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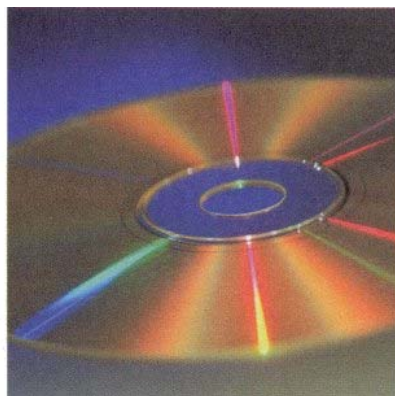
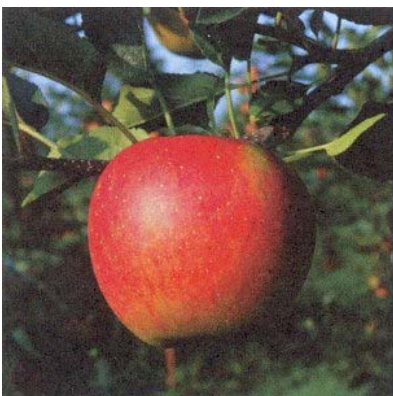
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Literature Review of the Evidence Base for a Hospice at Home Service



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August 2008

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Literature Review of the Evidence Base for a Hospice at Home Service

August 2008

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1. Executive Summary

In 2005 138,454 people in England and Wales died from cancer. Though the majority of patients would prefer to die at home, less than a quarter are able to do so. For many patients, their preferences and choices for place of death will not be realised. Giving patients more choice in their place of death has been the focus of the recent government document *End of Life Care Strategy*.

This literature review aimed to identify the evidence base for a hospice at home service at the end of life for facilitating death at home to narrow the gap between preference and reality. This study defines ‘hospice at home’ as hospice style care provided in the home environment; this means specialist palliative care, equipment and medication is available 24/7. However, services operating under this term are not uniform across the literature. Terms encountered in the literature that are used to describe ‘hospice at home services’ or elements of it include: palliative home care, out-of-hours palliative care, hospital at home, home care, community palliative care, specialist palliative care, rapid response teams, and crisis intervention.

Studies were found via electronic databases, through professional contacts and by checking reference lists. This review looks at who is more likely to die at home, different types of palliative home care, outcomes used to evaluate services and methodology for an evaluation.

Though most people would prefer to die at home, there are several inequalities in who is more likely to achieve this. Patients are more likely to die at home if they: receive palliative home care, have an informal caregiver, are younger, are male, have a stable disease trajectory or diagnosis, prefer to die at home, and have higher socioeconomic status. However, patients who have these characteristics are also more likely to be referred to hospice at home schemes, and therefore these correlations may have more to do with referral practices than actual patient differences.

Hospice at home schemes can be divided into two models based on the length of service input. ‘Hospice at home’ and ‘palliative home care’ provide regular care for long periods (e.g. two weeks or longer). ‘Rapid response’ teams only provide emergency or crisis care for short periods (48 hours or less), though the former model may also have emergency response capabilities. The rationale for discussing them separately is that rapid response usually runs in addition to palliative home care services and the principle of it is different to that of normal hospice at home services.

Studies on the effectiveness of ‘hospice at home’ and ‘palliative home care’ services are inconclusive. High quality RCTs and systematic reviews have often found these services to have no significant effect on increasing the number of patients dying at home or improving quality of life, though more descriptive evaluations often report more positive results. There have been some findings that suggest that these services are cost effective since users generally require fewer inpatient days and thus reduce NHS costs.

'Rapid response' teams have been less well studied, but report positive results. Two studies in the UK showed that rapid response teams were able to maintain most patients at home during a crisis and had above average death at home rates. Caregivers also reported that they felt less stressed following intervention of the service. Only one study evaluated cost effectiveness and it found the incremental costs of running the service to be higher than standard inpatient care. Both studies lacked controls and therefore these improved rates of home death cannot conclusively be attributed to the service, rather than other factors.

The mixed results of hospice at home services often reflect the difficulties of conducting trials in end-of-life care – difficulty of randomisation and recruitment, and high drop out rates due to death. Studies without controls often show positive results, whilst those with controls often have more modest or non-significant results, with increases in home deaths by only a few percent at most.

Studies of both models of hospice at home suggest that there may be various elements that make a hospice at home service successful. Firstly, professionals note the importance of the informal caregiver, as this person performs much of the day to day care and can report changes in symptoms and status to the professional. However, caregivers often experience high levels of stress which may then lead to the patient being admitted into hospital or hospice. Therefore providing support and caregiving relief during stressful times to the caregiver may help to maintain the patient at home.

Secondly, timing of services is important. Services should not begin too far in advance of death as this level of care can often not be sustained, nor will they likely be effective if death is imminent. Services should be available 24/7 and able to respond quickly to emergencies.

Third, home services should provide the same level of relief and comfort than one would expect from a hospital or hospice. This involves having specialists available 24/7 who can administer medication and provide a high level of care, if needed. Patients and caregivers need to be reassured that the care they receive at home is to the same standard as what would be received in an inpatient setting.

Pilgrims Hospices should therefore aim to provide a service that fills holes in local community care service provision. This would likely consist of a rapid response service that would run in addition to the community support service already offered. This service would need to be evaluated using control groups in order to form the strongest level of evidence. It should evaluate death at home rate, quality of life measures, and cost effectiveness.

2. Introduction

In 2005 138,454 people in England and Wales died from cancer (ONS, 2007). Though previous studies have shown that over 50% of cancer patients wish to die at home (Higginson and Sen-Gupta, 2000; Townsend *et al*, 1990), only 22.5% of deaths from cancer occurred at home (ONS, 2007). Given ideal circumstances, two thirds of terminally ill patients would wish to die at home (Townsend *et al*, 1990). For many patients, their preferences and choices for place of death will not be realised.

This literature review aimed to identify the evidence base for a hospice at home service at the end of life for facilitating death at home so that the gap between preference and reality can be narrowed. The review looks at different types of hospice at home, outcomes used to evaluate services and methodology for evaluating such a service. The last section makes recommendations based on the literature for a hospice at home service given the context of the Pilgrims Hospices.

This report on hospice at home services is divided into two sections: the first discusses the most common interpretation of hospice at home and the research that has been done around this definition. The second discusses a new rapid response concept for hospice at home, which has not been well studied.

3. Methodology

The electronic databases of CINAHL, British Nursing Index, DARE, EMBASE, Cochrane Review Database, Kings Fund, Medline, and PsycINFO were searched. The search was not limited by year or language. The search terms included combinations of: hospice, terminal care, palliative care, terminally ill, hospice at home, home care, home health care, palliative therapy, community care, home nursing, and home care services. Articles were also found by checking reference lists and through professional contacts. A second search for rapid response services was carried out after reading through key articles and discussion with the Pilgrims Hospice. The second search was done in Cochrane, British Nursing Index, CINAHL, Embase and Medline using the above terms with the addition of either rapid response or crisis intervention. For a full search strategy, see Appendix 14.1 and 14.2.

4. Search Results

The first search for ‘hospice at home’ returned 223 articles and the second for ‘rapid response’ services returned only seven articles (see Appendix 14.3 for the full list of articles). The literature defines ‘hospice at home’ broadly which was reflected in the wide range of articles that were found.

Abstracts were reviewed and studies were categorised according to their main theme. Where abstracts were not available titles were used. Of the abstracts and/or titles that included information about their methodology, 9 were systematic reviews, 13 randomised controlled trials, 2 controlled studies, 1 correlational study, 14 comparative studies, and 51 qualitative studies. The remainder of the titles and/or abstracts did not include sufficient information about their design to categorise them, but generally seemed to be of a qualitative or comparative nature. Papers were selected for further scrutiny if they evaluated a hospice at home service or an aspect of hospice at home, such as professional support for caregivers of terminally ill patients at home.

5. Quality of the Literature

Eight systematic reviews were reviewed first as these are considered the highest level of evidence (Greenhalgh, 1997). A general conclusion from the systematic reviews was that studies on hospice at home services in the UK are not comparable to studies based on services from North America and the rest of Europe, largely because of fundamental differences in the health care systems (Hearn and Higginson, 1998; Smeenk *et al*, 1998; Salisbury *et al*, 1999; Wilkinson *et al*, 1999). Results of systematic reviews tended to discuss studies from the UK separately from the rest of the body of literature (Salisbury *et al*, 1999; Wilkinson *et al*, 1999). Also, the systematic reviews revealed that factors important to achieving home death vary by country (Gomes and Higginson, 2006). Therefore it was decided that only studies evaluating services from the UK would be included in the review as these are the most appropriate models on which to base a hospice at home service for the UK. Systematic reviews were included where results from the UK were discussed separately. This resulted in 28 studies (30 articles) being included in the review.

