health care or insurance costs can be crippling,¹² whilst in many other places, co-payments for medicines or the costs of travel must be found. In high income countries, a majority of people die in retirement, which means that they are experiencing terminal illness at a time when their incomes have fallen. For younger people, or working caregivers, a reduction in paid work to provide care will also reduce household income.¹³ Some welfare systems provide financial support for the end of life, but access to funds may be neither universal nor timely. In the UK, MacMillan Cancer Relief (a large charity providing services and support to terminally ill people) has estimated that more than nine million GB pounds (16 million US \$) of state benefits are not being claimed by patients or carers at the end of life,¹⁴ whilst a small survey of people given assistance with claiming attendance allowance in a northern British city described lengthy delays in accessing the benefit, despite eligibility being based on a predicted short survival period.¹⁵

These issues are most important for the wellbeing of the patient in their last illness, but they should also be a concern for providers aiming for equitable care. There is growing evidence that greater susceptibility to financial strain and the accumulation of stressors across the life-course makes some social groups more vulnerable to adverse events.¹⁶ This means that social consequences of illness, of which financial hardship is one, may exacerbate inequalities in health and mortality between people in different socioeconomic groups in particular.¹⁷

The aim of this study is to review evidence of the existence of financial stress and strain for people with terminal cancer and their caregivers, to determine how common it is, and identify any consequences for health of the patient or caregiver.

Methods

We searched Medline, Embase, CINAHL, Web of Science and Scopus from 1966 to June 2006, for studies that provided data on illness associated financial problems experienced by adult patients or caregivers with terminal cancer. The term ‘financial stress’ was used to cover any reported objective illness-related financial burden, whilst financial strain was defined as the subjective perception of financial hardship. These are our own definitions, chosen to reflect the concepts underlying previous, more specific definitions,^{10,16} but anticipating the diversity of measures used by researchers.

The search strategy was based on thesaurus and text word terms relating to malignancy, end of life, terminal and palliative care, financial circumstances, care giving and quality of life. In addition, specific searches were made for the quality of life measures used in end of life research that are known to include a financial domain (e.g. The Caregiver Quality of Life Index–Cancer Scale).¹⁸ Websites of relevant organisations such as Age Concern and The Carers Association and the bibliographies of retrieved articles were scrutinised. The tables of contents of the following journals were searched by hand from the year stated to June 2006: Palliative Medicine (1994); Journal of Palliative Care (1994); Journal of Pain and Symptom Management (1995); Quality of Life Research (1997); British Journal of Cancer (1999) and Cancer (1997).

We included studies that presented data on patients at the end of their lives, determined either by authors' description, or by being in receipt of palliative or terminal care services, or where the stated prognosis was less than one year. Information on financial strain during curative cancer treatments was not considered. No study designs were excluded, but only English language publications were retrieved. Although the focus of interest was cancer, data from studies that considered other diagnoses alongside cancer were included.

If authors reported on whether or not financial advice was given, without providing data on the perceived need for advice, they were excluded. Validation studies for quality of life measures that did not report full patient information and outcomes were also excluded.

Titles and abstracts of papers were first reviewed, and the full text of potentially relevant papers retrieved. Two reviewers (BH and PH) extracted data on study design, location, participants, measures of financial strain or stress and outcomes. The quality of studies in the final sample was appraised using criteria adapted from existing measures^{19,20} to be relevant to the study question, and the anticipated high proportion of cross sectional studies. (Box 1). To provide a guide to study quality, a score was awarded relating to how many criteria were met by each paper; high (four or five), medium (three), low (one or two).

Findings

Included studies

From a list of 2764 titles generated from the electronic searches, 24 papers based on 20 studies fulfilled our inclusion criteria and were included in the review. There were 13 papers from the USA,²¹⁻³³ five from the UK,³⁴⁻³⁸ and one each from Australia,³⁹ India,⁴⁰ Israel,⁴¹

Italy,⁴² Japan⁴³ and Sweden.⁴⁴ Four adopted a qualitative methodology and are discussed separately. Fourteen of the remaining 16 quantitative studies were of purely cross sectional design. The 11 interview surveys were conducted face to face (7), by telephone (3) or by post (1). Three studies required the patient or carer to complete a questionnaire but it is not clear whether an interviewer was present; and one was a case note review. One study analysed longitudinal panel data,³² one interviewed caregivers on two occasions. Eleven studies were conducted with caregivers after the death of the patient, or included a retrospective component in a prospective study.

