

Patterns of access to community palliative care services: a literature review

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Abstract

Policies state that access to palliative care should be provided according to principles of equity. Such principles would include the absence of disparities in access to healthcare that are systematically associated with social advantage. A review of literature a decade ago identified that patients with different characteristics used community palliative care services in variable ways which appeared inequitable. The objective of this literature review is to review recent literature to identify whether such variability remains. Searching included the use of electronic databases, scrutinising bibliographies and hand searching journals. Articles are included if they were published after 1997 (the date of the previous review) up to the beginning of 2008, and if they report any data which investigates the characteristics of adult patients in relation to their relative utilisation of community palliative care services with reference to a comparator population. Forty eight studies met the inclusion criteria. Patients still access community palliative care services in variable ways. Those who are older, male, from ethnic minority populations, not married, without a home carer, are socio-economically disadvantaged, and who do not have cancer are all less likely to access community palliative care services. These studies do not identify the reasons for such variable access, or whether such variability is warranted with reference to clinical need or other factors. Studies tend to focus on access to specialist palliative care services, without looking at the complexities of service use. Studies need to move beyond description of utilisation patterns, and examine whether such patterns are inequitable, and what is happening in the referral or other processes which may result in such patterns.

Key words:

Palliative care; primary health care; literature review; home care services

Introduction

Equity of access to services is core concept guiding palliative care policy¹. Such goals are reflected globally, with the recent Korea declaration on hospice and palliative care stating that access to hospice and palliative care should be a human right, and that hospice and palliative care must be provided according to the principles of equity, irrespective of race, gender, sexual preference, ethnicity, faith, social status, national origin and the ability to pay for services².

Equity in health care can be defined in different ways, but issues of access to healthcare are common to most definitions³⁻⁵. An equitable service can be defined as one that offers equality of access to healthcare to individuals in equal need, where the service or treatment available to individuals should depend only on their need for treatment and not on factors that are irrelevant to that need³. Such definitions of equity of access to healthcare must be differentiated from the related, but separate issue of inequalities in health⁶. In addition, whilst equality of access requires that all individuals in need have the same opportunity to use the health services, equality of utilisation requires that they actually use the service³. Most studies in this field are studies of utilisation, rather than access.

Despite the centrality of equity in policy, it is a decade since a review of research highlighted that patients access or utilise community palliative care services in variable ways that seem inequitable⁷. Many patient related characteristics were associated with the likelihood of being referred to or using palliative home care services. Issues such as not having a carer at home, being older, being male, being socially disadvantaged, and having particular illnesses such as a haematological malignancy all decreased the likelihood of use of such services. Some of these patient characteristics may relate to clinical variables and support

requirements and may justify differential treatment. However, other variables suggested that the opportunity to access or utilise home care was unevenly distributed⁷.

It is timely to review research in this field again to determine whether community palliative care services now meet policy objectives, such that variability reflects different needs and demands, not inequity in access. There are indications that variability of access and use may still exist. A recent review of the literature concerning whether age affected access to specialist palliative care services for cancer patients found that older patients still appear disadvantaged⁸. In addition a review of the problems and issues of accessing specialist palliative care indicated that age, ethnicity and diagnosis may still be issues⁹. However, both reviews do not comprehensively review the literature regarding all possible patient characteristics which may affect access, across both general and specialist palliative home care services, and for patients with any diagnosis. It is therefore appropriate to review literature to examine whether patients access community palliative care services equitably to determine what progress has been made since 1997, and what the current priorities for policy, practice and research in this field should be.

Review methods

Search strategy and selection criteria

This search was guided by the question: Do adult patient (or carer) characteristics affect access to or utilisation of community palliative care services?

The search strategy encompassed three main strands: the search of electronic databases, hand searching the indexes of relevant journals, and searching the reference lists of relevant studies and published reviews. Literature searches were carried out using Ovid Medline (1997 – 2008), Cinahl (1997 – 2008), PsycINFO (1997 – 2008), ASSIA (1997 – 2008), CancerLit in Pubmed (1997 – 2007), Embase (1997 – 2008) and the Cochrane databases. The start date was set as the date the earlier published search finished⁷, with the finish date being studies identified at the beginning of 2008. Each search was constructed differently to use the relevant search terms or MESH/Thesaurus/Keyword headings for each database. All searches essentially combined all terms found (and their truncated forms) for the three foci of the search: palliative care; community care; and access (Table 1).

< insert table 1 around here >

In addition to searching electronic databases, bibliographies of review articles and the studies obtained were scrutinised, as using electronic databases alone has been demonstrated to not identify all relevant studies, particularly in fields where there is complex evidence, where clinical trials do not predominate, and where search terms cannot identify the diffuse nature of palliative care¹⁰⁻¹². In addition, the tables of contents of journals commonly reporting palliative care studies were hand searched ('Palliative Medicine', and 'Journal of Pain and Symptom Management',).

Abstracts of each study retrieved from the search were scrutinised, and studies were reviewed in full if they investigated the characteristics of adult patients (or their carers) which appeared to affect referral to or utilisation of community palliative care for adults, with no

limitations regarding methodological approach. 'Community palliative care' was interpreted as any care delivered within the patient's home setting, or care delivered in a non-hospital setting whilst the patient remains living at home. Studies were included if they encompassed any care given to patients in the palliative phase of their illness within such community settings – taking the prognosis of the patient as the starting point where possible. Most studies identified examined aspects of specialist palliative care delivery (provided by those who generally exclusively provide palliative care, with additional training and expertise, and including care given by professionals such as community palliative care specialist nurses, doctors specialising in palliative medicine, and day hospice care). Studies were also included where care was provided to patients in the palliative phase of any illness by non-specialists (often referred to as general palliative care), which included the care given by professionals such as district nurses and general practitioners. There were no restrictions on the country of research, but the language of publication was restricted to English.

Critically appraising the studies reviewed

There is no definitive approach to critical appraisal of studies in reviews which integrate the findings of studies using a variety of methodological approaches. This essentially narrative review aimed to critically appraise studies in a way which has utility for understanding how the conduct of the research impacts on the findings, their implications for practice, and their interpretation by others. This is essentially a 'fitness for purpose' argument^{13,14} in addition to a core appraisal of methodological rigor. Boaz and Ashby¹³ summarise this by asking four questions of research reports: quality and transparency in reporting (is the research presented in such a way that can be appraised and used by others?); methodological quality

(was the research technically well executed?); appropriateness of the methods (does the research approach match the defined purpose of the study); and quality of the messages in the research (does the research address important policy and practice questions in a way that is both useful and useable)? These are the key questions which guide the reporting of the strengths and limitations of the research reviewed.

A review score is also given to aid an overall judgement of the quality of the research. The review score used was developed in response to the lack of criteria suitable to appraise studies from different methodological backgrounds¹⁵. It is used here both because the appraisal domains map onto the questions above, and because it was used in the most recent published review into access in palliative care⁹. The review score examines nine study domains: abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, results, transferability or generalisability and implications and usefulness. Each domain can be scored from 1 (very poor) to 4 (good), such that a study can score between 9 and 36 points.

Results

Identifying the characteristics of patients referred to community palliative care services continues to be a well researched area, with forty eight studies identified. Generally, studies compare patients referred to a community palliative care service either with those enrolled in a different form of palliative care service, or some estimation of the palliative care/terminal care cancer population. A judgement is then made about the impact of particular patient

characteristics on the likelihood of referral ⁷. One difficulty was that many hospice studies did not indicate whether their study was assessing access to in-patient hospice or home hospice, or both. These were primarily US studies, and are included here due to the widespread use of home hospice models of care. No studies were excluded on the basis of their quality score, both because any cut off score would be arbitrary, and because most studies scored between 25 – 28 so few studies would have been excluded on the basis of their quality.

For the purposes of this review these patient characteristics are grouped into three areas: demographic characteristics (age, gender, ethnicity, and marital status), social characteristics (socio-economic information, carer information) and medical characteristics (diagnosis and functional status). The results of the studies are summarised in relation to these themes in table 2, and an overview of each of the studies given in table 3 in more detail.

< Insert tables 2 and 3 around here >

Demographic information

Age

Studies reporting the mean or median age of patients referred to community palliative care services demonstrate that most patients receiving palliative care services are in early old age (e.g. 69 years ¹⁶ 70 years ¹⁷, 66 years ¹⁸, 68 years ¹⁹, 72 years ²⁰, 73 years ²¹).

However, more relevant to access issues is whether such median ages reflect the ages of those who may benefit from palliative care. Studies consistently demonstrate that the likelihood of being referred to community specialist palliative care services varies with age. Most studies listed in table 2 demonstrate that younger patients are more likely to be referred to palliative care services than a comparator population. There are also some studies which demonstrate the opposite: that older patients are more likely to be referred²²⁻²⁶. Other studies demonstrated no impact of age on referral^{17,18,27-29}.