Using a hierarchy of evidence, studies are graded by their design methodology, with those near the top (systematic reviews and randomised controlled trials) forming a stronger evidence base for the effectiveness of an intervention than those nearer the bottom (descriptive studies and expert advice) (Greenhalgh, 1997). Few studies found in this review ranked high methodologically. Many had problems with recruitment, both to the trial and for baseline comparisons, which led to lack of power (Grady and Travers, 2003; Grande *et al*, 1999 and 2000). Studies also cited the ethical and practical complications of randomisation (Grande *et al*, 1999; Hearn and Higginson, 1998; King *et al*, 2000). Studies varied in what outcomes were measured, but the most common ones were death at home (Grande *et al*, 1999 and 2000; Hearn and Higginson 1998; Higginson *et al* 2003; King *et al*, 2000) and quality of life of the patient – usually in relation to symptom control – or satisfaction (Higginson *et al*, 2003; Salisbury *et al*, 1999; Smeenk *et al*, 1998; Wilkinson *et al*, 1999).

6. Defining ‘Hospice at Home’

This study defines ‘hospice at home’ as hospice style care provided in the home environment; this means specialist palliative care, equipment and medication is available 24/7. However, services operating under this term are not uniform across the literature. Some

services do not provide care 24/7, or others do but only care assistants are available out-of-hours. Some respond rapidly to emergencies, but do not provide day to day care. Most of these services do not operate in isolation, i.e. a hospice at home service provides rapid response, but Marie Curie nurses provide day to day care, and therefore teasing out the effect of one service alone is complicated. Terms encountered in the literature that are used to describe 'hospice at home' services or elements of it include: palliative home care, out-of-hours palliative care, hospital at home, home care, community palliative care, specialist palliative care, rapid response teams, and crisis intervention.

To add to the confusion, there appears to be an evolution in the definition of 'hospice at home'. Older studies (before 2000) defined hospice at home in terms of more general community care, sometimes with specialist palliative care teams, and with the focus more on regular home visits. More recent studies define it in terms of the input of specialist palliative care teams that may only operate in response to crises or emergencies. This is complicated further as most studies do not describe their service with sufficient detail, which makes comparing the effectiveness of services difficult.

Because 'hospice at home' is not well defined, most systematic reviews found in this search (Gomes and Higginson, 2006; Harding and Higginson, 2003; Higginson *et al*, 2003; Smeenk *et al*, 1998) have included all types of services described above. They have also overlooked one potentially crucial element – 24/7 nursing. Some studies included in systematic reviews have provided 24/7 care, others have not. Other systematic reviews found in this search did not specify if services provided 24 hour care. Studies of services that provide 24/7 care have often found that most calls for care occur out-of-hours (Grady and Travers, 2003; King *et al*, 2000). It may be reasoned that these services may have a greater effect and benefit to patients than those that do not, and perhaps their provision is not comparable to those that are only available during normal hours.

Though the purpose of this review was to assess the evidence base for 'hospice at home' services, not many have been evaluated nor have they been reviewed separately from other types of palliative home care. Therefore this review covers all three types of palliative care available at home. For the purposes of this review, 'hospice at home' refers to palliative care available 24/7 at home, 'palliative home care' refers to services not available 24/7, and 'rapid response' refers to services available 24/7, but only on an on-call basis.

This review divides services into two types based on the length of service input. Hospice at home and palliative home care provide regular care for long periods (e.g. two weeks or longer). Rapid response only provides emergency or crisis care for short periods (48 hours or less), though the former model may also have emergency response capabilities. The rationale for discussing them separately is that rapid response usually runs in addition to palliative home care services and the principle of it is different to that of normal hospice at home services. Hospice at home and palliative home care are well studied, though generally not more effective than conventional community care. Rapid response is not well studied, but is theoretically sound in that preventing emergency admissions to hospital or hospice should help maintain people at home so they may eventually die there. Services will be discussed in relation to: family factors and impact, service implications, and costs.

7. ‘Hospice at Home’ and ‘Palliative Home Care’

Hospice at home and palliative home care services generally aim to improve quality of life, facilitate death at home or increase time spent at home during the end stages of terminal illness. Studies generally compare the effect of hospice at home services to conventional care (Armes and Addington-Hall, 2003; Hearn and Higginson, 1998; Higginson *et al*, 2003; Salisbury *et al*, 1999). Conventional care is defined as care in hospital, hospice or standard community care services. High quality systematic reviews and RCTs have mostly yielded ‘no effect’ results between hospice at home and conventional services.

Few articles were found that evaluated hospice at home and palliative home care service impact on increasing death at home (Grande *et al*, 2000; Hearn and Higginson, 1998; Higginson *et al*, 2003). The results of these studies are described in Table 1 below. Only one systematic review (Hearn and Higginson, 1998) found that specialist palliative care teams increased the likelihood of dying at home compared to conventional community care services.

Table 1. Studies that include analysis of death at home rate

| Author | Study type | Type of service | Control/ Comparison group | Increase death at home? | Decrease time in institutional setting? |
|--|-------------------|-----------------------------------|---------------------------------|-------------------------------|---|
| Grande <i>et al</i> , 2000*; Grande <i>et al</i> 1999* | RCT | CHAH, 2 weeks, 24hr nursing care | Standard care | No | No |
| Hearn and Higginson, 1998 | Systematic review | Specialist palliative care teams | Conventional services | Yes | Yes |
| Higginson <i>et al</i> , 2003 | Systematic review | Palliative and hospice care teams | Conventional care | No | (not evaluated) |

* Included in Higginson *et al* 2003 systematic review

7.1 Family Factors

This section discusses factors within the home that support or inhibit death at home, and the impact on the family structure. Factors relating to informal caregivers are discussed separately to those relating to the patient.

Patient profile

A number of studies have looked at the profile of patients who die at home (Exley *et al*, 2005; Gomes and Higginson, 2006; Grande *et al*, 1998; Grande *et al*, 2002; Grande *et al*, 2003; Higginson *et al*, 1999). Seven variables appear to impact on the likelihood of death at

home: use of home services, age, gender, disease diagnosis, socio-economic status, informal care giving and preference for home death. However, differences in these variables also appear in referral rates to home services, which can thus impact on place of death. Therefore these factors may indicate a bias in referral practices rather than who is actually more likely to die at home.

Patients are more likely to die at home if they are in receipt of hospice at home services (Gomes and Higginson, 2006; Grande *et al.*, 1998). However, evidence from other countries suggests that if these services are provided by an inpatient facility, then that may increase their chances of an inpatient death (Grande *et al.*, 1998). This may be because the barriers to inpatient care are reduced in these situations which then gives the patient more options for care should they change their preference for place of death during the course of their illness. It may also be that services provided by hospitals or hospices prefer to treat more complex cases in an inpatient facility rather than at home. Another study (Grande *et al.*, 2003) found that patients who died at home started receiving home care closer to the time of death (71 days compared to 142 days), which may indicate that adequate home care cannot be sustained for long periods of time.

Older people are less likely to die at home than their younger counterparts (Higginson *et al.*, 1999, Karlsen and Addington-Hall, 1998). This may be due to the fact that older people are less likely to be referred to hospice at home services (Grande *et al.*, 1998; Grande *et al.*, 2002), possibly indicating age discrimination in referral practices. Once referred to the service, older people are no less likely to die there than younger patients (Grande *et al.*, 1998).

Men are more likely to die at home than women (Grande *et al.*, 1998; Higginson *et al.*, 1999; Karlsen and Addington-Hall, 1998). One study found a gender disparity in both carers and patients – men who were cared for by women (wife or daughter) were more likely to die at home than women being cared for by men (Grande *et al.*, 1998). One potential explanation for this gender gap may be that there is greater expectation that women are more used to playing a care giving role than men and therefore assume the role with greater ease. It may also be that many women outlive their husbands and therefore are often alone and frail in their final years, making it more difficult for them to die at home without an informal support system.

Patients who die at home are more likely to have had a longer and more stable disease course (Exley *et al.*, 2005; Gomes and Higginson, 2006; Grande *et al.*, 2002; Grande *et al.*, 2003). Having a longer and more predictable disease trajectory allows patients to make appropriate arrangements for end-of-life care. Patients who have been in and out of hospital over the course of their illness are also more likely to die in hospital (Grande *et al.*, 1998). Patients who die at home are more likely to have had cancer as a single cause of death (Grande *et al.*, 2002; Grande *et al.*, 2003). Patients dying from cardio-respiratory disease were more likely to be confused about their diagnosis and to be less aware that they were dying (Exley *et al.*, 2005). There may also be confounding factors as to who is more likely to be referred to hospice at home; one study found that patients who died shortly after referral (8 days) were less likely to be admitted to the hospice at home service than those that lived longer (16 days) (Grande *et al.*, 1999 and 2000). This suggests professionals, and perhaps families, are reluctant to provide care at home if death is imminent.