Three US³⁰⁻³² and two large UK studies^{34,35} recruited from the general population, rather than through a specific service or hospice. Ten studies recruited more than one hundred participants; most of these were from the US. The mean or median age of participants was 58 years or above in all studies, though entry was restricted to over 65 or 70 years in two studies.^{31,32}

Data from different studies were not pooled due to the differences in question phrasing and some diversity in patient populations.

As the financing of the health system and provision of safety net services will affect the patients' experience of financial strain, the studies from the USA are discussed separately. The proportion of the population not covered by comprehensive health care insurance is high; over 15% of the population were uninsured for all or part of 2003 (. In addition, Medicaid provision varies from state to state.

Financial stress and strain associated with terminal cancer in the USA

Descriptions of the studies from the US are shown in Table 1. All the nine US studies measured objective financial stress, and in addition, five included some assessment of individual perception of financial circumstances, or strain. The majority of questions on financial hardship concerned how funds were obtained to cover illness related costs, and the size of the financial burden. For example: using all or most of the decedents' savings, spending more than 10% of their income, selling assets, taking out a mortgage or loan, taking on an extra job. Some studies also asked about giving up a job to take on caring responsibilities.

Use of most or all of savings was reported by between 17% and 38% of cancer patients or their proxies. The proportion of families reporting that someone gave up a job to provide care ranged between 10% and 40%. However, the small number of African American carers in Welch's telephone survey, (111 (8%)) reported far higher levels of financial hardship than their white counterparts on all measures.³⁰ Where subjective perceptions of economic burden were reported with objective measures, the former were more common than the latter, and increased for patients with greater care needs, or those of African American ethnic origin.

Financial stress and strain associated with terminal cancer outside of the USA

Outside of the USA, the emphasis in enquiries about financial circumstances was on the need for financial support, and perceptions of financial circumstances, rather than on objective questions relating to the effects of high outgoings or lower incomes. This is in keeping with the greater provision of welfare benefits and state funded health care in other countries. The findings from seven identified studies are shown in Table 2. A need for more financial help (not specified) was reported by between 16% and 32% of the participants in the two largest

studies. The range of participants receiving various UK state benefits was wide, but findings are difficult to interpret without data on need, or precise eligibility criteria at the time of the study.

Qualitative research

Four studies adopted a purely qualitative approach to data collection,^{33,35,38,39} though in three of these, few details of the data are presented. Parker and colleagues reported in-depth on the financial burdens of care-giving in Australia (See Table 3). They identified three themes, relating to patient care, impact on the carer's lifestyle and access to financial support. Despite a comprehensive scheme to cover the costs of medication in Australia, more than half of the bereaved carers had incurred extra costs. Loss of pension income after the death of a spouse, and the costs of nursing homes and funerals were potent sources of worry.

Table 3 here

Consequences of financial stress or strain

Only one study from the US, SUPPORT,²⁴ explored the effect of financial strain on patient treatment choices. The authors found that patients experiencing financial problems were more likely to choose care aimed at keeping them comfortable, rather than extending their lives.

Discussion

Financial strain affects a significant minority of households of terminally ill cancer patients in different health systems. Although research on quality of life at older ages suggests that

finances are less important to patients than their health or social functioning, it is still among the top three concerns.⁸ Surprisingly, in light of this, there are few data describing the consequences of financial circumstances for the health and wellbeing of the households of persons with terminal illness.

Comparison with other work

This study was concerned with terminal cancer, but its findings are supported by research with patients still receiving active treatment,⁴¹ a proportion of whom will be close to the end of their lives. The research into information needs is useful for planning support services, but was omitted from this review because it provides no information on whether financial hardship was suffered, and what the consequences of this were for the patient or their family. Financial concerns do feature in work on information needs from both the USA and UK,^{4,5} but are not always identified as areas in which caregivers and patients need support.^{42,43} Whether financial worries are perceived as a legitimate concern of health professionals by staff or patients, or whether stigma prevents people admitting to troubles, are unknown. A study comparing the perspective of patients and their carers showed that using up all the family money was more of a concern for patients than carers.⁴⁴ Emanuel and colleagues gathered data on support needs from almost 1000 carers of terminally ill people. The 15% of people who used only paid help to provide their non-medical needs were more likely to be poor, and elderly.⁴⁵ It is likely that they are under or uninsured, and amongst the most vulnerable to financial stresses and strains.