Some of this difference might be related to different comparisons being made to either reference populations of those who may need care, or with those receiving other forms of care. However within these typologies, many different approaches were reviewed: using different reference populations, comparing different hospice types, comparing hospice and hospital etc. It may be that some of the differences are an artefact of the comparison made, particularly when comparisons across studies are complicated by the very different structures, settings and operational procedures of the palliative and general care services studied. However, no consistent trend depending on comparison made can be determined: two of the studies finding that older people were more likely to be referred makes a comparison to a general population^{22,23}, the other three make a comparison across palliative care providers²⁴⁻²⁶.

Whilst the evidence does point to older people being less likely to be referred to or use home based specialist palliative care services, it is hard to discern why this is. Five possible explanations are suggested. First, the recent systematic review considering the impact of age on referral to specialist palliative care services suggests that the issue of inequality

versus inequity is not explored⁸. They suggest that the differential is inequitable only if elderly peoples' healthcare needs are the same as those who are younger. It may be that older people may have fewer complex palliative care symptoms or needs^{30,31}. However, a recent prospective study investigating whether age has an impact on symptoms, problems and needs of advanced cancer patients found that there was remarkable similarity between different age groups³². Differential needs may therefore not be the reason.

Second, the needs of older people may be well met by generalists such as district nurses and general practitioners. Nearly every study reviewed considers issues of access to specialist palliative care services. However, it has been shown that patients not referred to a Hospital at Home scheme are also less likely to be receiving most other forms of care such as district nursing, hospital admission, hospice inpatient or night nursing³³. It may be therefore that older patients are less likely to access any form of palliative care provision.

Third, older people have different attitudes towards palliative care which may affect their use of services. This has been investigated, however, and found not to affect care³⁴.

Fourth, it may be carer's age, not patient's age which affects access to services. One study has demonstrated that carer age is as important a predictor of palliative home care use as patient age, hypothesising that younger carers may have greater support needs, or show greater effectiveness in obtaining help³⁵. This is a relatively small study in comparison to some of the larger population-based studies, but the hypothesis warrants further investigation.

Fifth, the differences may be partly explained as an artefact of some research designs.

Because the probability of death increases with advancing age, and those who are older survive for less time after a serious diagnosis, systematic bias will be introduced when care received prior to death is examined with respect to age³⁶.

Whilst it appears that older patients are less likely to access services, the reasons for this are not still clear cut.

Gender

The evidence about whether gender affects referral to palliative care services is equivocal, with studies split on whether gender had an impact. Many studies conclude that gender does not influence referral to community palliative care services^{17,18,28,33,37-41}.

Of those studies which did identify a difference, the majority reported that women were more likely to be referred (or men less likely)^{23,26,42-47}. Only one study reported the converse, that men were more likely to be referred (or women less likely)⁴⁸.

It may be that there is a slight tendency for women to be referred more readily to community palliative care services, but again few hypotheses for why this may be so have been raised. As with the data regarding age above, it may be that carer gender has as much impact as patient gender. This is explored further when examining marital status and carer support.

Ethnicity

Ethnicity as a variable of study is frequently omitted from studies of patient characteristics. In some UK studies, for example, between 14- 30% of referrals to the palliative care services studied did not provide data on ethnicity^{19,28}, a known issue in UK palliative care ⁴⁹.

Of the studies reporting ethnicity, 4 studies found that ethnicity had no impact on referral patterns ^{21,40,50,51}. All but one⁴⁰ are studies from the US. One study found that Hispanics are significantly less likely to use hospice than non-Hispanic whites, but that this difference disappears after adjustments for age, marital status, sex, educational attainment, income, area of residence and type of insurance were made ⁵².

Studies finding that those from black and ethnic minority populations are less likely to access palliative care services include studies reporting that African Americans are less likely to access care ^{25,48}, that black patients are less likely to access care ⁴⁷, that non-white, non-black patients use services less ⁴⁵, or that non-white patients are less likely to be referred ⁵³⁻⁵⁵. Australian studies have either found that those of non Australian descent are more likely to access care ^{39,56}, or that indigenous people are less likely to access care ³⁸.

Only one study reports that non-white patients had a referral advantage ²⁶. This study primarily investigates referral timing, and found that non-white patients enrolled in hospice

(mostly home hospice) four days earlier than white patients. There is evidence that when home care specifically is studied, non-white patients may be more likely to be referred, when compared to other forms of palliative care⁵⁷. It has been identified that general practitioners are more likely to refer members of ethnic groups to home based hospice than in-patient hospice because they feel that home care services are more compatible with the families wish to care for the patient and home, and that that such patients have little grasp of the concept of hospice⁵³. Those from different ethnic groups have also been found to perceive hospice care in different ways, with hospice care seen as a negative choice for those of Chinese origin living in the UK⁵⁸.

These studies indicate that ethnicity may have an impact on referral decisions, but with a caveat; some of these differences may not only be because of ethnicity per se, but also that those from black and ethnic minority communities may differ in their age structures, income levels, places of residence etc. which could impact on the use of palliative care services⁵². There are many differences between the cultures and contexts of these studies, particularly different issues surrounding ethnic origin in the UK and US. As with the earlier data on age, there are no data given on any estimation of need, or the patients' ability to benefit from services, and so it is difficult to judge whether the different access patterns are related to systematic bias, differential need, or some other factor.

Social information

Marital status

Most of the studies reporting marital status find that being married increases the likelihood of being referred to home specialist palliative care ^{21,25,38,41,44,48,51,56,59}. Whilst there are a few studies finding no difference ^{17,39,60}, no studies find that being married decreases the likelihood of being referred.

Many authors conclude that marital status is a proxy variable for having a carer at home. This is discussed further when investigating carer data, and the presence of a carer in the home.

Carers

Most studies demonstrate that variables which increase the probability of having home based informal carers improve the likelihood of patients being referred to palliative care services, whilst living alone decreases the likelihood ^{21,24,25,41,48,56}. The perception of whether the family have the ability to achieve home as a preferred place of death can also affect referrals ⁴⁶. One variable which may affect this perception is the age of the carer, and a recent study demonstrates that those with younger carers are more likely to receive Marie Curie or Macmillan nursing support ³⁵.

These findings appear to lend support to the hypothesis that those referred to palliative care services are those assumed to have sufficient support to facilitate home care, whether this is a spouse (especially a female spouse), or other carer. For US studies this may reflect the criteria of many home hospice services requiring there to be an informal carer before a referral is made. This raises questions about the burden a carer would be expected to

shoulder at home, and whether the care provided after a referral meets the expectations of both the carer and patient.

Socio-economic characteristics

Studies investigating referral use a variety of different descriptors to investigate the impact of socio-economic characteristics. These include educational levels, home owning, health insurance, income and deprivation.

Four studies found that having a lower educational level increases the likelihood of referral to specialist palliative care ^{16,17,21,59}. However, two studies found the converse, that those with the greater educational levels are more likely to access care ^{37,48} and one study found that education had no influence ²⁶.

The studies which point to the influence of income are less equivocal, with most studies examining income finding that those receiving high to middle income levels are more likely to access care ^{21,42,48}. Only one study found that income did not make a difference ²⁶.

Several studies investigate the impact of type or place of residence on access, finding that those who own their own homes ^{41,48}, who live in less deprived areas ³³ or who do not live in rural areas ^{38,40,45,61} are more likely to access care.

The data on health insurance are difficult to interpret. Some studies find that those without health insurance are more likely to access care ^{21,51,56}, or those who do not have a particular

type of insurance (fee for service insurance) ⁴⁵. One study found that those with Medicare are more likely to access care ⁵⁰.

Whilst data on the impact of socio-economic factors on referral is not clear cut, the trend from these studies indicates that those who may be anticipated to have fewer socioeconomic disadvantages are more likely to access care. As with other factors, such findings only point to the existence of variability in referrals, not the reason. It may be that referrers are making choices based on whom they feel may be better able to be cared for and supported at home, which could prioritise those who have the financial and social means to support themselves more effectively. An alternative explanation could be that people with such characteristics are better equipped to seek out or request specialist support in the home. No studies reviewed went further than the descriptions here to investigate these or other hypotheses, usually again because they are reliant on the use of routinely collected, retrospective data. Again, there is a real need to explore the reasons behind these apparent inequities further.

Medical information

Diagnosis

It is important to note that most of the diagnoses discussed in studies are cancer diagnoses, as the studies reported here focus almost exclusively on cancer patients. Of the studies investigating the patients' primary cancer diagnosis, many found that the diagnosis had no impact on the likelihood of referral to specialist palliative home care ^{17,18,28,29,44}.