Patients from lower socio-economic groups or from deprived areas are less likely to die at home (Grande *et al*, 1998; Higginson *et al*, 1999; Karlsen and Addington-Hall, 1998). Patients are more likely to be referred to hospice at home services if they are from less deprived areas (Grande *et al*, 1998). Grande *et al* (1998) found that professionals were more likely to refer patients to hospice at home services if they perceived there to be more resources in the home. Poorer patients may be less able to buy in the services they need and may also put a higher demand on primary care services which means fewer patients can be cared for at home due to rationing of services (Higginson *et al*, 1999).

Not surprisingly, patients with an informal caregiver are more likely to die at home (Gomes and Higginson, 2006; Grande *et al*, 1998). This may be explained in part because patients with a caregiver are more likely to be referred to hospice at home services (Grande *et al*, 1998). Informal caregivers are an invaluable resource and professionals often rely on them to provide many aspects of care and supply them with information about the patient's condition (Armes and Addington-Hall, 2003).

A preference for home death by both the patient and caregiver is a significant factor for achieving death at home (Gomes and Higginson, 2006; Karlsen and Addington-Hall, 1998). Home is generally the preferred place of death (Higginson and Sen-Gupta, 2000; Townsend *et al*, 1990), but this may fluctuate over the course of the illness (Wilkinson *et al*, 1999). Expressing a preference for place of death may help motivate professionals and caregivers to provide better support because the patient's wishes have been clearly communicated.

The patient's quality of life is affected by symptom distress (McMillan and Small, 2002; Portenoy *et al*, 1994; Salisbury *et al*, 1999). In one study (McMillan and Small, 2002) the most frequently reported symptoms were: lack of energy, pain, dry mouth, and shortness of breath. Lack of energy caused the greatest distress, followed by dry mouth and pain. Two systematic reviews (Salisbury *et al*, 1999; Smeenk *et al*, 1998) concluded that there is no difference in quality of life between those cared for at home or at inpatient facilities. Another study (Wilkinson *et al*, 1999) found that satisfaction with palliative care also did not differ between inpatient units, hospitals or in the community. It did find that complaints over care are more wide ranging in the hospital setting, whereas problems with community care stem from problems with access to services, equipment and out of hours care (Wilkinson *et al*, 1999).

The role of informal caregivers

Informal caregivers are often integral to successful hospice at home services. Studies have shown that patients are more likely to die at home if they have an informal caregiver and that home care support cannot replace the essential role of the caregiver (Gomes and Higginson, 2006; Grande *et al*, 1998). Patients with informal caregivers are more likely to be referred to hospice at home services, and as we saw in the previous section receipt of services increases chances of dying at home (Grande *et al*, 1998). Younger caregivers are more likely to access home care services (Grande *et al*, 2006). Proot *et al* (2003) argues that success as a caregiver depends on vulnerability, which is characterised by: carer burden, restricted activities, fear, insecurity, loneliness, facing death, lack of emotional support, and lack of practical and information-related support. Things that decrease vulnerability include: continuing previous activities, having hope, keeping control, satisfaction and the availability of good support.

Professionals who were interviewed in one study (Armes and Addington-Hall, 2003) believed that patients who lived alone without a caregiver were at a disadvantage. This may be because professionals often rely on caregivers to provide them with accurate information about the patient's condition (Armes and Addington-Hall, 2003). However, the perception and interpretation of symptoms may be dependent on the personality type of the caregiver and patient (Armes and Addington-Hall, 2003), which may compromise their ability to give an objective assessment of symptoms to professionals. Relatives of the patient often perceive suffering to be higher than what is perceived by GPs and nurses (Millar *et al*, 1998). GPs tend to underestimate pain and overestimate emotional suffering (Clark *et al*, 2000). This poses a potential problem as often it is the perception of the caregiver that impacts on admission to institutional care. Barriers to adequate pain management often lie with the professional rather than with the patient and family.

Carer burden is associated with symptom distress in the patient and more care involvement on the part of the caregiver. One study (Hinton, 1996) found that 41% of patients whose caregivers were stressed or tired by caring were admitted to hospital in the following week, despite receiving palliative home care support. During the eight years of this particular service provision, there was only a 7% increase in home deaths. Hinton concludes that it is likely the high quality of inpatient care available in the area has increased the number of patients preferring an inpatient death.

Even though professionals often rely on carers for information, carers do not always know what needs to be reported to professionals (Armes and Addington-Hall, 2003). Studies have shown that caregivers would like to have more information about the condition and prognosis of the patient (Harding *et al*, 2002; Harding and Higginson, 2003). Caregivers in one study (Harding *et al*, 2002) reported that they enjoyed attending a support group with other caregivers where they could learn and share experiences. However, they reported that they still wanted more information on the patient's trajectory and what deterioration to expect.

There is little evidence around the effectiveness of interventions targeted at supporting caregivers (Harding and Higginson, 2003). One systematic review (Harding and Higginson, 2003) found that most interventions have not been sufficiently evaluated, and that they add more to the knowledge about acceptability and feasibility of interventions than effectiveness. Harding *et al* (2002) found that caregivers who attended a short-term intervention group aimed at providing information felt less isolated at the end of it. The caregiver group only had 25% uptake, which parallels the national average of 22.5% of patients who die at home (ONS, 2007). Place of death was not evaluated in this study, so it is not possible to determine if supporting these caregivers improved chances of dying at home.

7.2 Service implications

Aspects of service provision discussed in the literature can be broken down into: professional input (specialists, GPs and nurses), location and medication.

Specialist services

Several studies have shown that specialist palliative care teams have little or no impact on facilitating death at home compared to conventional services (Grande *et al*, 1999 and 2000; Higginson *et al*, 2003; Hinton, 1996). The study by Hinton (1996) of a hospice based home

care team that supplemented a community care team found that after eight years of service provision, there was only a 7% increase in home deaths, though this was found to be significant. Year on year comparisons of this service were not statistically significant.

One systematic review (Hearn and Higginson, 1998) found that specialist palliative care teams increased the amount of time spent at home and increased the chances of the patient dying in their preferred place. The study does not differentiate between places of care, only the effect that care teams have.

A number of studies have suggested that the failure of hospice at home services to produce significant results may be due to the availability of high quality inpatient facilities or community care in areas where hospice at home services are operating (Grande *et al*, 1999 and 2000; Hinton, 1996). Grande *et al* (1999 and 2000) found in their study that 58% of controls died at home compared to 67% in the intervention group; the 9% difference was not statistically significant. It is notable that even the control group achieved a home death rate more than double the national average of 22.5% (ONS, 2007). They concluded that new hospice at home services may not be needed in an area with sufficient community care already operating, in this case Marie Curie nursing services.

However, the above conclusion may also have to do with timing in receiving services. The same study (Grande *et al*, 1999 and 2000) also suggested that taking up home services so close to the time of death (less than two weeks) may not improve chances of dying at home because factors may already be in place that may predetermine place of death. The high rate of home death in both arms (58% control, 67% intervention) suggests that patients who have managed to stay at home on their own or with receipt of standard services (Marie Curie nursing, or other usually available resources) until the last two weeks of life will likely be able to remain there until death regardless of any additional services being offered. Therefore it could be argued that many barriers to dying at home would have been faced prior to two weeks before death and thus death at home may be predetermined by this stage.

However, another study found that patients who started services closer to the time of death were more likely to die at home (71 days: home death group; 142 days: inpatient death group) (Grande *et al*, 2003). The authors concluded that it may not be possible to sustain some services for long periods in the community. It may also be that caregivers find it difficult to maintain patients at home for long periods of time and therefore patients are admitted when caregivers can no longer cope. The difference in time between these two studies is considerable and therefore the optimal time for receipt of services is likely to be longer than two weeks, but less than three months.

One systematic review found that palliative home care did not reduce inpatient admissions compared to standard care (Smeenk *et al*, 1998), though the authors state that more research is needed. In addition, this review only included one service that provided 24 hour care. As suggested in the previous section frequent inpatient admission throughout the illness increases chances of inpatient death. Therefore avoiding admissions should improve chances of a home death.