Strengths and limitations

Five studies recruited from the general population, rather than through a specific service or hospice.^{30-32,34,35} As patients that have received a service may be systematically different

from those who are unable to obtain such care, population based methods of recruitment are less prone to selection bias. This is of particular importance when considering financial strain, which may itself have affected decisions over accessing particular health services. The few large studies, such as SUPPORT in the USA, and the Regional Study of the Care of the Dying in the UK were generally of much higher quality than the smaller studies. Heterogeneity in the study populations and questions makes it difficult to pool data or draw conclusions on the proportions of terminally ill people affected by financial strain. Failure to report the patients' socioeconomic status was common, with only one study reporting on how financial strain varies with socioeconomic position.³⁴ The omission of any measure of baseline financial circumstances posed no methodological problems for the studies that included specific questions about loss of a major income, a percentage of income, or the decedent's savings. Social position will affect perception of the burden of end of life costs, as clearly a more affluent household is likely to absorb some of the increased needs without experiencing any strain to their finances. Responses to more general questions, such as whether more financial help was needed, may therefore be strongly influenced by financial position.

A high proportion of the studies were conducted with bereaved carers, after the death of the patient. This method is widely used in palliative and terminal care, and its validity has been shown to be better for objective information such as service use, compared to subjective concerns such as pain.^{46,47} Hence reporting of financial stressors may be more reliable than financial strain.

Implications

This review has highlighted the paucity of evidence on the consequences of financial strain for the patient and household in terminal cancer. The available studies show that adverse

financial consequences occur, but the evidence base does not indicate how much importance should be placed on tackling this issue, with other competing priorities in palliative and terminal care. Further research into the social and health care consequences of ignoring this issue is required.

Despite the relative paucity of information on the pathways between financial stress and strain, health status and, ultimately, quality of life, our findings provide some support for tackling the consequences of financial strain as a part of holistic palliative care. As market orientated reforms sweep health systems across the world, rising health care costs present a new barrier to some patients, whilst in tax funded welfare systems, some people feel the need to purchase supplementary services. If financial strain results, the health services themselves may be a major cause of deteriorating quality of life, and should shoulder some of the responsibility for ensuring that this issue is addressed. Some practical steps have already been taken; ways of improving the documentation of financial needs have been developed,⁴⁸ for example, whilst the effectiveness of welfare advice to all patients in primary care is the subject of ongoing research.⁴⁹ The need for financial support and advice emphasises the necessity of the multidisciplinary team in palliative care. Whilst household finances may be out with the expertise of the health care worker, acknowledging the existence of money worries may be important to the patient – professional relationship. There is also some evidence that patients would find discussion or advice about these issues from health professionals very acceptable, which would accord with the adoption of a holistic palliative care approach. As discussion of death has become more accepted in health care delivery, it may be that money remains a final taboo.

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Box 1. Criteria for assessing the internal validity of the studies

1. The sample was **selected** in such a way as to be representative of the population from which it was drawn.
2. The patient sample was **large** enough that important financial and health effects could be identified with reasonable probability.
3. The statistical significance of the outcomes measured was assessed using **appropriate statistical** tests.
4. The effects of terminal illness care on pertinent aspects of patients' and caregivers' circumstances were measured using **validated instruments**.
5. The effect of likely **biases**, such as socioeconomic position prior to the terminal illness, are accounted for in design or analysis.

