

## A randomized controlled trial of a hospital at home service for the terminally ill

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**Abstract:** This study evaluated the impact of a Cambridge hospital at home service (CHAH) on patients' quality of care, likelihood of remaining at home in their final 2 weeks of life and general practitioner (GP) visits. The design was a randomized controlled trial, comparing CHAH with standard care. The patient's district nurse, GP and informal carer were surveyed within 6 weeks of patient's death, and 225 district nurses, 194 GPs and 144 informal carers of 229 patients responded. There was no clear evidence that CHAH increased likelihood of remaining at home during the final 2 weeks of life. However, the service was associated with fewer GP out of hours visits. All respondent groups rated CHAH favourably compared to standard care but emphasized different aspects. District nurses rated CHAH as better than standard care in terms of adequacy of night care and support for the carer, GPs in terms of anxiety and depression, and informal carers in terms of control of pain and nausea. Thus whilst CHAH was not found to increase the likelihood of remaining at home, it appeared to be associated with better quality home care.

**Key words:** randomized controlled trial; palliative care; hospital at home

**Resumé:** Cette étude évaluait l'impact d'un hôpital de Cambridge en hospitalisation à domicile (CHAH) sur la qualité de vie des patients, sur la probabilité qu'ils restent à domicile durant les 2 dernières semaines de vie et sur les visites du médecin généraliste (GP). L'étude était de type contrôlée randomisée, comparant le CHAH à des soins conventionnels. L'enquête s'est déroulée auprès de l'infirmière du domicile, du GP et des soignants informels du patient dans les 6 semaines suivant la mort des patients et 225 infirmières du domicile, 194 GP et 144 soignants informels de 229 patients ont répondu. Il n'y a pas eu de preuve évidente démontrant que le CHAH augmentait la probabilité de rester à domicile durant les 2 dernières semaines de vie. Cependant le service a permis de réduire les interventions du GP en dehors des heures de visite. Les groupes répondants ont évalué positivement le CHAH par rapport aux soins standard mais de façon différente. Les infirmières ont trouvé leur offre de soins plus adéquate pour les soins de nuit et le soutien aux soignants, les GP pour la prise en charge de l'anxiété et de la dépression, et les soignants informels pour le contrôle de la douleur et des nausées. Ainsi, tandis que l'on n'a pas montré que le CHAH était susceptible d'augmenter la probabilité du maintien à domicile, il a été associé à une amélioration de la qualité des soins à domicile.

**Mots-clés:** étude randomisée contrôlée; soins palliatifs; hospitalisation à domicile

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## Introduction

There has been a considerable increase in the number of palliative home care teams in the UK in recent years.<sup>1</sup> So far there has been limited evaluation of their impact. The randomized controlled trial (RCT) is posited as the gold standard for service evaluation.<sup>2</sup> However, very few successful RCTs of palliative home care have been conducted<sup>3</sup> and of these only one trial in the UK.<sup>4,5</sup> In these trials, the home care interventions were associated with an increase in likelihood of dying at home,<sup>6</sup> high patient satisfaction,<sup>7,8</sup> a decrease in symptom distress and social dependency<sup>9</sup> and improved cost effectiveness.<sup>5</sup> Only one trial reported a negative result for home care, finding that home care patients had worse perceptions of their own health than those not receiving home care.<sup>9</sup> An RCT of hospice care, provided both as inpatient and home care, reported that hospice patients and their carers showed more satisfaction with care or involvement in care, and somewhat less carer anxiety, compared to the control group.<sup>10</sup>

Other studies of specialist team home support reviewed by Hearn and Higginson<sup>11</sup> show similarly positive results.<sup>12-18</sup> Team support has been associated with greater likelihood of home death,<sup>13</sup> lower inpatient length of stay,<sup>12,14</sup> lower costs,<sup>12,14,15</sup> better quality of life and adequacy of care.<sup>15</sup> Teams providing combined home and hospital support were also associated with greater satisfaction<sup>16</sup> and improvement in variables such as symptoms, patient anxiety and communication<sup>17</sup> for patients under their care.