There is conflicting evidence over the effect of specialist palliative care teams and their impact on patient and carer satisfaction. One systematic review (Hearn and Higginson, 1998) found that compared to conventional care, specialist palliative care teams increase patient

and caregiver satisfaction. Another systematic review (Wilkinson *et al* 1999) found that satisfaction with palliative care did not vary between inpatient units, hospitals or the community.

One study (Munday *et al*, 2002) found that special palliative care units were reluctant to publicise a 24 hour nursing service to GPs for fear that GPs would inappropriately refer too many patients. This was in contrast to what GPs actually did and reported- many did not think there was a need for the service because they did not have many patients to refer.

GPs and nurses

The role of GPs and non-specialist nurses has not been widely evaluated with respect to palliative home care. Ewing *et al* (2006) found that GPs and district nurses assess emotional symptoms (depression and anxiety) as higher than would a patient. GPs tended to overestimate the severity of nausea, vomiting, fatigue and breathlessness, though the authors noted that this finding was in contrast to some other studies.

With respect to reducing workload, one study (Todd *et al*, 2002) found that 77% of GPs in a 24-hour home nursing scheme believed that the hospice at home programme made no difference to their workload or increased it, whereas 65% of nurses thought it reduced it. The GPs and nurses in this study expressed reservations about hospice at home programmes. It was unclear if studies in this review provided 24 hour access to care.

Medication

Medication compliance may be an issue with patients receiving care at home (Armes and Addington-Hall, 2003; Zepetella, 1999). One study (Zeppetella, 1999) found that 60% of palliative home care patients were noncompliant with medication; 33% took less medication than they were prescribed and 16% took additional medication (usually over the counter). Ninety per cent of patients had two or more prescribers. Patients who viewed their GP to be their primary prescriber were more compliant than those who saw the hospital as their main prescriber. Medications that were prescribed four times a day were the most likely to be omitted or reduced.

Medication compliance is important for maintaining people at home as it is a common form of pain and symptom management at home. One study (Armes and Addington-Hall, 2003) found that patients were admitted to inpatient care when: there was confusion with taking medications, they did not take it properly, or when they refused to take medication. Hinton (1996) reported that medication was viewed as a helpful type of care by patients and relatives.

Higginson and Wilkinson (2002) found that patients who received their medication via a syringe driver were four times as likely to die at home as those who received medication by any other method. The authors did not have a reason for this and did not suggest that the relationship was causal, but did recommend that syringe drivers be widely available for patients cared for at home.

7.3 Costs

Cost analyses generally compare the cost of providing a home care service for one patient compared to if they were admitted to inpatient facilities, such as a hospital or hospice.

A systematic review by Hearn and Higginson (1998) found that specialist palliative care teams can reduce the number of inpatient days and increase the amount of time spent at home at equal or lower costs to conventional services.

A randomised controlled trial (Jones *et al*, 1999) showed that a hospital at home scheme delivered care at similar or lower costs to acute inpatient care. However, this study included all types of hospital care and not just end-of-life care.

Another RCT (Raftery *et al*, 1996) found that a coordinating service for terminally ill patients was more cost effective than standard services alone. The service operated to coordinate the appropriate services for patients, but not to provide services itself. Though outcomes were no different between the groups, the coordinating group had considerably less inpatient days and fewer nursing home visits.

These cost analyses from the UK generally do not include every cost incurred, especially by those being cared for at home. The analyses do not always consider the additional financial costs incurred by the patient and/or caregiver when they are cared for at home (e.g. heating, laundry). This is an important factor as home care services often show a savings due to fewer inpatient days (Hearn and Higginson, 1998; Raftery *et al*, 1996), but these ‘overhead costs’, which account for the higher cost of hospitals and hospices, may have only been transferred into the home and are thus absorbed by the family.

7.4 Conclusions on ‘Hospice at Home’ and ‘Palliative Home Care’

Achieving death at home or increasing the amount of time spent at home is not always the primary outcome of studies on hospice at home and palliative home care services, though that is usually the purpose of the service. Many studies evaluate other outcomes of the service, such as quality of life, pain management or satisfaction. Regardless of the outcome being evaluated, palliative home care and hospice at home services have mixed results. Randomised controlled trials, though the highest form of evidence, often fail to find significant differences between hospice at home and conventional care. Randomisation is ethically complicated in allocating receipt of these services because it is impossible to blind participants or providers. Many have failed to reach statistical significance because of issues with recruitment and attrition, and therefore non-significant results may have more to do with the difficulties of conducting research in such a sensitive area than with the provision of the service itself.

Alternatively, if methodology is not a hindrance, it may be that whilst these services aim to provide specialist palliative care in the community, they are not always able to deal with the direst of circumstances at the moment they occur. However this is difficult to say given that most studies did not contain a full description of their service provision. Services did not

always appear to give sufficient attention and care to informal caregivers. Viewing caregivers more as members of the care team who should be kept informed, rather than as bystanders may help to maintain patients in their own homes. However there is a danger in overlooking the needs of the caregiver as a client. Providing the type of care and support that is received in hospital and/or hospice is what patients who fail to die at home and their caregivers require and therefore this provision should be the aim of hospice at home services.

8. 'Rapid Response' Teams for Crises

As discussed in the previous section, reasons why palliative care services have failed to increase death at home are varied. One of the reasons suggested here is that whilst these services are able to meet almost all of the needs of the patients, they are not able to meet a specific need which then results in admission to hospital or hospice. Patients are often admitted to hospital because of a crisis or challenge that could not be dealt with at home (Mantz and Crandall, 2000). The crisis is often with uncontrolled symptoms, carer fear or stress, not having medication available, or not having enough information about the patient's prognosis or disease trajectory (Mantz and Crandall, 2000). Theoretically, if the crisis can be dealt with at home then the patient should be able to remain there. Studies that have looked at the type of service that deals with specific events for short periods are called rapid response or crisis intervention services.

Rapid response services operate in addition to traditional community care. They provide intense care for a few days at a time and operate on a 24/7 on-call basis. These services do not necessarily focus on facilitating death at home, though it often follows or occurs during the episode of care. Rather, these services aim to resolve the crisis so that the patient can be discharged back to the community care team and remain at home. They operate at a time when the patient and/or caregiver is most vulnerable and when no other service is available or able to handle the situation. These services differ from hospice at home and palliative home care because they are focussed on resolving an acute problem and their input is for short periods.

Two studies have looked at rapid response crisis interventions (Table 2) (Grady and Travers, 2003; King *et al*, 2000; Travers and Grady, 2002). Both studies from the UK were descriptive evaluations, lacked control or comparison groups, and had small sample sizes (17 patients and 62 patients). They aimed to combine qualitative and quantitative measures. The attempt to collect quantitative baseline measures in the Grady and Travers (2003) study was thwarted by a high death rate. Both studies reported the number of patients who died during the study (41% and 29%). In both studies, less than 20% of patients needed to be admitted to institutional care.

A third study was found on a rapid response outreach service that operated mainly to transfer patients from inpatient facilities to home (Plummer and Hearnshaw, 2006). Only 9% of the activity of this service was to prevent admission to hospital or hospice, which is the focal point of the other two services. As the service does not serve the same purpose as the other two rapid response services and because it does not involve responding to patients already living at home, it will not be further discussed here.

Table 2. Studies evaluating rapid response services for crises.

| Author | Type of study | Type of service | Participants | Died at home during service (%) | Inpatient Admission (%) | Remained at home (%) | Died at home, later date (%) | Total died at home (%) |
|--------------------------|------------------------|--|--------------|---------------------------------|-------------------------|----------------------|------------------------------|------------------------|
| Grady and Travers, 2003 | Descriptive Evaluation | 5 days input, 24/7 nursing on-call, urban location | 62 | 18(29) | 7(11) | 37(60) | 8 (22.5)* | 26 (42)* |
| King <i>et al</i> , 2000 | Descriptive Evaluation | 48 hours input, 24/7 nursing on-call, rural location | 17 | 7 (41) | 3 (18) | 7 (41) | 7 (41) | 14 (82) |

* Not evaluated in study; assumes national average of 22.5% death at home rate for those who remained at home at the end of the service provision. Average death at home rate for Scotland was unavailable, therefore the average for England and Wales (22.5%) was used.

In the Grady and Travers study (2003) 18 of 62 patients died at home, which is a rate of 29%. Seven (11%) were admitted to hospital and 37 (60%) were discharged back to the community care team. The study did not follow patients beyond the episode of care and therefore did not record place of death for those that survived the intervention period. If we assume that of those 37 patients who were discharged to the community team and remained at home, 22.5% (the national average) or 8 patients died there, then that would bring the total number of patients who died at home who had received the service at some point to 26, or 42%. King *et al* (2000) found that 82% of patients died at home. However, because there are no controls in either study we do not know if patients referred to the service differ to those that were not.