Table 1 Financial stress and strain in terminal cancer – Studies from the USA

**Quality scores L low, M medium, H high*

Study	Design	Method (Year of data collection if stated)	Terminal illness	Age of patients	Participants	Terminal status	Measure of financial stress or strain	Outcome	Quality *
Emanuel 2000, Slutsman 2002 ^{21,22} USA (nationally representative)	Cross sectional analysis (SUPPORT)	Interview survey 1996/7	Cancer (52%)	Mean age 66.5 years	988 patients (87.4% response rate), 893 caregivers (97.6% response)	Doctor defined	1) Subjectively perceived economic hardship 2) Health care and related spending >10% of income (insurance status, out-of-pocket expenses for healthcare, but excluding insurance premiums) 3) Sold assets, taken out mortgage, used savings or taken an extra job to pay for health related expenses	For people with high versus few care needs 45% v 35% felt that the costs of their illness was a moderate or great economic hardship 28% v 17% spent > 10% of their income on health care 16% v 10% had used savings, sold assets, taken extra job or mortgage. There were no differences between responses of patients in managed care or fee for service.	H
McCarthy 2000 ²³ USA (5 geographically different areas)	Retrospective analysis from prospective cohort (SUPPORT)	Interview survey	Cancer (colon or non-small cell lung)	Median age 61-66 years in subgroups	316 (61%) colon cancer and 747 (80%) lung cancer	Retrospective data	10 items about the impact of illness on their family. Data presented on the three items thought to be most important	In >40% of families, someone quit a job to care for the patient, nearly 33% lost a major source of income, 25% lost all or most of their savings.	H
Covinsky 1996 ²⁴ USA (5 geographically different areas)	Cross sectional analysis (SUPPORT)	Interview survey	19% cancer	Median age 63, interquartile (IQ) range 51-72	3158 patients	Doctor defined	As above, plus preferences elicited for life extending or supportive care only	27% reported at least one aspect of economic hardship. 24% reported loss of all or most of savings, 11% reported change in family plans because of illness (e.g. moving to less costly house, putting off medical care for others in family).	H
Covinsky 1994 ²⁵ USA (5 geographically different areas)	Cross sectional analysis (SUPPORT)	Interview survey	Nine diagnostic categories, including cancer	Mean age 62	2129 (80%) of patients who survived index hospitalisation and went home (92% interviews with surrogates)	Doctor defined	As above	31% reported loss of all or most of savings, 29% reported loss of major source of income, 20% someone quit their job. Younger age, lower income and poor functional status were associated with loss of savings, adjusting for disease severity. Under 65 years, insurance status was not correlated with loss of savings in multivariate analysis.	H
Siegel 1991 ²⁶ USA (Clinics in Rhode Island, New York, Pennsylvania)	Longitudinal, prospective survey	Telephone interviews	Cancer	Mean age patients 60 (SD 12.5), caregivers 54 (SD	483 patients, and informal caregivers (90% of patients who named a	Patients with recurrent or non-resectable disease, who	All caregivers who had provided financial support were asked if they had had to borrow money, use savings/investments to care	Mean score on financial burden 1.79, SD 1.02. 48% scored 2, 25% scored 3.	M