A systematic review of hospital at home schemes<sup>19</sup> showed that most services were early discharge schemes (10 of 11 reviewed) and only one involved palliative care patients.<sup>8</sup> Hospital at home for conditions other than palliative care was associated with increased patient satisfaction, but not necessarily carer satisfaction,<sup>20-25</sup> and with reduced hospital stay,<sup>23-27</sup> while results on cost were less clear.<sup>28,29</sup>

In nearly all the studies reviewed home care was considered the more positive support option. However, more RCTs specific to palliative care are required. Results from evaluations of general hospital at home services are unlikely to be directly applicable as these are aimed towards clearly defined treatments and/or periods of care, and are

predominantly directed towards patients with low dependency needs who normally survive their episode of care. They are therefore quite different from palliative care services. In nonrandomized studies of palliative care services the home care group may have performed better simply because it had fewer care needs and was most suited for home care<sup>12-16</sup> or due to changes not specifically related to team support *per se*.<sup>17</sup> Even the few RCTs of palliative home interventions conducted differ considerably in the type of positive outcome reported, probably due to differences in time periods, services evaluated and measures used. We are therefore far from understanding the likely impact of palliative home care services.

The limited number of RCTs can at least in part be attributed to the particular problems that palliative care presents for RCT design. Sample attrition, the vulnerability of the patient group, the often unpredictable course of illness, and patients' and carers' frequent inability to complete measures all combine to make RCTs difficult within this field.<sup>30-32</sup>

This paper reports one randomized controlled trial's attempts at tackling these problems when evaluating a palliative care intervention that occurred even closer to death than in previous trials. The service evaluated was the Cambridge Hospital at Home for palliative care (CHAH), which aims to improve care provision for terminally ill patients and to increase their choice of place of care. CHAH care was compared with existing standard care in the area, whether primary or secondary care. The trial aimed to test whether CHAH differed from standard care in terms of perceived symptom control, adequacy of care and patients' ability to remain at home during their final 2 weeks. The impact on general practitioner (GP) workload was also investigated.

## Method

### Sample characteristics

Trial participants were consecutive referrals to CHAH over a 15-month period. CHAH is available for terminal care for patients of all diagnoses whose prognosis is 2 weeks or less, as estimated by a clinician, and for respite care for patients with cancer, motor neurone disease and AIDS. Patients must be over 15 and resident in the former Cambridge Health District.

### **Intervention**

CHAH provided up to 24 h practical nursing care in the home for a maximum of 2 weeks. The service was predominantly used for terminal care during patients' final 2 weeks of life, although respite care could be provided at any point during an illness requiring palliative care. Referrals mainly came from primary care (admission avoidance), and less than one-third from secondary care (enabling discharge). During the project the CHAH team comprised six qualified nurses (two at EN level and four RGN), two nursing auxiliaries and a CHAH coordinator, also at RGN level. All had a specific interest in palliative care and most had Marie Curie nursing experience. Agency nursing care could be used in addition if required. The CHAH office was on the same site as the Marie Curie nursing service and inpatient hospice and administratively under the same palliative care manager, but run as a separate service with a separate funding stream. This location appeared to facilitate informal cooperation between services and access to specialist medical advice.

Both CHAH and control patients could receive the standard care provided locally. This included care in hospital or hospice, or care at home with input from GP, district nursing, Marie Curie nursing, Macmillan nursing, evening district nursing, Social Services, private care and a Flexible Care nursing service. The latter was a home nursing service, similar to Marie Curie nursing, but funded by the community NHS Trust and available to all diagnostic groups. Thus the trial compared CHAH and standard care with standard care only.