8.1 Family factors

Patient profile

In the Grady and Travers (2003) study, patients reported that their pain and nausea improved following the intervention, though because of the small sample size were not able to test for statistical significance. The number of patients who rated their pain as severe on the Palliative care Outcome Scale (POS) fell from ten to three on the second assessment after the intervention. Of all patients 70% reported an improvement in their problem.

The role of the caregiver

Patients were most often referred to the service because of carer stress (65%) (King *et al*, 2000). Patients were also referred because of a sudden deterioration in their state (29%) or because of communication issues between the family and professionals. Following use of the service, caregivers felt relieved and less stressed, and had less fear of a future crisis (King *et al*, 2000). In the Grady and Travers (2003) study, all caregivers and patients were positive about their experience with the service, but as only 32 caregivers participated in the interviews, it could be that only those who had a positive experience with the service wished to speak about it. Also, all of the patients in the King *et al* (2000) study and most if not all in

the Grady and Travers study (2003) had a caregiver, which alone is likely to increase the number of people dying at home.

8.2 Service implications

Rapid response services are available 24/7, but often operate mainly during out-of-hours periods (King *et al*, 2000). A study by Worth *et al* (2006) of patient, carers and professionals views showed that patients are often reluctant to call for help during out-of-hours for fear of being seen as a bother. A rapid response service would be of benefit to clients because they would be aware that the service is dedicated to providing care to them at all times, especially during out-of-hours when they may not want to bother their GP for help.

Specialist Services

Both of these services operated in addition to community care services and therefore had short, but intensive involvement in patient care at home. In the King *et al* (2000) study care was provided for a maximum of 48 hours, after which the patients' status was reviewed. The majority (66%) of care episodes lasted longer than 12 hours, but less than 36 hours. More than half (55%) of referrals occurred at weekends.

In the Travers and Grady (2003) study the maximum time period for receiving the service was five days. Between 8pm and 8am an on-call system was used with staff rotating. They recorded that a significant amount of activity occurred during these hours. The length of these visits lasted between 30 minutes and 8 hours.

Location of the service

The service in the King *et al* (2000) study covered a rural population in the highlands of Scotland and within a radius of 25 miles. The Grady and Travers (2003) study covered a population in the north east of Glasgow. Based on both their results it would appear that the location of the population covered (rural vs urban) did not deter the service from making an impact on outcomes.

Medication

Travers and Grady (2002) identified that access to medication was important to the success of the service. They described the content of five 'emergency drug bags' that they took on call-outs. These emergency kits were supported by recommendations by Mantz and Crandall (2000). Administering drugs comprised 10% of all home visit activity in the King *et al* (2000) study.

8.3 Costs

As neither study used controls or a comparison group, their estimates for cost savings were based on admission avoidance and service costs. Grady and Travers (2003) reported that their incremental costs were £1804 more for the hospice at home service compared to inpatient care (based on a three day service use average). Whilst they expected the costs to decrease

with increased throughput, it was still anticipated to cost more than inpatient care. Too few carers completed the cost questionnaire to be used in the analysis.

King *et al* (2000) estimated the cost per case as £527. This did not include institutional overheads or medication costs, though arguably inpatient care would have similar additional costs.

8.4 Conclusions on rapid response teams

Generally these rapid response services appear to prevent crises admissions, though the evaluations conducted on these lacked the power to provide an adequate evidence base without a control group. Also they do not provide sufficient demographic data, so we do not know if, for example those dying at home were all wealthy with female caregivers. However, the principle of rapid response teams is sound in that preventing crises from escalating to hospital or hospice admission could ultimately lead to more home deaths.

These services are unique in that they provide care for one purpose: to maintain the patient at home (as opposed to facilitating death at home or improving quality of life, though these are likely implicit goals). It is therefore assumed that both patient and professional are aware of the patient's preference to die at home, which as we have seen increases the likelihood that the patient will die there. These studies appear to have impressive results, but as there is no context in which to view them, their success must be viewed with caution.

9. Evaluating Hospice at Home

This section discusses methods for evaluating hospice at home services and primary outcomes that have been used in previous studies.

9.1 Methodology

The efficacy of using RCTs for evaluating hospice at home services has been questioned in a number of studies, despite it being the gold standard of evidence. It is ethically questionable to deny patients a service that they may benefit from and want. Where RCTs have been used to evaluate services, they have not generally yielded positive results. Often randomised designs have not achieved the required sample size for statistical calculation.

There are even fewer good comparative studies with controls, which is arguably the most ethical and practical design.

Some studies have used historic data as a comparison group for descriptive evaluations. This involves comparing one year of service use to the previous year when the service was not operating. However, with these types of studies it is difficult to control for other factors that develop over time which may impact on the success of a service, such as advances in medicine or the provision of a new community service.

9.2 Outcomes

Death at home is arguably the easiest way to measure the success of a hospice at home service. This assumes that death at home is the priority above all else, such as quality of life. The benefit of this measure is that it does not require gathering data from the patient or caregiver at times when they are most vulnerable.

Pain and symptom management is a common way to evaluate the effectiveness of hospice at home services. Studies have generally found pain management at home to be comparable to that received in inpatient care, which could be seen as a success for the service. A number of scales have been developed for measuring pain, but it is not always easy to measure as there are often differences in ratings by patients, caregivers and professionals.

Quality of life has been shown to be closely related to pain and symptom management (McMillan and Small, 2002; Portenoy *et al*, 1994; Salisbury *et al*, 1999), and therefore has similar complications. Having a patient complete a quality of life questionnaire or interview is only possible at less strenuous points in the illness and using a caregiver as a proxy is not always reliable.

Satisfaction has also been used to evaluate services, usually in conjunction with quality of life, though this is usually done retrospectively with the caregiver after death has occurred. Satisfaction is usually asked about in relation to services received and appropriateness of place of death.

Quality of death is a measure that has not explicitly been used, as it is difficult to define and would rely on proxy rating. Quality of death has sometimes been ascertained through retrospective interviews with professionals and caregivers. This is often in relation to the aforementioned factors of quality of life, satisfaction and appropriateness of death.

10. Discussion

The search of the literature for an evidence base for hospice at home encountered a number of problems. Firstly, terminology used to describe hospice at home covers a wide range of services, from palliative community care to crises intervention and rapid response teams. When searching for 'hospice at home', it is clear that it has historically been thought of the provision of day to day hospice or hospital services in the home. Hospice at home services are now broadening to include 24/7 rapid response care, which coincides with policy shifts towards expanding the availability of palliative care services in the same way (DH, 2008; NICE, 2004). Also, because of the uniqueness of the healthcare system in the UK, it is difficult to make comparisons to studies of services from Europe and the US, which further limits the available data on which to model a service.

Hospice at home services in the UK do not always include the emergency type care that is sometimes required for the terminally ill, albeit for short time periods. Services are not always clearly described in the literature, though some do stipulate that they provide 24 hour

nursing care. However, even these services have not been shown to be more effective than standard community care. Services that are set up to provide routine support may not be able to cope with demands for sporadic, yet intense palliative home care.

The seeming ineffectiveness of hospice at home may in part come from the methodology that is used to evaluate it. Though RCTs are the gold standard of evidence, their utility is questionable in this context when it is impossible to blind participants to the study's intervention and when preference is an important factor for predicting death at home. This has been suggested by authors of RCTs and evaluations (Grande *et al*, 1999; King *et al*, 2000). Therefore, whilst there appears to be little high quality evidence to support hospice at home services, this may not mean that the service is ineffective, but rather that the methodology is. However, even non-randomised controlled or observational studies have not conclusively shown that hospice at home is more effective for facilitating death at home (Higginson *et al*, 2003).

It therefore may be more prudent to look at why hospice at home recipients have been admitted to hospital or hospice. It has already been argued that a strong preference for home death and a competent caregiver are important factors for remaining at home (Gomes and Higginson, 2006). Studies do not always record why patients were admitted to inpatient facilities, though one systematic review showed that prevalence of symptoms did not affect place of death (Gomes and Higginson, 2006), meaning that patients who died in hospital had similar symptoms to those that died at home. Research has shown that there is often very little or no difference in pain and symptom management, satisfaction and quality of life for those in hospital, hospice or at home. Some studies argue that patients who have entered inpatient care could have been maintained at home. Therefore, patients and caregivers perhaps choose inpatient admission even though they would prefer to die at home because they believe that they would receive better care in a facility. Therefore one of the barriers to maintaining patients at home may be that emotions and insecurity override rationale and thus patients are admitted. Gomes and Higginson (2006) found that previous admission to hospital and the availability of inpatient beds favoured a hospital death, suggesting that it is the way in which symptoms are dealt with and previous experience are what is important.