				14.4)	caregiver)	had had chemotherapy or radiotherapy in the last month	for the patient. This was scored 0 no financial problems, 1 out of pocket expenses, 2 financial support, 3 financial support but used savings or loan.		
Houts 1988 ²⁷ USA (Pennsylvania)	Cross sectional survey	Interview survey 1985	Cancer	33% > 64 years, 33% 40-64.	433 bereaved carers of cancer decedents. Random sampling within age strata	Retrospective	Questions on meeting medical expenses, paying non-medical costs of the illness, meeting basic living expenses	15% of decedents had unmet needs in the financial domain. This extrapolates to 4,120 in the state of Pennsylvania with unmet needs in the last month of life.	M
Hwang 2004 ²⁸ USA (One Hematology/Oncology Service in New Jersey)	Cross sectional survey	Self completed questionnaire 1999-02	Cancer	Median age 68, range 29-96	296 (95%) consecutive male patients of a Hematology / Oncology clinic.	Advanced cancer, with at least one distressing symptom	14 item 'Unmet Needs Questionnaire', which assesses financial needs as one of the fourteen areas. Patients asked if they have any problems, (and if so, to rate on 3 point scale), additional help with this problem rated on 3 point scale	20% reported unmet needs in the economic domain, which was third most commonly cited. Psychological distress and younger age predicted economic unmet needs in multivariate analyses.	M
Weitzner 1999 ²⁹ USA	Cross sectional survey	Self completed questionnaire	Cancer	Mean age of caregivers 59 years (range 22-94)	239 (90%) caregivers minimum sixth grade education and no cancer themselves	Patients of a hospice service	The Caregiver Quality of Life Index-: a four item quality of life instrument, using visual analogue scale. Financial well-being is one of four items.	Mean score on financial item 56.8, SD 34.1, range 0-100. Note it had not been tested for convergent/divergent validity or test retest reliability. Internal consistency acceptable.	M
Welch 2005 ³⁰ USA	Cross sectional survey	Telephone interviews 2000	Cancer 26% white decedents, 32% African American decedents	Mean age 78 (white decedents) 72 (African Americans)	1578 (65%) of eligible bereaved carers of all deaths in 22 states, over 3 months . 85% white, 8% African American	Retrospective	Survey questions based on five domains of end of life care, plus financial impact.	For white decedents, 38% used all or most of decedents savings to pay for care, 31% found it very or somewhat difficult to cover costs in the last year, in 10.3% families someone quit work to care for the patient. For African Americans, figures were 56%, 47% and 13% respectively	H
Tilden 2004 ³¹ USA – Oregon state	Cross sectional survey	Telephone interviews 2002	Cancer 32%	>65years	1189 caregivers of decedents (randomly sampled) who died natural deaths in community settings	Retrospective	69 item questionnaire, which included family financial hardship and out of pocket expenses	66% experienced at least one form of financial hardship. 34% used most or all of the decedents/family's savings, 32% reported that finances affected by costs of care, 26% reduced hours or quit job to care for decedent, 2% increased hours or took extra job to cover costs. Medications were the most commonly reported costs (65%), followed by transport (47%), special equipment or supplies (38%), paid help (34%) and nursing home (35%).	M
McGarry 2005 ³² USA (nationally representative)	Longitudinal analysis of panel data	Secondary data analysis	Unknown	>70 years at start of survey in 1993	271 married decedents & their spouses, from Asset and Health	Retrospective	Total household income from all sources \$, wealth measured by assets (housing, vehicles,	56% of the difference in financial situation between widow(er)s and control group was due directly or indirectly to the death. The proportion	H

					Dynamics cohort of the Health and Retirement Study. Comparison group of married couples who survived		financial, less any amount owing, but not including pensions), out of pocket medical spending, ratio of out of pocket medical spending to income in wave 1.	of income spent on medical expenses was inversely related to income, with the poorest quartile spending 70% of their income.	
McMillan 1994 ³³ USA (Florida hospice)	Longitudinal (4 week interval)	Self completed questionnaire	Cancer	Mean age of caregivers 58 (range 30-87), patients 67 (range 36-90)	68 caregivers for cancer patients in one hospice	Patients with cancer enrolled in hospice care	Patient and caregiver assessments of their own financial wellbeing, using Caregiver Quality of Life Index, as above	Scores on financial domain were no different to non-care giving control group, but fell between admission to hospice and week 4 of stay.	M

Table 2 Financial stress and strain in terminal cancer – Studies from outside of the USA