Of the studies finding a diagnosis effect, results are inconclusive for most cancer diagnoses. The picture is perhaps clearest for those with haematological malignancies with a number of studies finding that such a diagnosis (i.e. leukaemia, lymphoma, myeloma) reduces the likelihood of referral^{37,39-41,62}. Other diagnoses found to reduce the likelihood of referral include brain cancer⁴¹.

For other cancer diagnoses, studies present more conflicting evidence. For example having breast cancer presents a confusing picture with two studies identifying fewer referrals^{40,63}, and others more^{41,64,65}.

It is also notable that the diagnoses explored are mostly cancer diagnoses, not addressing the needs of patients and the end of life that do not have a cancer diagnosis. It is clear that those with non-malignant disease who are at the end of life have significant health care needs⁶⁶. However, it is estimated that only about 5% of referrals to specialist palliative care services in the UK have a non-cancer diagnosis⁶⁷, whilst greater numbers of such patients are able to access services in some other contexts, notably the US^{68,69}. One study identifies that those with non-malignant disease are less likely to be referred to a hospital at home scheme³³, and another that those who have substance abuse problems, psychiatric disease or dementia are likely to be referred to a hospice earlier²⁶.

Research into referral of patients with non-cancer diagnoses to palliative care services indicates that people are willing to refer to specialist palliative care services, particularly in the hospital setting^{70,71}. This intention however, seems to translate into a much smaller number of actual referrals. One study found that whilst 68% of those who died from cancer during their study period had contact with a specialist palliative care team, only 8% of those with selected non cancer conditions had such contact, a dramatic difference³⁸. It has been

suggested that prognostication may be an issue, with patients in one study without cancer referred to the home care team having advanced disease and short prognoses, so identifying when a terminal stage has been reached is difficult for referrers^{71,72}.

Again, whilst this research demonstrates variability in referrals, it may be that those with different diagnoses have different needs which could be met in different ways. In particular the needs of those with malignant and non-malignant diseases may differ considerably. However, there are indications that those with non-malignant diseases have significant needs that are not met by specialist palliative care services⁷³.

Functional status

The evidence about whether the functional status of patients affects referral is equivocal. It is particularly difficult to compare results across studies, not only because of the different contexts and comparisons noted earlier, but also because of the range of different measures of functional status used. Some studies indicate that patients referred to specialist palliative home care are less well on a number of measures^{24,25,27,41}. Other studies indicate that it tends to be more able, fitter patients who are referred to services^{46,56}.

These findings are of concern. First, most studies investigating the impact of patient characteristics on referral do not incorporate a measure of functional status. Whilst there may be many reasons, one explanation is the reliance of many of these studies on a retrospective analysis of routinely available data which may not incorporate information on functional status. Second, functional status should be a key indicator of referral.

Commentators and policy documents suggest that the key criterion for referral should be an

assessment of need. Functional status is likely to be one characteristic which indicates need, and yet this appears to be a significantly under researched area ^{9,74}.

Discussion

This review indicates that people with certain characteristics remain more likely to access specialist palliative home care. For example, younger, married, wealthier people with a carer at home appear to be more likely to be referred to or utilise services. There appears to be little change to the patterns of use described a decade ago.

General critique of reviewed studies

The emphasis on investigating which patients access palliative care services must be questioned. One reason for the large evidence base may be the ability to study such patient characteristics using retrospective, routinely available data. Researchers continue to investigate this area, with similar studies, with similar findings, across different countries reviewed between 1997 and 2008. Indeed there has been a recent call for more research investigating utilisation patterns⁷⁵. A related body of work investigating the association between similar patient characteristics and place of death, has recently been criticised for having no theoretical basis underlying the research questions, with no rationale for grouping or identifying the factors given⁷⁶. Such a criticism could also be levelled at this access work, with factors investigated often apparently chosen because of their presence on routine databases, rather than a predicted, theoretically driven rationale. Whilst it can be argued that all studies have a theoretical orientation by virtue of the way a research question is framed⁷⁷, it is notable that little of the literature reviewed was explicitly theoretically driven, or related findings to extant theory. There is therefore little overt theoretical direction to the

research reported here provided by the literature review, and ultimately little guidance therefore on areas to subsequently study.

A recent review of the literature on age and access makes additional criticisms of those studies which are also applicable to many studies reviewed here; they have inadequate descriptions of specialist palliative care services; and the quality of outcomes data is often poor, relying on retrospective investigations of use, routine data or proxy recall, but where there could be inconsistent recording or the validity of proxies could be questioned, and questions asked of proxies insufficiently comprehensive⁸.

Retrospective methods have been also been criticised because they can fail to identify those in the palliative phases of illness, and can study different cohort of patients to studies which prospectively study those who are dying^{36,78,79}. Studies which retrospectively study those who have died may produce very different results to those who study those who have been identified as dying³⁶. It has been recommended that studies, prospective or retrospective, should specify the features which identify patients as 'dying' from the outset, to study care provided to those who have actively been identified as dying, rather than those who died within a specified time period.

The scope of the research

This literature also focuses almost exclusively on access and utilisation patterns within specialist palliative care services. There is little information available about the patterns of access of patients to general palliative care, with only one study looking at the patient characteristics which influenced visits from a family physician⁴². Those providing general care such as general practitioners and district nurses may be critical to access patterns, not

only providing much care in the community, but also referring patients to specialist care. It may be the choices these referrers make, and whether the specialist teams choose to accept a referral, which affects these patterns of access, and which could be important to investigate. For example, research has identified that the judgments palliative care professionals make about each other can affect referral patterns⁸⁰.

The country context of the studies may also be important. For example, many studies draw on US data, and service use in that country is affected by issues such as Medicare insurance rules, and the increased use of hospice by patients with non-malignant illnesses⁸¹. It may be that there are other differences between care contexts, such as the timing of referral to care, and the time from referral to death. This potentially makes generalising from a study in a different country difficult, and so the evidence base upon which a particular country's referral patterns could be based is smaller than initially envisaged. Any comparisons are made more difficult by the lack of description of services studied or services potentially available to patients. The lack of contextual information for referral decision making practices is an issue which needs to be addressed in future research.

Patients' and carers' views are also notably absent from much of the research reviewed, although this is a field which appears to be rapidly expanding. It appears that patients also note professional barriers to referrals, and that their own views on care can affect referral practices. It may be appropriate therefore for any study investigating influences on referral practices to incorporate the views of patients or carers.

Development of research since 1997

Grande *et al.*⁷ suggested that future research should build on the knowledge current at that time and try to establish the mechanisms by which social disadvantage affects access, and whether age affects attitudes towards palliative care services and decisions about their use. They recommended the use of prospective observational and interview based research rather than the use of retrospective, routine data that dominated the research reviewed from before 1997. However, whilst the studies reviewed here raise awareness again of the differential use of palliative care services, they still do little to aid understanding of the reasons for such differences. Hypothesised reasons, such as differences in abilities for patients or carers to request services, different needs of patients, different assessments of ability to cope at home, or systematic bias in referral practices, have not yet been thoroughly investigated.

It may be that apparent inequities in access are an artefact of the different needs of patients and/or carers, or their perceived ability to benefit from services. Reviewed studies appear to assume notions of horizontal equity, that all patients potentially accessing care are equal, and should have equal treatment⁸². It may be that vertical equity is a more appropriate concept, that patients access care in unequal ways that are equitable because of their unequal needs. There are indications that lower uptake may not equate with unmet need in some patient groups⁷³. However, few studies relate any aspect of referral or access to a measure of clinical need, patient/carer demand, or subsequent benefit from services, and so such issues have not been explored in studies.

Research into different patients' access patterns also focuses attention on patient characteristics as a possible explanatory factor, rather than the potential impact of professional, service or organisational factors. Indeed, it could be said that the association between patient characteristics and access has been interpreted in some studies as causal,

rather than an association. Ahmed *et al.*⁹ conclude from their review that future research should focus on determining the adequacy of provision of palliative care for those receiving inequitable care. A note of caution should be sounded, as the assumption of inequitable care may be incorrect, and the provision of care has not been shown to be inadequate.

Recommendations for future research

It is clear that patients with different characteristics access and utilise community palliative care services in different ways. There is little need for future research to continue to describe patterns of service use. What researchers have rarely done is move beyond such descriptive work to examine whether such different utilisation patterns are truly inequitable and what is happening in the referral or other processes which may result in the observed referral and utilisation pattern. Sadly, this was recognised in the earlier review, with Grande *et al.*⁷ suggesting that the retrospective review of routine data had been useful in allowing an understanding of the patterns of referral, but that researchers need to develop studies which investigate how and why these characteristics have an impact. This suggestion has been largely ignored, with few studies making any attempt to explore issues rather than describe patterns of use.