A Canadian study by Mantz and Crandall (2000) suggested that crises are generally preceded by an uncontrolled deterioration or change in symptoms. This then triggers the emotional response, or crisis, in either the patient or caregiver. Armes and Addington-Hall (2003) looked at why patients in the UK were admitted to inpatient facilities from hospice at home services. This was a small scale qualitative study of interviews conducted with 10 patients, 6 caregivers and 31 service providers. The study found that misunderstandings between caregivers and professionals on symptoms and their management were the main source of crises developments. The authors suggest the need for education for caregivers on symptoms and what should be monitored for providing feedback to professionals. A systematic review on caregiver interventions was unable to conclude what type of intervention, if any, is most effective for supporting caregivers (Harding and Higginson, 2003). NICE guidelines (2004) recommend the development of informal support systems, like peer support groups and self-help activities. However, research in peer support has shown that while caregivers find them useful, peer groups do not meet all their informational needs. It is perhaps the patient and caregiver response to symptoms that triggers admission to institutional care, and therefore controlling this response through education and professional support may help maintain people at home.

Despite service providers best efforts, the literature suggests that there will always be an inequality in who dies at home in favour of those with caregivers. However caregivers can also be an obstacle as their fear or stress often leads to inpatient admission, though many patients would not initially be at home without a caregiver. Informal care giving, which is usually unpaid, is an advantage to the health service as they provide much of the day to day care. But caregivers may experience better outcomes if they were viewed as a service user eligible for their own support and care. This seems obvious as each caregiver inevitably experiences the patient's death which may lead to psychological distress. Providing sufficient support to the caregiver may help control their emotional responses to deterioration and symptoms, thus helping to maintain the patient at home, as well as being a preventative measure for maintaining mental and physical health after the death of the patient.

An appropriate response to crises by the patient, caregiver, and the professional is needed to maintain patients at home so they may eventually die there. Therefore services that respond to these crises, such as rapid response teams, may have the greatest benefit. Rapid response teams have been outlined as the next step in terminal care in NICE guidelines and the Department of Health's *End of Life Care Strategy*. However, they will need to be supported by continuous home care service, to identify events that precede a crisis, ensure the patient's quality of life, and prevent carer burnout. Hospice at home will require a multidimensional approach, but it may be that how we respond to crises is what matters and is what previous hospice at home services were missing.

11. Conclusion

The literature indicates that a successful intervention may have the following characteristics:

1. Operates in addition to community care services and is offered for an appropriate length of time throughout the course of the illness.
2. Has specialist input available at all hours, everyday and can respond rapidly when needed.
3. Provides the necessary equipment and medication when needed.
4. Views informal caregivers as integral to the care team in need of knowledge and information, but does not overburden them with caring expectations as they are experiencing intense physical and mental strain.
5. Works with community care services to identify potential risk factors for crises.

Regardless of the service provided, it is imperative that appropriate trials with useful outcomes be conducted to determine the effectiveness of hospice at home services. Useful outcomes should look at whether patient preferences have been met and whether patients were able to exercise choice in place of death.

12. Recommendations

The Pilgrims Hospices currently supports community care services provided by local PCTs with specialist advice. This is similar to the service provided in the Hinton (1996) study,

which has a modest impact. Currently 29% of patients in receipt of services are able to die at home, nearly 7% above the national average (ONS, 2007). Since community services are already operating in this area and to prevent duplication, it would be practical and cost effective to utilise and support the services by providing a rapid response service.

We recommend that the Pilgrims Hospices service aim to ‘catch’ those that would normally slip through community care and end up in hospital or hospice. This would involve setting up a rapid response service aimed at resolving crises in the community. This is what has been outlined in the *End of Life Care Strategy* (DH, 2008) recently announced by the Department of Health. The strategy aims for a rapid response service similar to the Marie Curie Cancer Care Rapid Response Team. The aim of this service is inpatient admission avoidance and therefore requires specialist input available 24/7.

In order to do this we would first need to identify what percentage of people that die in an institution were formerly at home and entered the institution because of a crisis and why the decision was made to admit the patient. This will help to identify what the service can hope to achieve and approximately how many inpatient admissions can be avoided. It would also indicate what type of care the service would need to provide.

The service should also include some form of education for caregivers and patients, to educate them on their diagnosis, what symptoms are normal and what should be reported to professionals. Good communication and information from professionals is what many caregivers want. This should help reduce patient and caregiver uncertainty and insecurity which often precede a crisis.

A service such as this should provide care whenever needed, and therefore should not be restricted by time, though it is expected that it would be utilised in the few weeks before death when patients and caregivers are most experiencing the most strain. This would ensure fewer inpatient admissions and might be an investment in facilitating death at home.

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14. Appendices

14.1 Search strategy – First search

| No. | Database | Search term | Info added since | Results |
|-----|------------------------|--|------------------|---------|
| 1 | CINAHL (R) – 1982-date | palliative ADJ care | Unrestricted | 17435 |
| 2 | CINAHL (R) – 1982-date | PALLIATIVE-CARE#.MJ. | Unrestricted | 5472 |
| 3 | CINAHL (R) – 1982-date | palliative ADJ care | Unrestricted | 17435 |
| 4 | CINAHL (R) – 1982-date | TERMINALLY-ILL-PATIENTS#.MJ. OR TERMINAL-CARE#.MJ. | Unrestricted | 15515 |
| 5 | CINAHL (R) – 1982-date | home | Unrestricted | 96016 |
| 6 | CINAHL (R) – 1982-date | 2 OR 4 | Unrestricted | 15515 |
| 7 | CINAHL (R) – 1982-date | 5 AND 6 | Unrestricted | 3162 |
| 8 | CINAHL (R) – 1982-date | PT=CLINICAL-TRIAL | Unrestricted | 24370 |
| 9 | CINAHL (R) – 1982-date | PT=MASTERS-\$ OR PT=DOCTORAL-\$ | Unrestricted | 13474 |
| 10 | CINAHL (R) – 1982-date | PT=RESEARCH | Unrestricted | 377209 |
| 11 | CINAHL (R) – 1982-date | 8 OR 9 OR 10 | Unrestricted | 377225 |
| 12 | CINAHL (R) – 1982-date | 7 AND 11 | Unrestricted | 1229 |
| 13 | CINAHL (R) – 1982-date | limit set 12 YEAR>2000 | Unrestricted | 786 |
| 14 | CINAHL (R) – 1982-date | nursing ADJ home | Unrestricted | 24166 |
| 15 | CINAHL (R) – 1982-date | 13 NOT 14 | unrestricted | 503 |
| 16 | CINAHL (R) – 1982-date | 8 AND 7 | Unrestricted | 24 |
| 17 | CINAHL (R) – | home ADJ health ADJ care | Unrestricted | 17572 |

| | | | | |
|----|------------------------|-----------------------|--------------|-------|
| | 1982-date | | | |
| 18 | CINAHL (R) – 1982-date | HOME-HEALTH-CARE#.DE. | Unrestricted | 20218 |
| 19 | CINAHL (R) – 1982-date | 13 AND 18 | Unrestricted | 146 |
| 20 | CINAHL (R) – 1982-date | 19 NOT 16 | Unrestricted | 140 |

| No. | Database | Search term | Info added since | Results |
|-----|-------------------------|---|------------------|---------|
| 2 | PsycINFO – 1806 to date | PALLIATIVE CARE#.DE. OR TERMINALLY-ILL-PATIENTS#.DE. OR HOSPICE#.W..DE. | Unrestricted | 6919 |
| 4 | PsycINFO – 1806 to date | HOME-CARE#.MJ. | Unrestricted | 2425 |
| 5 | PsycINFO – 1806 to date | 2 and 4 | Unrestricted | 255 |

| No. | Database | Search term | Info added since | Results |
|-----|----------------------------|--|------------------|---------|
| 4 | King's Fund – 1979 to date | TERMINAL-CARE#.DE. OR PALLIATIVE-CARE#.DE. | Unrestricted | 628 |
| 6 | King's Fund – 1979 to date | HOME-CARE#.DE. OR COMMUNITY-CARE#.DE. | Unrestricted | 4376 |
| 7 | King's Fund – 1979 to date | 4 and 6 | Unrestricted | 77 |