Study	Design	Method (Year of data collection if stated)	Terminal illness	Age of patients	Participants	Terminal status	Measure of Financial strain	Outcome	Quality (Low, medium, high)
Cartwright 1992 ³⁴ UK (10 areas of England)	Cross sectional survey	Interviews (bereaved carers) 1987	Various	>65 years for 75% working class, 83% middle class	639 (80%) random sample of bereaved carers	Retrospective	Thought that more financial help was needed, Had received supplementary benefit, heating allowance, rate or rent rebate	32% (292) working class and 16% (136) middle class had needed more financial help, 50% working class received rebates, 13% heating allowance and 26% supplementary benefit. For middle classes, figures were 30, 4 and 12% respectively	H
Addington-Hall 1995 ³⁵ UK (20 health districts England and Wales)	Cross sectional survey	Interviews (bereaved carers) 1990	Cancer	>65 years for 75%	2074 (71%) random sample of bereaved carers of cancer decedents	Retrospective	Structured questionnaire, reporting need for, use of and unmet need (More financial help needed - received attendance allowance and needed more financial help, did not receive attendance allowance and needed more help)	25% were said to have needed more financial help. 26% had received attendance allowance, of whom 31% were reported to have needed more financial help, compared to 23% of those who did not receive attendance allowance	H
Koffman 2003 ³⁶ UK (Inner London)	Cross sectional survey	Interviews (bereaved carers) 1998	Cancer (68% of black Caribbean, 70% whites)	Mean age 72 (SD 15) white decedents, 69 (12) black decedents	59 Informal carers from sample of 50 (47% response) black Caribbean and 50 (45% response) white who had borne the brunt of care giving	Retrospective	Questions on specific benefits received by deceased, total number of financial benefits, whether the deceased had needed additional financial support.	80% (24) of the black carers and 26% (7) of the white carers reported that more financial support had been needed. Attendance allowance was received by 16 (55%) of black and 13 (52%) white decedents	M
Beck-Friis 1993 ⁴⁰ Sweden	Cross sectional survey	Postal survey 1989-90	Cancer 87%	Median age 71 (38-92)	Caregivers of patients in a home care programme	Retrospective	Ratings of aspects of home care provided, including 'acceptable economic support' on 9 point Likert scale	2% almost completely satisfied, 56% were partially satisfied with economic support	M
Chaturvedi 1994 ³⁶ India	Cross sectional survey	Interview survey	Cancer	Mean age 50.2 (SD 14)	50 consecutive patients of an oncology clinic	Patients of a hospice service with advanced cancer	Shortened version of Devlen's concerns checklist, includes finance	Financial concerns were the 3 rd most commonly reported (54%, moderate or severe for 34% of these) after pain and other physical symptoms.	M
Singer 2005 ³⁷ Israel (Beer_sheva)	Cross sectional survey	Interviews 1999/01	Cancer (Not stated)	Mean age 60 (SD 15) home care, 55 (SD 15) non-homecare	76 (32%) caregivers of patients of a home palliative programme, 83 (21%) carers of people who died in oncology institute	Retrospective - patients died in home palliative care programme, or the oncology institute	Self perceived economic status (bad, moderate, good) Scores for economic burden on a five point scale (1 not difficult to 5 very difficult)	33% carers of people who died at home perceived their economic status to be bad, versus 19% of carers of people who died in oncology institute. The home care group were of lower socioeconomic status. Economic burden scores were higher for home care though meaning of figures presented is unclear.	M
Harding 2005 ³⁷ UK (1 hospice in London)	Audit of clinical notes	Note review 2002/3	Not stated – in hospice deaths - majority cancer	Mean age 72 (SD 12)	145 patients from a random sample of hospice deaths in six months 2002/3	Retrospective – in hospice deaths	Extraction of data from patient notes, including on informal caregivers needs and problems during the hospice stay	44% (64) notes documented needs or problems relating to finance / state welfare payments amongst informal carers.	L

Table 3 Qualitative research into financial stress and strain in terminal cancer

Study	Method	Participants	Assessment of financial stress or strain	Findings
Morasso 1999 ³⁸ Italy	Semi structured interviews 1995/6	89 (95%) randomly selected from a sample of 324 people admitted to 13 different centres, whose Karnofsky performance score deteriorated to 50 or 60.	Content analysis of semi structured interviews covering physiological, safety, self esteem, self-fulfilment and love and belonging needs.	12/89 people reported needs relating to financial support for treatment or other practical issues.
Spruyt 1999 ³³ UK	Semi-structured interviews 1986-93	18 (50% of eligible) informal caregivers of Bangladeshi patients of a community palliative care team	Topic guide for semi structured interviews designed by authors – included practical help, and impact of illness and death on the family, other services utilised.	Six families received financial help, including one off payments and help with welfare benefits. Nine families reported serious financial difficulties after the death.
Parker 2002 ³⁵ Australia	Qualitative study: focus groups, in-depth interviews, survey data 1997-98	12 bereaved carers in focus group, 20 in-depth interviews, 86 (75%) respondents to questionnaire survey - all carers of patients who had died in one hospice over a 3 month period	Data were collated from 136 carer responses from all three methods, and main themes identified.	Three themes emerged: costs relating to patient care, impact on carer lifestyle and access to financial assistance. Data are presented to illustrate the way in which care-giving presents a financial burden, and to suggest that the current support is inadequate to meet the needs of caregivers.
Shiozaki 2005 ³⁹ Japan	Qualitative interview study 2003	22 consecutive respondents to questionnaire survey administered to 1225 bereaved relatives of cancer patients who died in palliative care units, and reported need for improvement in care	Content analysis of respondents reasons for dissatisfaction with inpatient palliative care.	One of seven identified themes was economic burden. 10/22 reported that not being covered by national health insurance was a source of dissatisfaction.