It may be that researchers have not developed thinking in this field for a number of reasons. Much of the research reviewed here employs quantitative methods, with a preponderance of retrospective analyses of routinely available data. Whilst there is no question that many of these are rigorously conducted studies, the impact of such choices is that areas to study are essentially pre-determined, and cannot be influenced by the findings of previous studies. In addition, as previously discussed, most of these studies are not theoretically driven, with no

rationale given for the choice of particular variables from such routine databases. This makes interpretation of the data harder, and appears to restrict the suggestions for future research arising from such findings. These choices appear to restrict the issues examined regarding what facilitates or acts as a barrier to access or utilisation of community palliative care services. A research approach which is theoretically driven, yet facilitates the discovery of unanticipated influences, and allows an in-depth understanding of what affects referrals may therefore be appropriate when studying this area further.

Most current research in this field is also narrow in scope, focusing usually on use of a particular specialist palliative care service, rather than examining this in the context of possible use of a broader range of services, including those provided by generalist providers. Decisions about the use of services are complex, and are likely to be influenced not only by patient characteristics, but by a range of other issues including contextual ones such as the availability, use of, and attitudes towards other services⁸⁰. Future research should emphasise the importance of context and the use of alternative services. Indeed, there are parallel themes in the research literature which examine both professional and organisational issues which may affect access^{9,83}, and patient barriers such as preferences about and attitudes to services^{34,84}. It is important to develop research which examines the impact of patient characteristics that also takes account of these issues and the possible interactions between them.

In conclusion, most studies reviewed use quantitative methods to investigate whether particular patients are referred to or access (specialist) palliative care services, not the processes preceding referral and the influences on such access and utilisation decisions. There is a sound understanding of what is happening, but not of how or why. There are also poor descriptions in many studies of the context of care and hence decision making

practices. Whilst there is an implicit assumption of inequity, there is little evidence to support this assumption, as studies rarely assess need or demand for services rather than patterns of utilisation.

Table 1 Examples of terms used in the literature review search strategy

| Terms for palliative care <i>And</i> | Terms for community care <i>and</i> | Terms for access <i>and</i> |
|--|--|---|
| <p>All combined with <i>or</i></p> <p>Palliative Palliative care Specialist palliative care Terminal Terminal care Terminally ill End of life End of life care Hospice Hospice care</p> | <p>All combined with <i>or</i></p> <p>Primary care Primary health care Community care Home care Home health nursing Community nursing staff General Practitioners Family Practice Family medicine Family Physicians Home health aides Home care services Home visiting programs</p> | <p>All combined with <i>or</i></p> <p>Access Access to care Referral Barriers Obstacles Decision making Equity of care Equality of care Inequity and inequality Rationing Gatekeeping Evaluation of care Assessment of need Unmet need Health care need Health services needs and demands Health care utilization Self referral Professional referral Health service accessibility Delivery of health care</p> |

Table 2.5 Summary of the themes of research investigating which patients are referred to community palliative care services
(Key: + indicates more likely to be referred with that characteristic, - less likely, 0 no effect found, N/A characteristic not studied or reported).

| Author, date, country | Demographic information | | | Social information | | | Medical information | |
|---------------------------------------|--|---|----------|--------------------|---|---|-----------------------------|---|
| | Age | Ethnicity | Gender | Marital status | Socio-economic | Carers | Diagnosis | Functional status |
| Ngo-Metzer <i>et al.</i> (2008) US | N/A | Asian-American/Pacific islanders - | N/A | N/A | N/A | N/A | N/A | N/A |
| Beccaro <i>et al.</i> (2007) Italy | Older - | N/A | Gender 0 | Married + | Higher education + | Living alone - | Haematological malignancy - | N/A |
| Connor <i>et al.</i> (2007) US | Older + | White + | Female + | N/A | South West US + | N/A | Malignancy + | N/A |
| Haas <i>et al.</i> (2007) US | N/A | African American/Hispanic – (when living in areas which high % ethnic minority) | N/A | N/A | Living in area which high ethnic minority population - | N/A | N/A | N/A |
| Jakobsson <i>et al.</i> (2007) Sweden | Older + (compared to hospital care) | N/A | N/A | N/A | Those in residential care + (compared to hospital care) | N/A | N/A | Disoriented + (compared to hospital care) |
| Grande <i>et al.</i> (2006) UK | Receiving Marie Curie/Macmillan nurse care younger + | N/A | N/A | N/A | N/A | Receiving Marie Curie/Macmillan nurse care younger carers + | Cancer + | N/A |
| Keating <i>et al.</i> | Older + | Ethnicity 0 | Female + | Marital status | High income | N/A | Lung cancer | N/A |

| Author, date, country | Demographic information | | | Social information | | | Medical information | |
|---|-------------------------------------|---|--|---------------------------------------|--|--|--|--|
| | Age | Ethnicity | Gender | Marital status | Socio-economic | Carers | Diagnosis | Functional status |
| (2006) US | (adjusted) Age 0 (unadjusted) | | (adjusted) Gender 0 (unadjusted) | 0 | + | | +, breast cancer - | |
| Locher <i>et al.</i> (2006) US | NA | Non-white + (home care) White + (home hospice) | Female + (home care) | Unmarried + (home care, hospice care) | N/A | N/A | Pancreatic cancer +, Prostate cancer - | N/A |
| Peters and Sellick (2006) Australia | Older - | N/A | N/A | Married + | Non-Australian descent + Without health insurance + | Lived with someone + | N/A | Gastrointestinal symptoms – Lower score on symptom measures + High sense of personal control + |
| Rosenwax and McNamara (2006) Australia | Older - | Indigenous - | Gender 0 | Married + | Live outside major city - | N/A | Cancer + | N/A |
| Burge <i>et al.</i> (2005) Canada (visits from a family physician) | N/A | N/A | Females + | N/A | Middle to high income + | Admitted to palliative care programme + Made more speciality visits + More inpatient stays + | Breast cancer + Survived over 61 days + | N/A |
| Luckan <i>et al.</i> (2005) US | N/A | N/A | N/A | Married + | N/A | N/A | N/A | N/A |

| Author, date, country | Demographic information | | | Social information | | | Medical information | |
|---|--------------------------------------|-----------------------------------|-------------------------------|---|---|-------------------|---|-------------------------------------|
| | Age | Ethnicity | Gender | Marital status | Socio-economic | Carers | Diagnosis | Functional status |
| Solloway <i>et al.</i> (2005) US | Younger + (compared to nursing home) | N/A | Male – (compared to hospital) | Married + (compared to hospital and nursing home) | Roman Catholic – (compared to nursing home and hospital) Medicare + | Family distress + | Diagnosis 0 | Pain assessment + |
| Welch <i>et al.</i> (2005) US | N/A | African-American 0 | N/A | N/A | N/A | N/A | N/A | N/A |
| Ahlner-Elmqvist <i>et al.</i> (2004) Sweden | Age 0 | N/A | N/A | N/A | N/A | N/A | Longer from diagnosis to inclusion time + (with shorter time after enrolment) | Lower Karnofsky performance index + |
| Currow <i>et al.</i> (2004) Australia | N/A | N/A | N/A | N/A | Country of birth, educational level, residential region 0 Higher income + | N/A | Cancer + | N/A |
| Gagnon <i>et al.</i> (2004) US | Older age + | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| Lackan <i>et al.</i> (2004a) US | N/A | Hispanic vs. Non-Hispanic White 0 | N/A | N/A | N/A | N/A | N/A | N/A |
| Lackan <i>et al.</i> (2004b) US | Younger + | Non-Hispanic White + | Female + | Married + | Living in areas with higher | N/A | Lung or colorectal cancer + | N/A |

| Author, date, country | Demographic information | | | Social information | | | Medical information | |
|---------------------------------------|-------------------------|----------------------------|----------|--------------------|---|---------------------------------|---|---|
| | Age | Ethnicity | Gender | Marital status | Socio-economic | Carers | Diagnosis | Functional status |
| | | | | | income/education levels + | | | |
| Chen <i>et al.</i> (2003) US | Older age + | N/A | N/A | N/A | Less education + | More people in household + | N/A | More co-morbid conditions, worse ADL scores + |
| Colón and Lyke (2003) US | N/A | African American, Latino - | N/A | N/A | N/A | N/A | N/A | N/A |
| Costantini <i>et al.</i> (2003) Italy | Age 0 | N/A | Gender 0 | Marital status 0 | Lower education + | N/A | Diagnosis 0 Longer diagnosis to death time + | N/A |
| Greiner <i>et al.</i> (2003) US | Younger + | African American - | Female - | Married + | Higher income + College education + Not owning a home - | High levels of social support + | N/A | N/A |
| Lackan <i>et al.</i> (2003) US | Younger + | Ethnicity 0 | N/A | Married + | Varied by geographical area + | N/A | N/A | N/A |
| McCarthy <i>et al.</i> (2003a) US | N/A | Non white, non black - | Male - | N/A | Having fee for service insurance – Rural community - | N/A | N/A | N/A |
| McCarthy <i>et al.</i> (2003b) US | N/A | N/A | N/A | N/A | Managed care patients (versus fee for service) + | N/A | N/A | N/A |