| No. | Database | Search term | Info added since | Results |
|-----|------------------------|--|------------------|---------|
| 7 | DH-DATA – 1983 to date | TERMINAL-CARE#.DE. OR PALLIATIVE-CARE#.DE. | Unrestricted | 1000 |
| 9 | DH-DATA – 1983 to date | HOME-CARE#.DE. | Unrestricted | 2514 |
| 10 | DH-DATA – 1983 to date | 9 and 7 | Unrestricted | 92 |
| 11 | DH-DATA – 1983 to date | HOME-CARE-OF-PATIENT#.DE. | Unrestricted | 1618 |
| 12 | DH-DATA – 1983 to date | 11 AND 7 | Unrestricted | 70 |
| 13 | DH-DATA – 1983 to date | 10 OR 12 | Unrestricted | 92 |
| 16 | DH-DATA – 1983 to date | HOSPICE-CARE.DE. | Unrestricted | 28 |
| 17 | DH-DATA – 1983 to date | 9 AND 16 | Unrestricted | 3 |
| 18 | DH-DATA – | 17 NOT 13 | Unrestricted | 1 |

| | | | | |
|--|--------------|--|--|--|
| | 1983 to date | | | |
|--|--------------|--|--|--|

| No. | Database | Search term | Info added since | Results |
|-----|-----------------------|---|------------------|---------|
| 2 | EMBASE – 1996 to date | PALLIATIVE-THERAPY#.MJ. OR CANCER-PALLIATIVE-THERAPY#.MJ. OR TERMINAL-CARE#.MJ. | Unrestricted | 7879 |
| 4 | EMBASE – 1996 to date | HOME-CARE#.DE. | Unrestricted | 11015 |
| 5 | EMBASE – 1996 to date | 2 AND 4 | Unrestricted | 477 |
| 6 | EMBASE – 1996 to date | hospice | Unrestricted | 3285 |
| 7 | EMBASE – 1996 to date | 5 AND 6 | Unrestricted | 165 |
| 8 | EMBASE – 1996 to date | 5 NOT 7 | Unrestricted | 312 |
| 9 | EMBASE – 1996 to date | Limit set 8 PRIORITY=Y AND H=Y AND ADULT=Y | Unrestricted | 32 |

| No. | Database | Search term | Info added since | Results |
|-----|------------------------|---|------------------|---------|
| 2 | MEDLINE – 1996 to date | HOSPICE-CARE#.MJ. OR HOSPICES#.W..MJ. | Unrestricted | 2674 |
| 4 | MEDLINE – 1996 to date | HOME-CARE-SERVICES#.MJ. OR HOME-NURSING#.M. | Unrestricted | 10599 |
| 5 | MEDLINE – 1996 to date | 2 AND 4 | Unrestricted | 363 |

| No. | Database | Search term | Info added since | Results |
|-----|--------------------------------------|--------------------------------|------------------|---------|
| 1 | British Nursing Index – 1994 to date | hospice | Unrestricted | 807 |
| 2 | British Nursing Index – 1994 to date | terminal ADJ care | Unrestricted | 3999 |
| 3 | British Nursing Index – 1994 to date | TERMINAL-CARE-DOMICILIARY#.DE. | Unrestricted | 362 |
| 4 | British Nursing Index – 1994 to date | neonatal | Unrestricted | 3330 |
| 5 | British Nursing Index – 1994 to date | 3 NOT 4 | Unrestricted | 359 |

14.2 Search strategy – Second search

| No. | Database | Search term | Info added since | Results |
|-----|--------------------------------------|---|------------------|---------|
| 1 | CINAHL (R) – 1982-date | rapid ADJ response | Unrestricted | 555 |
| 2 | CINAHL (R) – 1982-date | crisis ADJ intervention | Unrestricted | 1925 |
| 3 | CINAHL (R) – 1982-date | CRISIS-INTERVENTION#.DE. | Unrestricted | 1185 |
| 4 | CINAHL (R) – 1982-date | 1 OR 2 OR 3 | Unrestricted | 2462 |
| 5 | CINAHL (R) – 1982-date | hospice | Unrestricted | 18898 |
| 6 | CINAHL (R) – 1982-date | PALLIATIVE-CARE#.DE. OR TERMINAL-CARE#.DE. OR HOSPICE-CARE#.DE. OR HOSPICES#.W..DE. OR TERMINALLY-ILL- PATIENTS#.DE. | Unrestricted | 21693 |
| 7 | CINAHL (R) – 1982-date | 4 AND 6 | Unrestricted | 44 |
| 8 | British Nursing Index – 1994 to date | rapid ADJ response | Unrestricted | 45 |
| 9 | British Nursing Index – 1994 to date | crisis ADJ intervention | Unrestricted | 127 |
| 10 | British Nursing Index – 1994 to date | CRISIS-INTERVENTION#.DE. | Unrestricted | 117 |
| 11 | British Nursing Index – 1994 to date | 8 OR 9 OR 10 | Unrestricted | 171 |
| 12 | British Nursing Index – 1994 to date | hospice | Unrestricted | 809 |
| 13 | British Nursing Index – 1994 to date | TERMINAL-CARE- HOSPICES.DE. OR TERMINAL- CARE-NURSING.DE OR TERMINAL-CARE.DE. OR TERMINAL-CARE- SERVICES.DE. OR TERMINAL- CARE-SYMPTOM-RELIEF.DE. OR TERMINAL-CARE- DOMICILIARY.DE. | Unrestricted | 3998 |

| | | | | |
|----|--------------------------------------|--|--------------|-------|
| 14 | British Nursing Index – 1994 to date | 12 OR 13 | Unrestricted | 4054 |
| 15 | British Nursing Index – 1994 to date | 11 AND 14 | Unrestricted | 6 |
| 16 | MEDLINE – 1950 to date | rapid ADJ response | Unrestricted | 2172 |
| 17 | MEDLINE – 1950 to date | crisis ADJ intervention | Unrestricted | 4878 |
| 18 | MEDLINE – 1950 to date | CRISIS-INTERVENTION#.DE. | Unrestricted | 4518 |
| 19 | MEDLINE – 1950 to date | 16 OR 17 OR 18 | Unrestricted | 7043 |
| 20 | MEDLINE – 1950 to date | hospice | Unrestricted | 10291 |
| 21 | MEDLINE – 1950 to date | PALLIATIVE-CARE#.DE. OR HOSPICE-CARE#.DE. OR HOSPICES#.W..DE. OR TERMINAL-CARE#.DE. OR TERMINALLY-ILL#.DE. OR HOME-CARE-SERVICES#.DE. | Unrestricted | 88237 |
| 22 | MEDLINE – 1950 to date | 20 OR 21 | Unrestricted | 90278 |
| 23 | MEDLINE – 1950 to date | 19 AND 22 | Unrestricted | 183 |
| 24 | EMBASE – 1974 to date | rapid ADJ response | Unrestricted | 1986 |
| 25 | EMBASE – 1974 to date | crisis ADJ intervention | Unrestricted | 2395 |
| 26 | EMBASE – 1974 to date | CRISIS-INTERVENTION#.DE. | Unrestricted | 2065 |
| 27 | EMBASE – 1974 to date | 24 OR 25 OR 26 | Unrestricted | 4381 |
| 28 | EMBASE – 1974 to date | hospice | Unrestricted | 4852 |
| 29 | EMBASE – 1974 to date | PALLIATIVE-THERAPY#.DE. OR HOSPICE-CARE#.DE. OR TERMINAL-CARE#.DE. OR CANCER-PALLIATIVE- THERAPY#.DE. OR CANCER- PATIENTS#.DE. | Unrestricted | 62900 |
| 30 | EMBASE – 1974 to date | 28 OR 29 | Unrestricted | 65036 |
| 31 | EMBASE – 1974 to date | 27 AND 30 | Unrestricted | 67 |

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14.4 Notes on selected articles

| Authors | Title | Notes | Type |
|---|---|---|------|
| Addington -Hall JM, MacDonald LD, Anderson HR, Chamberlain J, Freeling P, Bland JM <i>et al</i> | Randomized controlled trial of effects of co-ordinating care for terminally ill cancer patients | Not home care specific. Coordinators for NHS services had no effect on patient or carer outcomes. | RCT |
| Armes P, Addington-Hall J | Perspectives on symptom control in patients receiving community palliative care | Very small sample. Communication issues around carer knowledge, training and expectations around the end of life. Professionals relied on carers to provide them with | Qual |