### **Procedure**

CHAH was resourced so as to accommodate approximately 100 patients per year. As 750–800 patients die annually from cancer alone in the CHAH catchment area (East Anglian Cancer Registry, *ad hoc* request), we anticipated that demand for CHAH would far exceed capacity. Randomization was therefore considered an acceptable means of allocating patients to the limited spaces available. A pilot study of 6 months did show that approximately 200 patients would be referred and 100 admitted per year. However, it also showed that many patients due to receive CHAH care failed to be admitted to the service because of rapid deterioration, early death or other change in circumstance, such as

inpatient admission for symptom control or the informal carer feeling unable to cope. Due to such attrition, to ensure that CHAH places were filled, the randomization ratio was set at 4:1 CHAH to standard care. Details of power calculations for this study are provided elsewhere.<sup>31</sup>

Patient allocation for each referral was assigned from a random number table by the researcher, and concealed in sequentially numbered, opaque, sealed envelopes. For each new referral the CHAH coordinator opened the next sealed envelope in the sequence, which identified the allocation of the patient to CHAH or control condition.

Under certain circumstances a patient could be assigned to CHAH without randomization: (1) if referred when CHAH was operating well under capacity, the patient would be admitted to ensure CHAH places were filled; (2) if referred as an emergency when no standard care was available, CHAH would be provided as a stopgap. These patients were excluded from the study.

### **Outcome measures**

Demographic data were collected on referral. GPs, district nurses and informal carers were sent a postal questionnaire within 6 weeks of the patient's death and asked to rate symptoms and support in the patient's final 2 weeks of life. One reminder was sent to nonrespondents. The final 2 weeks of life were chosen as the period for assessment as this was the time during which CHAH support was most likely to have been received. Furthermore, by using death as the common anchor point CHAH patients and controls would be at a similar stage of terminal illness. Initial attempts at gaining prospective data from patients themselves had yielded too little data for analysis, as patients were too ill to complete even abbreviated questionnaires.

GPs, district nurses and informal carers assessed the same items. Questionnaire items were based on past research into needs and symptoms.<sup>33–35</sup> Respondents were asked to rate on a three-point scale whether they would have liked more help for the patient or carer with an aspect of care. Symptom severity was rated on a four-point scale. Table 1 shows the items assessed; a lower score represents less problem. In addition, the GP and district nurse were asked to report whether the patient had spent time at home during their final 2 weeks of life. GPs were also asked to record any

visits made to the patient in the final 2 weeks of life.

Informal carers of all patients were asked to assess symptoms and care. GPs and district nurses were only asked to assess symptoms and care for the subgroup of patients who had been at home some or all of their final 2 weeks. Comparison of place of death, GP visits and informal carer assessments was therefore possible for all patients (Comparison 1, Figure 1). Comparison of GP and district nurse assessments of patients was only possible for patients who were at home (Comparison 2, Figure 1): their ratings constitute a comparison only of home care with and without CHAH. Respondents were not told that the survey was part of the CHAH evaluation, but merely asked to make a general assessment of provision of care and symptom control towards the end of the patient's life. Results relating to the association between CHAH care and place of death are reported elsewhere.<sup>31</sup>

#### Statistical analysis

We report an intention to treat analysis with patients allocated to CHAH and the control condition being referred to as the 'CHAH group' and 'control group', respectively, whether they actually received the treatment to which they were allocated or not. For completeness we mention results from a more extensive analysis<sup>36</sup> in which controls in addition were compared with CHAH patients who actually received CHAH in their final 2 weeks. However, in the latter analysis we can no longer assume that the control and CHAH group only differed in terms of the intervention itself.<sup>32</sup>

Chi-square tests were used for nominal data. Student's *t*-test were used for interval data with normal distribution and Mann-Whitney U-tests for ordinal data and for interval data with skewed distribution.<sup>37</sup> Although analysed with Mann-Whitney U-tests, GP visits and questionnaire ratings are reported as means and standard deviations for clarity of presentation. Tests are two-tailed with  $\alpha = 0.05$ . Analysis was conducted using SPSS 6.0 for Windows.