| Author, date, country | Demographic information | | | Social information | | | Medical information | |
|--|-------------------------|--------------------|----------|--------------------|-----------------------|--|---|---|
| | Age | Ethnicity | Gender | Marital status | Socio-economic | Carers | Diagnosis | Functional status |
| Miller <i>et al.</i> (2003) US (likelihood of receiving continuous hospice home care) | Younger than 65 - | African-American - | N/A | Married + | N/A | Caregiver at home vs. living alone - | Hospice stay of less than 7 days - | In severe pain + |
| Ngo-Metzger et al. (2003) US | N/A | Asian American - | N/A | N/A | N/A | N/A | N/A | N/A |
| Potter <i>et al.</i> (2003) UK | Age 0 | N/A | Gender 0 | N/A | N/A | N/A | Diagnosis 0 | N/A |
| Tang (2003) US | N/A | N/A | Female + | N/A | N/A | Perceived greater family ability to achieve preferred place of death + Home as preferred place of death + | Longer length of survival + Use of emergency care in final days of life + | Lower levels of functional dependency + |
| Burge <i>et al.</i> (2002) Canada | Younger age + | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| Grande <i>et al.</i> (2002) UK | Younger age + | N/A | Gender 0 | N/A | Less deprived areas + | To have had specialist or generalist nursing input before last month of life + | Causes other than cancer on death certificate – Been diagnosed within a month of death - | N/A |
| Hunt <i>et al.</i> (2002) Australia | 80 or older – | Race 0 | Gender 0 | N/A | Country residents – | N/A | Survival from diagnosis to | N/A |

| Author, date, country | Demographic information | | | Social information | | | Medical information | |
|-----------------------------------|--|--|----------|------------------------------|--|---|--|--|
| | Age | Ethnicity | Gender | Marital status | Socio-economic | Carers | Diagnosis | Functional status |
| | | | | | Socioeconomic status 0 | | death <3 months, prostate, breast, haematological malignancy - | |
| Higginson and Wilkinson (2002) UK | Age 0, but older patients received fewer hours of care | No comparison possible (68% white, 2% other, 30% missing data) | Gender 0 | N/A | N/A | N/A | Diagnosis 0 | N/A |
| Skilbeck <i>et al.</i> (2002) UK | Younger age + | N/A | N/A | N/A | N/A | N/A | Referral at diagnosis - | N/A |
| Virnig <i>et al.</i> (2002) US | Younger than 80 + | Black - | Male - | N/A | N/A | N/A | Diagnosis 0 | N/A |
| Casarett (2001) US | Referrals from academic centre younger + | Ethnicity 0 | N/A | Academic referrals married + | Academic referrals public insurance - | N/A | N/A | Academic referrals nursing home -, academic referrals nursing care + |
| Casarett and Abraham (2001) US | 'bridge' referrals younger + | Ethnicity 0 | N/A | 'bridge' referrals married + | 'bridge' referrals Medicare/aid -, high income +, less education + | 'bridge' refs informal carer living with them + | N/A | N/A |

| Author, date, country | Demographic information | | | Social information | | | Medical information | |
|---|------------------------------------|-------------|--|---|-------------------------|--|---|-------------------------------------|
| | Age | Ethnicity | Gender | Marital status | Socio-economic | Carers | Diagnosis | Functional status |
| O'Mara and Arenella (2001) US | N/A | Ethnicity - | N/A | N/A | N/A | N/A | N/A | N/A |
| Yang <i>et al.</i> (2001) Taiwan | Younger + (compared to inpatients) | N/A | N/A | Married + (compared to acute care patients) | Education - | Spouse as caregiver – (compared to team consultation) | N/A | N/A |
| Addington-Hall and Altmann (2000) UK | Younger age + | N/A | Gender 0 | Married + | Own home + | Living children and siblings+, Live alone or in nursing home – Informal carer lived with patient or was spouse + | Lymphoma, leukaemia, myeloma -, brain cancer -, digestive cancer, breast cancer + | More dependent in self-care tasks + |
| Christakis and Iwashyna ²⁶ US (referring to earlier referral to hospice) | Older age + | Nonwhite + | Women + | N/A | Education 0 Income 0 | More hospital beds, greater hospice capacity, higher % generalists + | Substance abuse, psychiatric disease or dementia + | N/A |
| Karim <i>et al.</i> (2000) UK | N/A | Non-white - | N/A | N/A | N/A | N/A | N/A | N/A |
| Costantini <i>et al.</i> (1999) Italy | Age 0 | N/A | Female admitted to hospice, not home pcu + | N/A | N/A | N/A | Diagnosis 0 | N/A |
| Fountain (1999) UK | N/A | Non-white - | N/A | N/A | N/A | N/A | N/A | N/A |
| Hunt and McCaul (1998) Australia | Aged 40 – 60+ | N/A | Gender 0 | Married 0 | Rural - , UK/Europe | No of children 0 | Haematologic al – | |

| Author, date, country | Demographic information | | | Social information | | | Medical information | |
|--------------------------------------|-------------------------|-----------|----------|--------------------|---|--------|--|-------------------|
| | Age | Ethnicity | Gender | Marital status | Socio-economic | Carers | Diagnosis | Functional status |
| | 80 or older - | | | | born + | | Survival over 6 months+ | |
| Johnston <i>et al.</i> (1998) Canada | Younger age + | N/A | Gender 0 | N/A | Living in Halifax County (close to service) + | N/A | Survival over 6 months + Head and neck cancer + Haematological cancer, lung cancer - | N/A |
| Gray and Forster (1997) UK | Younger age + | N/A | Gender 0 | N/A | Social class 0 | N/A | Cancer site 0 Longer survival from diagnosis + Particular GP practices + | N/A |

Table 3 **Studies investigating which patients are referred to community palliative care services**

| Author, Date, Country | Research question/ theme | Research approach | Participants | Findings/outcomes | Appraisal of study and quality score |
|---|--|---|--|--|--|
| Ngo-Metzger et al. (2008) ⁸⁵ US | To explore the rates of use of hospice use of older Asian-American and Pacific Islander patients and white patients. | Retrospective analysis of last year of life of cancer patients using existing database data. (death between 1988 and 1998) | 206 997 eligible patients (85% white, 4% AAPI, 11% other ethnicity). | AAPI's had lower rates of hospice enrolment after adjustment for demographic and clinical factors. | 26. Large database, so difficult to disaggregate what type of hospice used. |
| Beccaro <i>et al.</i> (2007) ³⁷ Italy | To analyse the socio-demographic factors associated with the referral of cancer patients for palliative care. | Interviews with bereaved carers or professional carers regarding care of randomly sampled decedents from population of Italian cancer deaths. | 1 289 care givers (67.8% response). | Patients referred to domiciliary palliative care teams were more likely to be younger, married, have a caregiver, have a longer time since diagnosis, have a higher educational level. Less likely to have a haematological malignancy. No difference gender or care givers age. | 27 No information on what specialist palliative care entailed. Only cancer patients. But large population based sample. |
| Connor <i>et al.</i> (2007) ²³ US | To describe the whole population of hospice users and nonusers in the United States. | Retrospective analysis of routinely collected national mortality and hospice use data (over 65 years) for 2002. | 1 811 720 deaths and 518 078 hospice users | Hospice use more likely among females, whites, older people, with malignancies, and those living in South west US. | 27 Population based study, and not possible to disaggregate from this data what type of hospice used. |
| Haas <i>et al.</i> (2007) ⁸⁶ US | To examine whether the racial composition of the census tract where an individual | Retrospective analysis of routinely collected data from SEER data base for | 70 669 patients | Hospice most commonly used by individuals when live in area with fewer | 26 Interesting comparison of ethnicity and socio- |