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| | | information about the patient's condition- important that carers are knowledgeable to accurately report to professionals. | |
| Clark D, Ferguson C, Nelson C | Macmillan Carers Schemes in England: results of a multicentre evaluation | Provides description of 'support' services- not nursing or SPC. Did not trial or test the service, carers describe the services they provide (sitting service). Provides some ideas for a service, but are not evidence based. | Eval |
| Ewing G, Rogers M, Barclay S | Palliative care in primary care: a study to determine whether patients and professionals agree on symptoms | Primary care setting, GPs, DNs and patient perspectives. Professionals overestimated emotional problems, GPs underestimated pain, in contrast to other studies. | Comp |
| Exley C, Field D, Jones L | Palliative care in the community for cancer and end-stage cardiorespiratory disease: the views of patients, lay-carers and health care professionals | Looks at impact of primary health care teams- not specialist palliative care teams (i.e. not what PH provides). Cancer patients had better outcomes than cardio respiratory patients, perhaps because of better lay understanding of cancer outcomes than CR outcomes. | FG |
| Finlay IG, Higginson IJ, Goodwin DM, Cook AM, Edwards AGK, Hood K, et al | Palliative care in hospital, hospice, at home: Results from a systematic review | Poor quality systematic review, search strategy not explicit. (Not included in review.) | SR |
| Gomes B, Higginson IJ | Factors influencing death at home in terminally ill patients with cancer: systematic review | Complicated network of factors. Strongest factors seem to be caregiver preference, patient preference, living with relatives, extended family support. Previous admission to hospital decreases chances of death. Included odds ratio. | SR |
| Grady A, Travers E | Hospice at home 2: evaluating a crisis intervention service | Does not evaluate percentage of death at home since it is not aimed at that but rather maintain people at home. | Eval |
| Grande GE, Addington-Hall JM, Todd C | Place of death and access to home care services: are certain patient groups at a disadvantage? | Patients with informal caregivers more likely to die at home and access palliative home care. Provision of home care does not remove dependence on caregiver. Women and older people less likely to die at home. | LR |
| Grande G, McKerral A, Addington-Hall J | Place of death and use of health services in the last year of life | Patients are more likely to die at home if they have a single cause of death (cancer), have had the diagnosis for a while (were more likely to plan ahead and receive Macmillan advice), and if they received intensive services right at the end of life (may be because it is not possible to provide long-term home care; will depend on medic ability to prognosticate). | Retro case cntrl |
| Grande G, McKerral A, Todd C | Which cancer patients are referred to Hospital at Home for palliative care? | Significant differences in referral- this is likely to be the case for PH. May just be that H@H can only serve a specific population. Median death 10 days after referral - can have successful prognostication. | Des, retro comp |
| Grande G, Todd C, Barclay SIG, Farquhar MC | Does hospital at home for palliative care facilitate death at home? Randomised controlled trial | No significant differences between services, were not able to show that H@H service allowed more patients to die at home. Did not reach statistical power: problems with randomisation, recruitment and attrition. | RCT |
| Grande G, Todd C, Barclay S, Farquhar MC | A randomized control trial of a hospital at home service for the terminally ill | CHAH. Intervention provided 24 hour nursing care at home. Conventional care (control) included hospital, hospice or standard home care. The intervention did not increase time | RCT |

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| | | spent at home in last 2 weeks, but CHAH was associated with better perceptions in quality of care from GPs, carers, and nurses. | |
| Harding R, Higginson I | What is the best way to help caregivers in cancer and palliative care? A systematic literature | Did not identify all literature (only used electronic databases). Difficult to make claims because the studies it is based on are small, generally descriptive and use untested measures. Sitting service discussed. Interventions for carers should be: theory based, focus on specific needs, address issues of access and acceptability, clear and modest aims, be evaluated rigorously. | SR |
| Harding R, Leam C, Pearce A, Taylor E, Higginson IJ | A multi-professional short-term group intervention for informal caregivers of patients using a home palliative care service | Carers liked support and experience sharing - may have provided a normalising effect for carers, made them feel not so isolated. Group may have been more effective if it focussed more on education on patient condition and illness trajectory. | SR |
| Hearn J, Higginson IJ | Do specialist palliative care teams improve outcomes for cancer patients: a systematic literature review | Multiprofessional teams with specialist input are beneficial in palliative care. Conventional care alone for patients with advanced cancer is inadequate. Specialist teams can improve satisfaction and identify and deal with more patient and family needs. Few RCTs available. | SR |
| Higginson IJ, Finlay IG, Goodwin DM, Hood K, Edwards AG, Cook A et al | Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? | Good quality, includes meta -regression, -analysis and -synthesis. Some evidence that palliative care teams improve pain and symptom control. RCTs show no effect, lower quality studies tend to show more effect- may be that patients need to choose their type of care and randomisation doesn't allow for this. | SR |
| Higginson IJ, Jarman B, Astin P, Dolan S | Do social factors affect where patients die; an analysis of 10 years of cancer deaths in England | Older age, high deprivation (Jarman score), and ethnic minority less likely to die at home. In general, higher deprivation means smaller proportion of patients dying at home. | Retro rev |
| Higginson IJ and Sen-Gupta GJA | Place of care in advanced cancer: a qualitative systematic literature review of patient preferences | 49-100% of patients wished to die at home. Inpatient hospice care second preference in advanced illness. | SR |
| Hinton J | Services given and help perceived during home care for terminal cancer | Higher demand on nurses, nightsitters and GPs in last week. Helpful care was medication, physical nursing help and psychological support. | Int |
| Jones L, Wilson A, Parker H, Wynn A, Jagger C, Spiers N et al | Economic evaluation of hospital at home versus hospital care: cost minimisation analysis of data from randomised controlled trial | Not palliative care specific - includes all patients who would be admitted to hospital. In these cases, hospital at home may be a viable cost alternative for long-term hospital care. Includes things to consider for cost analysis, e.g. cost to the family. | Prag RCT |
| Karlsen S and Addington-Hall J | How do cancer patients who die at home differ from those who die elsewhere? | More likely to die at home if preference was expressed and used specialist equipment; less likely to die at home if used health services for social care. | Survey |
| King G, Mackenzie J, Smith H, Clark D | Dying at home: evaluation of a hospice rapid-response service | Describes short-term (48 hours) rapid response service which operates in addition to community services. Indicators of effect are crises admissions and late discharge, interviews with nurses, GPs and carers. 14 of 17 died at home. Good satisfaction level. Lacks comparisons to conclusively link service to decline in crises | Eval |

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| | | admissions and higher death at home. | |
| Salisbury C, Bosanquet N, Wilkinson EK, Franks PJ, Kite S, Lorenzon M et al | The impact of different models of specialist palliative care on patients' quality of life: a systematic literature review | There is little good quality evidence for improvements in quality of life. Evidence for SPC success in other areas: carer and patient satisfaction, and costs. | SR |
| Smeenk F, van Haastregt J, de Witte L | Effectiveness of home care programmes for patients with incurable cancer on their quality of life and time spent in hospital: systematic review | Did not identify all literature (limited language, no gray lit). Effectiveness of home care programmes vs. standard care is unclear, though there are no negative findings. Can look at individual studies for ideas for service. | SR |
| Townsend J, Frank AO, Fermont D, Dyer S, Karran O, Walgrove A, Piper M | Terminal cancer care and patients' preference for place of death: a prospective study | 58% wished to die at home in given circumstance, 20% in hospital, 20% in hospice and 2% other. 69% who died in hospital wished to die elsewhere. In favourable circumstances, 67% would have preferred to die at home. Nearly 2/3rds of patients in hospital for last admission could have been cared for at home. | Int. |
| Travers E, Grady A | Hospice at home 1: the development of a crisis intervention service | Rapid response for crisis intervention, not specific to aiding death at home. However, intervening in all crises may then prevent people from entering hospital further along if it enhances their confidence in staying home. | Int, ques |
| Wilkinson EK, Salisbury C, Bosanquet N, Franks PJ, Kite S, Lorentzon M et al | Patient and carer preference for, and satisfaction with, specialist models of palliative care: a systematic literature review | Mixed reporting from studies. As of 1999 there is a dearth of good evidence (mostly small scale studies) to determine if one model is preferred over another. | SR |
| Zeppetella G | How do terminally ill patients at home take their medication? | Non-compliance may be partially due to lack of communication in addition to side effects or personal issues with it. Interviews and pill counting may not be entirely accurate, does not indicate how sample was chosen. Useful for communication issues that should be considered for PH service. | Int, pill count |

Key to study type:

Case cntrl = case control
Eval = evaluation
LR = literature review
Qual = qualitative study
Retro = retrospective

Comp. = comparison
FG = focus groups
Prag RCT = pragmatic randomised controlled trial
Ques = questionnaires
Rev = review

Des = descriptive
Int. = interviews
RCT = randomised controlled trial
SR = systematic review