## Results

### Participants

Of 262 patients referred, 21 (8%) were not randomized because of referral fluctuations and

'emergency' referrals. Of the 241 patients randomized, 12 patients had not died by the end of the study and were therefore excluded from analysis. Data were collected for 43 control patients and 186 patients allocated to CHAH. Of the patients allocated to CHAH, 113 (61%) were admitted to the service. Ninety-six (85%) patients admitted to CHAH received the service during their final 2 weeks of life. This in effect means that 52% of patients allocated to CHAH actually received the service during the period being assessed in the questionnaires (Figure 1). Failure to enter CHAH was due to deterioration and death shortly after referral, inpatient admission for symptom control, carer becoming unable to cope with home care or other changes in patient circumstances, but rarely lack of CHAH resources. In total, 185 patients spent some or all of their time at home during the final 2 weeks.

Of the 229 patients who entered the analysis, a key carer could be identified in 198 (86%) of cases. A GP and district nurse could be identified for 228 (99.6%) of cases. Response rates were 144/198 (73%) for carers, 194/228 (85%) for GPs, and 225/228 (99%) for district nurses.

The CHAH and control groups did not differ in terms of the proportion of patients diagnosed with cancer (87% versus 86%, respectively), proportion living alone (21% versus 17%), age (mean 72 years, SD 11, versus 73 years, SD 14), sex (50% male versus 54% female) or survival from referral (both median 11 days). However, patients who were admitted to CHAH had significantly longer survival from referral to death compared with patients allocated to CHAH but not admitted to the service (median 16 and 8 days, respectively,  $Z = 3.005$ ,  $P = 0.003$ ). Patients who spent time at home during their final 2 weeks had shorter survival from referral than those who did not, whether control or CHAH group (median 10 and 17 days, respectively,  $Z = 2.849$ ,  $P = 0.004$ ). Among patients who spent time at home during the final 2 weeks of life, the CHAH and control group did not differ in terms of cancer prevalence, proportion living alone, age, sex or survival from referral.

The results presented in the following section relate to the control and CHAH groups as a whole (intention to treat, Comparison 1, Figure 1). The results in the subsequent section relate to the subset of patients who spent time at home during their final 2 weeks (Comparison 2, Figure 1).