| Author, Date, Country | Research question/ theme | Research approach | Participants | Findings/outcomes | Appraisal of study and quality score |
|--|---|--|---|--|--|
| | resides is associated with hospice use | those with breast, colorectal, lung or prostate cancer | | African-American and Hispanic residents. | demographic information. |
| Jakobsson <i>et al.</i> (2007) ⁸⁷ Sweden | To explore which health-care resources persons use during their last 3 months of life and where this care is provided and examine the relationship between services used and subject characteristics. | Retrospective analysis of routinely collected data from death certificates and nursing and medical notes. | 229 participants randomly sampled from death notifications (stratified to take account of death frequencies in participant municipalities). Sudden death, accident, suicide or lack of health service use excluded. | Comparisons made between hospital based in patient care, outpatient care, GP services, care at residential care facilities and care in private homes. Older people, those in residential care, those who were disorientated, were more likely to access GP or residential care than hospital care. | 26 Unclear as to what 'home care' or 'GP care' entailed. |
| Grande <i>et al.</i> (2006) ³⁵ UK | To investigate how both patient and carer age relate to palliative care use, controlling for relevant variables | Structured interview with bereaved carers of those referred to a hospital at home service during a randomised controlled trial. Additional data collected from routine sources | 123 carers (57% response) | Patients who received Marie Curie and Macmillan nursing were younger and had younger carers. Those receiving Marie Curie and hospice care more likely to have cancer. Macmillan care recipients more likely to be in lower occupational classes and have carers who had reduced or stopped work | 25 Study only considers those who have already been selected to receive one service (Hospital at home). Relatively small sample |
| Keating <i>et al.</i> | To examine the relative importance of | Retrospective analysis of routinely | 3805 enrollees who died of lung, | Rates of enrolment did not differ by age at | 26 Attempt to look at |

| Author, Date, Country | Research question/ theme | Research approach | Participants | Findings/outcomes | Appraisal of study and quality score |
|---|--|---|--|--|--|
| (2006) ⁶³ US | patient characteristics, physician characteristics and local health centers in explaining variations in hospice enrolment. | collected data (Kaiser permanente health plan enrollees) | colorectal, breast or prostate cancer between 1996 and 2001. | diagnosis, sex, ethnicity or marital status (undadjusted). Adjusted figures for patient/physician characteristics, older, female, Lung cancer most likely, breast cancer least likely. More likely hospice use if live in area with higher income, less likely if die within 1-2 months diagnosis. Variation in hospice use according to physician characteristics, less likely if have a younger doctor, more likely if seen an oncologist, have doctor who sees more patients. | referrer characteristics as well as patient characteristics. |
| Locher <i>et al.</i> (2006) ⁵⁷ US | To describe patterns of home health and hospice use by older cancer patients and non-cancer persons. | Retrospective analysis of routinely available data from SEER database and Medicare claims | 120 072 with cancer diagnosed 1997 to 1999, eligible for services in 1999 and comparator group without cancer (160 707). | Higher service use for those with pancreatic cancer, fewest prostate cancer. Home health: non-white, unmarried more likely to use. Hospice: White more likely to use, married. | 26 Large sample. No contextual information on services. |
| Peters and Sellick | To compare patients receiving in patient | Structured interview based questionnaire | 58 patients (from a random sample of | Home care patients more likely to be | 29 Small sample with |

| Author, Date, Country | Research question/ theme | Research approach | Participants | Findings/outcomes | Appraisal of study and quality score |
|---|---|--|---|--|--|
| (2006) ⁵⁶ Australia | and home based palliative care on a number of dimensions | to patients with terminal cancer recruited from palliative care centres in 1999 | 93) (32 (71% response) in patients, 26 (54%) home based) | married, of non-Australian descent and without health insurance. More home care patients lived with someone, fewer over 80 although not statistically significant. Fewer home care patients reported diarrhoea, appetite loss or belching. Lower home care score for symptom measures. Higher home care score for personal control | poor recruitment, particularly of home care patients. No real description of the contexts of care provided |
| Rosenwax and McNamara (2006) ³⁸ Australia | To quantify the use of specialist palliative care during the last 12 months of life for people dying of cancer and selected-non cancer conditions | Retrospective analysis of routinely available data from three administrative databases (2000 – 2002) | 26 882 people who died (aged over 1 day) during the study period formed total population, with 7 399 cancer deaths, 608 from cancer and specified non-cancer conditions, and 6712 deaths from specified non-cancer conditions | Cancer: 24% received only community specialist palliative care, 19% hospital based care, 25% both forms. Cancer and non-cancer: 20% community care, 13% hospital, and 15% both. Non-cancer: 3% community, 4% hospital, 1% both. | 26 Useful breakdown over large population of disease type and access. No discussion of what type of community service offered |
| Burge <i>et al.</i> (2005) ⁶⁴ Canada | To examine the association between patient income and residence and receipt | Retrospective secondary analysis of linked population based data | 7 212 patients who died of lung, colorectal, breast or prostate cancer | 45% received at least one home visit. Most likely for those in middle to high income | 25 Data restricted to those with particular cancer diagnoses |

| Author, Date, Country | Research question/ theme | Research approach | Participants | Findings/outcomes | Appraisal of study and quality score |
|---|--|---|---|--|--|
| | of family physician visits during the end of life among patients with cancer | | between 1992 and 1997 in Nova Scotia | neighbourhoods, particularly outside major metropolitan areas, for females, have breast cancer, survived at least 61 days, admitted to PCP, made more speciality visits, more days as an inpatient | |
| Lackan <i>et al.</i> (2005) ⁸⁸ US | To investigate the association between marital status and hospice use in the US | Retrospective analysis of routine data from the Surveillance, Epidemiology and End Result (SEER) – Medicare database | 71 948 subjects with breast, colorectal, lung or prostate cancer diagnosed 1991-1996, died between 1991 – 1998. 28 779 (41%) used hospice | Hospice use greatest for married people. Significant interaction between marital status and gender suggests married males, married or ever married females more likely to use hospice | 24 |
| Solloway <i>et al.</i> (2005) ⁴⁴ US | To determine if the experience of dying differed among settings in New Hampshire | Retrospective state-wide analysis of adult deaths in hospitals, nursing homes and homecare/hospice agencies in 2 months in 2002 | 782 deaths reported (424 hospital, 148 nursing home, 210 home care/hospice) – 44% of adult deaths during study period | Significant differences among settings for mean age, gender, marital status, primary insurance, diagnosis, Advance directives, symptom assessment and provision of emotional and spiritual support | 22 A study of characteristics at death in service not at referral – referrals to other services could have been made earlier in disease process |
| Tyrer and Exley (2006) ²⁰ UK | To evaluate a new hospice at home scheme | Retrospective analysis of routinely collected data about those accessing the service | 155 patients accessed the service in 2003 | Population 52% male, median age 72, 83% white, 92% with cancer and were 68% already residing at home | 22 No comparison with population of those not using HAH made |

| Author, Date, Country | Research question/ theme | Research approach | Participants | Findings/outcomes | Appraisal of study and quality score |
|--|--|---|---|--|--|
| Welch <i>et al.</i> (2005) ⁵⁰ US | To compare the end of life care received by African-American and white decedents and their families | Cross-sectional retrospective telephone survey with surrogates for decedents over 22 states (adult, non-traumatic deaths) | 1 578 interviews (65% response) including 111 African-American decedents | No statistically difference between African-Americans and white decedents in rates of receiving hospice care during the last month of life | 27 Reliant on proxy reports of care. African Americans were underrepresented in the study |
| Ahlner-Elmqvist <i>et al.</i> (2004) ²⁷ Sweden | To compare patients receiving either hospital based advanced home care or conventional hospital care | Prospective non-randomised study, with patients allocated according to their preferences over a 2 ½ year period | 722 patients referred, of which 297 enrolled in study. 119 AHC group and 178 CC group | Two groups comparable in terms of socio-demographic characteristics. More CC patients had a higher Karnofsky performance index. Median time from diagnosis to inclusion greater for AHC group, with shorter survival after enrolment | 26 Self selection of participants to arms of care may have affected differences, but in a way which would be mirrored in non-study choices |
| Currow <i>et al.</i> (2004) ⁸⁹ Australia | To investigate a whole population method for determining palliative care need | Questions on palliative care use included in annual random face to face cross sectional survey of 4 400 people in South Australia | 3027 interviews conducted (70% response) | 47% indicated that SPCS was involved in care of someone close to them who had died. No difference in access by country of birth, educational level or residential. Higher income indicated higher use | 25 No definitions of what was meant by palliative care service. High numbers of people did not know whether palliative care service had been used |
| Gagnon <i>et al.</i> (2004) ²² Canada | To define the extent to which women dying of breast cancer had access to palliative care | Retrospective analysis of routine data sources for the years 1992 – 1998. Range of data sources used to | 2 291 women were identified as dying from breast cancer | Younger women (<50) less likely to receive care than middle aged women, older women (+70) more likely | 26 The predefined indicators may not indicate palliative care. The context of care could not be |