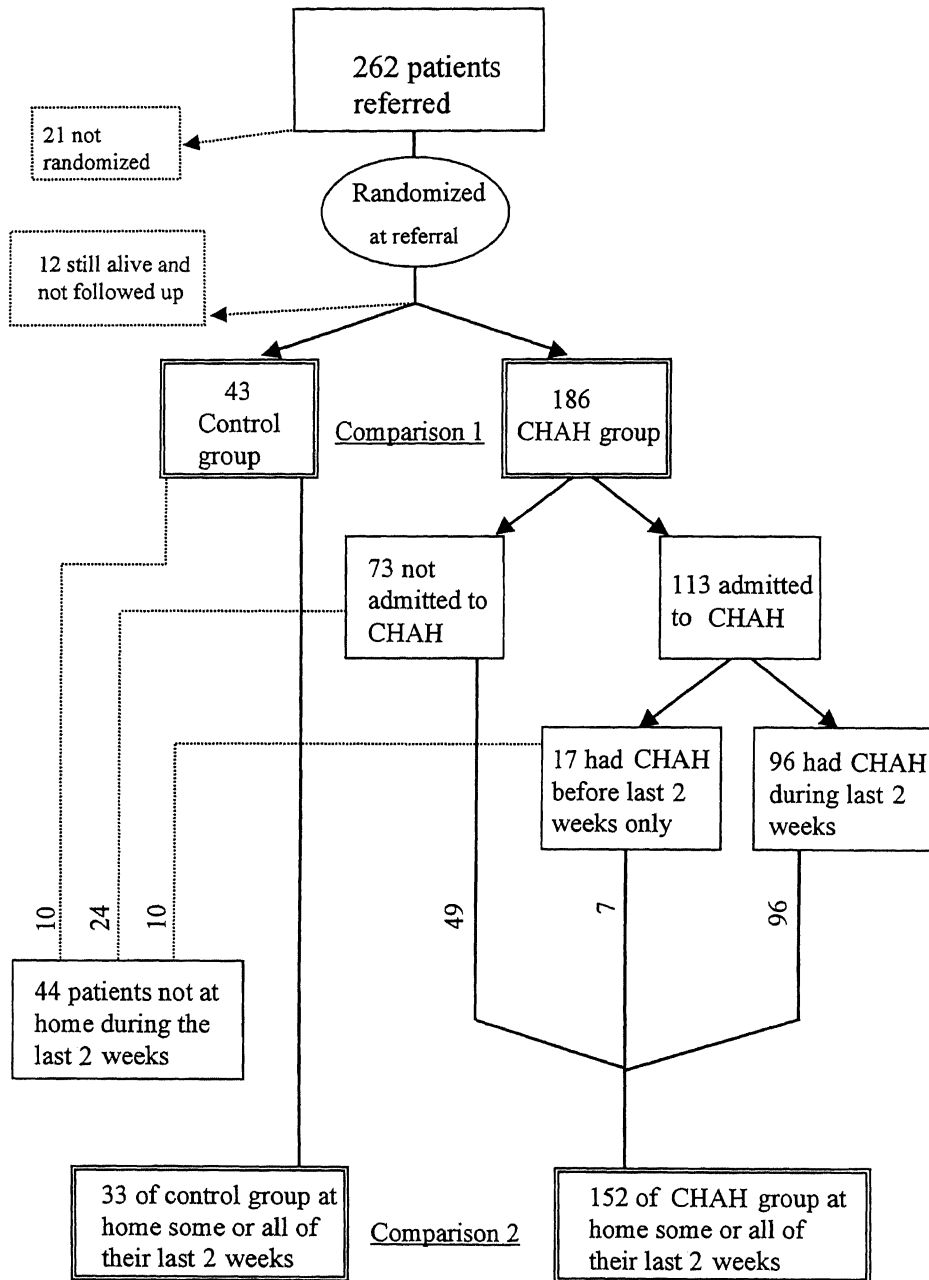


Figure 1 Patients entering the randomized controlled trial

**Comparison 1: Results relating to the control and CHAH groups as a whole**

*Likelihood of spending time at home in the final 2 weeks.* The control and CHAH group did not differ significantly in the proportion who spent time at home during their final 2 weeks (77% versus 82%;  $\chi^2 = 0.557$ ,  $df = 1$ ,  $P = 0.455$ ).

*Carer assessments.* Carers were more likely to give patients in the control group high ratings of pain compared with those in the CHAH group (mean 3.00 versus 2.52,  $Z = 1.971$ ,  $P = 0.049$ ). All other comparisons were nonsignificant ( $P > 0.05$ ) (Table 1). Previous analysis showed that when control patients were compared only with patients who received CHAH in their final 2 weeks of life, control

patients were no longer significantly more likely to have suffered pain ( $Z = 1.806$ ,  $P = 0.071$ ).<sup>36</sup>

*GP workload.* CHAH may affect GP workload in two ways. First, it may increase the number of patients being looked after at home. However, similar percentages of the control and CHAH group were at home in their final 2 weeks, suggesting that this is not the case. Second, CHAH may change the number of visits required for each individual patient being cared for at home.

The CHAH group had fewer GP evening home visits (mean 0.17 versus 0.61) and night visits (mean 0.04 versus 0.26) in the penultimate week of life compared to the control group ( $Z = 2.295$ ,  $P = 0.022$  and  $Z = 3.610$ ,  $P = 0.0003$ , respectively).

**Table 1** Informal carer ratings of need for more support and patient's severity of symptoms during patient's final 2 weeks