| Author, Date, Country | Research question/ theme | Research approach | Participants | Findings/outcomes | Appraisal of study and quality score |
|---|---|--|---|---|--|
| | | determine access to palliative care, not just home care services | | | specified |
| Lackan <i>et al.</i> (2004) ⁴³ US | To examine whether variability in hospice use determined by patient characteristics has changed over time | Retrospective cohort design using routine data from linked Surveillance, Epidemiology and End Results – Medicare database to study hospice use | 170 136 people identified who were 67+, diagnosed between 1991-96, and who died between 1991 – 1999, with breast, colorectal, lung or prostate cancer | Hospice use varied significantly by patient characteristics. Hospice use more likely if enrolled in managed care, younger, married, female, non-Hispanic white, living in urban areas, diagnosed with lung or colorectal cancer, and living in areas with higher income and education levels. Variation appeared to be decreasing over time | 27 Useful large study, which indicates that variability in use may be decreasing with the expansion of services over time |
| Lackan <i>et al.</i> (2004) ⁵² US | To investigate rates of hospice use between Hispanic and non-Hispanic white Medicare beneficiaries | Retrospective cohort study using routine data from the linked SEER – Medicare database | 34 336 subjects, 67+, with breast, colorectal, lung or prostate cancer, diagnosed 1991-96, died 1991 – 1998 | Hispanic and non-Hispanic Whites use hospice services at similar rates. A difference (in favour of whites) was found in unadjusted model, but disappeared in adjusted model | 26 SEER areas are different in some ways to other areas of US study only looked at older adults |
| Chen <i>et al.</i> (2003) ¹⁶ US | To identify factors that may influence hospice decision | Cross sectional structured interview with patients within one community based hospice, and | 234 patients with lung, breast, prostate or colon cancer (173 hospice, 61 non hospice) | Patients receiving hospice care were older, less educated, had more people in the household, more co- | 26 Only looking at specific cancers |

| Author, Date, Country | Research question/ theme | Research approach | Participants | Findings/outcomes | Appraisal of study and quality score |
|--|---|---|--|---|--|
| | | three teaching hospitals | | morbid conditions and worse activities of daily living scores. | |
| Colón and Lyke (2003) ⁹⁰ US | To compare the rate of use of hospice services of European American, African American and Latino hospice patients | Retrospective analysis of routine data from a community based hospice on all patients 1995 – 2001. Comparison with census data. | 1958 patients | African Americans used services and Latinos used services at a lower rate than expected compared to prevalence of groups in general population. Rate of use by European Americans increased over time, but use by African Americans decreasing over time. African Americans more likely to be single, to live alone and less likely to have a spouse. | 26 No appraisal of why such differences may exist. Possibly only relevant to context of New Jersey. |
| Costantini <i>et al.</i> (2003) ¹⁷ Italy | To determine the effect of a palliative home care team on hospital utilisation in the 6 months before death | Quasi-experimental design using retrospective data from existing records for PHCT users and matched cancer controls | 189 PHCT patients matched to 378 controls in one area of Italy in 1991 | No difference in age, gender, most demographic variables. More likely to be referred to PHCT if lower educational level, diagnosis to death time longer | 29 PHCT functions not well described. Reports data a decade old. No power calculation |
| Greiner <i>et al.</i> (2003) ⁴⁸ US | To examine racial/ethnic variations in rates of hospice use in a national cohort | Secondary analysis of the 1993 national mortality followback survey. (telephone survey with proxy respondents) | 11 291 individuals who died in 1993 | Being married, having a higher income, having some college education, being younger, having high levels of social support, associated | 27 Use of proxy respondents may have affected accuracy. Very large sample |

| Author, Date, Country | Research question/ theme | Research approach | Participants | Findings/outcomes | Appraisal of study and quality score |
|---|--|--|---|--|---|
| | | | | with hospice use. Being female, not owning a home and being African American negatively associated with hospice use | |
| Lackan <i>et al.</i> (2003) ⁹¹ US | To assess the use of hospice by women dying with breast cancer as a function of time period, geographic area and patient characteristics | Retrospective analysis of routine data from the linked Surveillance, Epidemiology and End Results – Medicare database to study hospice use | 25 161 women met the criteria: women 65+, diagnosed 1986-96, died 1991-1996 | 20.7% enrolled in hospice before they died. Use of hospice care inversely related to age and higher amongst those who were married. No differences in use by ethnicity. Rates of use varied by geographic area | 25 No information known about hospice type or availability in this national study. |
| McCarthy <i>et al.</i> (2003) ⁹² US | To examine whether receiving Medicare managed care insurance or fee for service insurance affected hospice use | Retrospective analysis of routine data on Medicare beneficiaries diagnosed with a range of cancers and who died in 1998 | 260 090 deceased Medicare beneficiaries with cancer aged over 66 | More likely if a managed care patient | 26 No information known about hospice type or availability in this national study |
| McCarthy <i>et al.</i> (2003) ⁴⁵ US | To identify factors associated with hospice enrolment and length of stay in hospice in patients dying with lung or colorectal cancer | Retrospective analysis of routine data on Medicare beneficiaries diagnosed with lung or colorectal cancer and who died in 1998 | 62 117 lung cancer and 57 260 colorectal cancer patients aged over 66 | Later hospice enrolment for men, non-white, non-black race, having fee-for-service insurance, residing in a rural community | 26 No information known about hospice type or availability in this national study |
| Miller <i>et al.</i> (2003) ²⁵ | Whether timing of hospice referral is associated with | Retrospective study of routinely collected patient data from 21 | 28 747 service using patients who died between 1998 – 1999 | Less likely to receive continuous hospice care if have hospice | 30 Useful, large, comparison across |

| Author, Date, Country | Research question/ theme | Research approach | Participants | Findings/outcomes | Appraisal of study and quality score |
|--|--|--|--|--|--|
| US | continuous hospice home care | hospice programs (same provider organisation) | | stay of less than 7 days, if younger than 65, if African-American or if have a caregiver at home vs. living alone. More likely to receive continuous hospice care if married, in severe pain. | many different sites country wide. No data on need |
| Ngo-Metzger <i>et al.</i> (2003) ⁹³ US | To examine hospice use by Asian and white patients, and assess whether utilisation differs depending on place of birth | Retrospective study (SEER database) of those dying from lung, colorectal, prostate, breast, gastric or liver cancer between 1988 – 1998. | 184 081 patients | Foreign born Asian Americans more likely to reside in low-income areas. Those who were Asian Americans and born abroad less likely to use hospice care than white patients. Consistent across diagnostic groups. | 26 No definition of hospice, as countrywide. |
| Potter <i>et al.</i> (2003) ¹⁸ UK | To describe patients referred to different components of palliative care services (inpatient hospice, inpatient hospital, community team, outpatients) | Retrospective case note review of 400 consecutive referrals to three palliative care centres | 400 patients whose case notes were reviewed | No difference between groups for age, sex or diagnosis | 23 The accuracy and comparability of the note taking between the teams participating was not assessed |
| Tang (2003) ⁴⁶ US | To identify determinants of the use of hospice home care services for terminally ill cancer patients | Secondary analysis of data from terminally ill cancer patients participating in a prospective study identifying | 127 patients were interviewed, who subsequently died | More likely if longer length of survival, family perceived ability to achieve preferred place of death, home as realistic preferred | 26 No contextual description of services. Prospective design does not rely on recall or record |

| Author, Date, Country | Research question/ theme | Research approach | Participants | Findings/outcomes | Appraisal of study and quality score |
|--|---|--|---|--|--|
| | | determinants of place of death (recruited from 6 sites, convenience sample) | | place of death, female, lower levels of functional dependency, use of emergency care in final days of life | keeping accuracy |
| Burge <i>et al.</i> (2002) ⁹⁴ Canada | To determine the rate of referral to a local palliative care programme | Retrospective study using routine data of all those dying in Halifax of cancer between 1992-7 | 4376 patients who died from cancer | Less likely if older than 65 years | 23 No explanation of the palliative care programme referred to |
| Grande <i>et al.</i> (2002) ³³ UK | To investigate the variables associated with referral to hospital at home for palliative care | Retrospective analysis of cancer deaths 1994-1995 of patients referred to service compared random sample of cancer deaths from routine records | 121 deceased cancer HAH patients and 206 cancer registry patients | More likely to be referred to HAH if younger, less deprived, longer diagnosis time, died from cause other than cancer, to have had other specialist input | 29 One of the few studies to track general as well as specialist service use. Some of the numbers using particular services are small |
| Higginson and Wilkinson (2002) ²⁸ UK | To describe and evaluate the care provided by Marie Curie nurses | Retrospective analysis of routine data collected by Marie Curie and cancer death registrations in England | 26632 requests for a Marie Curie nurse made in 26 months | No difference in age, main diagnosis or gender when compared to cancer deaths recorded with ONS | 22 Data from UK for referrals compared to English registry data, no comment on comparability |
| Hunt <i>et al.</i> (2002) ⁴⁰ Australia | To examine the uptake of designated palliative care services | Retrospective review of cancer deaths in 1999 using routinely collected data | 3086 deceased cancer patients (2105 palliative care service users, 981 non users) | Less likely if 80 or older, country residents, with survival from diagnosis to death of < 3 months, those with prostate, breast or haematological malignancy. More | 24 No disaggregation of patients by type of palliative care service accessed |

| Author, Date, Country | Research question/ theme | Research approach | Participants | Findings/outcomes | Appraisal of study and quality score |
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| | | | | likely if from UK, Ireland or Southern Europe | |
| Virnig <i>et al.</i> (2002) ⁴⁷ US | To examine whether rates of hospice use differ according to patient characteristics | Retrospective analysis of routine data on cancer deaths in the District of Columbia for those over 65 in 1996 | Records relating to 169 759 hospice deaths and 388 511 cancer deaths | Less likely if black or male. More likely if younger than 80 | 23 No contextual discussion of what as meant by 'hospice' |
| Casarett (2001) ⁵¹ US | To determine whether differences exist between patients referred to hospice (inpatient and homecare) from academic or non academic centres | Retrospective cohort study | All 1691 patients admitted to the hospice between 1997 – 1999 who had then died or been discharged. 411 had been referred from an academic centre | More likely if younger, higher incomes. Less likely with Medicare or Medicaid | 26 No disaggregation of homecare of in-patient care data |
| Casarett and Abrahm (2001) ²¹ US | To compare patients enrolled in a bridge program with those enrolled in hospice | Retrospective study of all patients admitted to the programs between 1997 – 1999 from routinely collected data | 284 patients enrolled in the bridge program and 1 000 enrolled in hospice | Bridge patients less likely to have Medicaid/care, were younger, more likely to be married, and more likely to be in highest income category. No difference in the number of needs | 26 Program described does not appear to be replicated in the literature elsewhere so transferability unclear |
| O'Mara and Arenella (2001) ⁵⁴ US | To determine the hospice coverage of care by racial and ethnic group | Retrospective analysis of routinely collected patient data compared to state-wide mortality data | 2191 patients cared for during 1997 by one US hospice (home care and in-patient) | The hospice cared for 31% of Caucasians who died, 19% of Hispanics, 20% African Americans, 20% Asians in the area. For cancer, 52% Caucasians, 40% Hispanics, 40% | 24 No description of context of hospice studied or the area in which it is sited. Very small numbers of ethnic minority patients represented in the data reported |

| Author, Date, Country | Research question/ theme | Research approach | Participants | Findings/outcomes | Appraisal of study and quality score |
|---|---|---|--|--|---|
| | | | | African- Americans and 48% Asians | (85% Caucasian use) |
| Yang <i>et al.</i> (2001) ⁵⁹ Taiwan | To determine the impact of different hospice care patterns on outcomes of care for terminal cancer patients | Cross-sectional study design with purposive sample of patient and nurses from five medical centres in Taiwan. (2 inpatient and home care, 1 home hospice and consultation, 1 home hospice and 1 acute care only) | 123 patients: 26 patients receiving inpatient hospice, 26 consultations, 23 home hospice, 38 conventional acute care | Significant difference in age (home hospice younger than inpatient, older than acute care), education (less likely to have high school or higher), marital status (more likely to be married than acute care patients, less likely than team consultation) and primary care givers (less likely to be spouse than team consultation) across the groups | 20 No description given of purposive sampling or the biases in recruitment this could have introduced. Very poor presentation of demographic characteristics |
| Addington-Hall and Altmann (2000) ⁴¹ UK | How do patients who received care from community specialist palliative care nurses differ from those who do not | Data drawn from the Regional Study of Care for the Dying, interviews with randomly selected relatives of those who died in 1990 | 2062 relatives/friends of those who died from cancer | More likely if dependent, breast cancer, under 75 yrs. Less likely haematological malignancy, dependent for more than year | 27 Reliant on reports of others as to care received |
| Christakis and Iwashyna (2000) ²⁶ US | To identify individual and market factors associated with the timing of hospice use | Retrospective review of routinely collected Medicare, census and area data | 151 410 Medicare funded hospice enrollees admitted to all hospices in 1993 and followed up until 1999 | Earlier hospice enrolment for nonwhites, women, older people, those with substance abuse, psychiatric disease or dementia. No association with | 27 No disaggregation of data on in-patient and home hospice care. Analysis only on elderly Medicare patients, but is very large cohort and |

| Author, Date, Country | Research question/ theme | Research approach | Participants | Findings/outcomes | Appraisal of study and quality score |
|--|---|---|---|---|--|
| | | | | income or education | covers 80% of hospice population. No data on need |
| Karim <i>et al.</i> (2000) ⁵³ UK | To examine the use of palliative care service by members of black/ethnic minority communities | Retrospective analysis of referrals to one hospice in Birmingham, and interviews with doctors about referral practices | 1681 referrals to hospice in 1996/7. 27 doctors (12 GPs from 24 and 15 hospital consultants from 22) | 144 (8.5%) of referrals for patients of BEM origin, compared to 21.5% BEM population | 22 Most of the GPs who did not take part were of South Asian origin and this may have affected the results, explanation of sampling limited |
| Costantini <i>et al.</i> (1999) ²⁹ Italy | To develop a staging system for terminal cancer patients, validated against survival | Multicentre (58) prospective study of a random sample of admissions to palliative care units (Mostly home or mixed hosp/home units) | 601 patients of 3901 registered patients (22%) referred over 6 months in 1995 | No difference in age or cancer site between referrals to different units, but females less likely to be admitted to home palliative care unit | 27 Appropriate method, although extending recruitment period may have resulted in better data. No data on need |
| Fountain (1999) ⁵⁵ UK | To examine the use of all specialist palliative care services in Derby by people from ethnic minorities over one year | Retrospective comparison of ethnicity data on referred patients compared to census data | 1035 patients referred to specialist palliative care services | Only 1.5% of referrals were from ethnic minorities compared to 4.6% for the overall catchment area | 16 No real description of how the study was carried out, or of differences between type of specialist palliative care provider |
| Hunt and McCaul (1998) ³⁹ Australia | To determine changes in proportion, types and usage patterns of hospice users over time | Retrospective analysis of hospice and population cancer deaths using routinely collected data in 1990 and 1993 | 2800 patients in 1990 (1239 hospice, 1561 non hospice), 2873 in 1993 (1060 hospice, 1813 non hospice) | Less likely if elderly, rural resident, haematological malignancy. More likely if 40 – 60 yrs, longer survivor and born in UK or Europe | 24 No disaggregation of data from different hospice types |

| Author, Date, Country | Research question/ theme | Research approach | Participants | Findings/outcomes | Appraisal of study and quality score |
|---|--|--|---|--|---|
| Johnston <i>et al.</i> (1998) ⁶² Canada | To assess the degree to which Nova Scotia cancer patients who may need palliative care are being referred to a comprehensive palliative care programme | Retrospective, population based study using routine administrative data for all adults who died between 1988 – 1994 | 14 494 adults died in study period, 2057 were registered with the palliative care programme | More likely to be enrolled in PCP if resident in Halifax County, younger, having received palliative radiotherapy, had head and neck cancer. Less likely with haematological malignancy or lung cancer | 25 No determination of use of different aspects of the palliative care programme (i.e. home care). No assessment of need for care |
| Gray and Forster (1997) ⁹⁵ UK | To identify and compare those who received specialist palliative care and those who did not | Retrospective study of deceased cancer patients identified from death register, cross referenced with data from palliative care services records | 521 patients who died in 1991 (157 received specialist palliative care, 354 did not) | More likely if younger, survived longer, had particular GP practice | 24 No disaggregation of data from different specialist palliative care services – including home care as well as other services |
| Jones and Strahan (1997) ⁹⁶ US | To present a summary of data collected in the 1994 National Home and Hospice Care Survey | A probability survey of home and hospice care organisations provided information on their characteristics, current patients and discharges | 61 000 patients were receiving hospice care at the time of the survey | Described current patients without reference to non hospice patients or other comparators: 55% female, 81% white, 69% over 65, 48% married, and 64% live with family members | - Data summary only so no quality score. Comprehensive data source for raw data on hospice use, but no disaggregation by type of hospice |

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