	Control mean (SD)	n	CHAH mean (SD)	n
<b>Support for patient</b>				
Night nursing	1.39 (0.70)	18	1.42 (0.73)	108
Medical care	1.29 (0.64)	21	1.15 (0.45)	108
Personal care	1.20 (0.52)	20	1.19 (0.52)	107
Psychological support	1.28 (0.67)	18	1.25 (0.54)	104
<b>Support for carer</b>				
Looking after patient	1.52 (0.75)	21	1.41 (0.69)	106
Practical running of household	1.32 (0.67)	19	1.24 (0.56)	107
Information	1.52 (0.81)	21	1.44 (0.72)	104
Psychological support	1.37 (0.76)	19	1.36 (0.65)	103
Transport	1.11 (0.47)	18	1.19 (0.56)	90
<b>Symptoms</b>				
Pain	3.00 (1.10)*	21	2.52 (0.93)	107
Nausea/vomiting	2.33 (1.06)	21	1.91 (0.90)	105
Constipation	2.62 (0.97)	21	2.24 (1.10)	102
Diarrhoea	1.55 (0.94)	20	1.51 (0.89)	98
Breathlessness	2.17 (1.15)	18	2.43 (1.17)	107
Anxiety	2.62 (1.02)	21	2.58 (1.07)	104
Depression	2.16 (1.07)	19	2.23 (1.05)	103

\* $P < 0.05$ .**Table 2** Mean (SD) GP visits in the final 2 weeks of life

	Daytime during week		Daytime during weekend		Evening		Night	
	Control	CHAH	Control	CHAH	Control	CHAH	Control	CHAH
Visits penultimate week								
Controls: $n = 37-38$								
CHAH: $n = 150-51$	2.32 (2.42)	2.18 (1.73)	0.39 (0.68)	0.35 (0.81)	0.61 (1.42)*	0.17 (0.46)	0.26 (0.55)**	0.04 (0.20)
Visits final week								
Controls: $n = 38$								
CHAH: $n = 150-51$	3.03 (3.18)	2.92 (2.20)	0.95 (1.56)	0.63 (1.07)	1.11 (1.56)	0.59 (0.91)	0.63 (1.10)	0.47 (0.82)

\* $P < 0.05$ , \*\* $P < 0.001$ .

**Table 3** District nurse, GP and informal carer ratings of need for more support during final 2 weeks, patients at home only

	District nurse				GP				Informal carer			
	Control mean (SD)	Total n	CHAH mean (SD)	Total n	Control mean (SD)	Total n	CHAH mean (SD)	Total n	Control mean (SD)	Total n	CHAH mean (SD)	Total n
Support for patient:												
Night nursing	2.03 (0.84)***	33	1.43 (0.64)	143	1.79 (0.86)	29	1.53 (0.70)	129	1.21 (0.43)	14	1.41 (0.71)	88
Medical care	1.14 (0.35)	28	1.07 (0.27)	126	1.11 (0.32)	27	1.13 (0.40)	130	1.24 (0.56)	17	1.10 (0.37)	88
Personal care	1.30 (0.53)	30	1.15 (0.45)	126	1.37 (0.69)	27	1.23 (0.51)	128	1.13 (0.34)	16	1.14 (0.44)	86
Psychological support	1.63 (0.76)	30	1.40 (0.61)	127	1.50 (0.75)	28	1.32 (0.61)	127	1.21 (0.58)	14	1.25 (0.53)	84
Support for carer:												
Looking after patient	1.81 (0.87)**	31	1.36 (0.60)	141	1.73 (0.83)	30	1.51 (0.66)	128	1.47 (0.72)	17	1.36 (0.63)	86
Practical running of household	1.35 (0.66)	31	1.22 (0.50)	136	1.25 (0.59)	28	1.20 (0.49)	127	1.27 (0.59)	15	1.15 (0.45)	86
Information	1.23 (0.56)	31	1.15 (0.40)	129	1.21 (0.57)	28	1.25 (0.53)	128	1.38 (0.72)	16	1.36 (0.65)	83
Psychological support	1.71 (0.74)	31	1.54 (0.66)	138	1.54 (0.69)	28	1.42 (0.62)	127	1.21 (0.58)	14	1.30 (0.58)	81
Transport	1.10 (0.40)	31	1.05 (0.29)	119	1.07 (0.28)	27	1.06 (0.27)	123	1.14 (0.53)	14	1.10 (0.39)	70

\*\*P < 0.01, \*\*\*P < 0.001.

**Table 4** District nurse, GP and informal carer ratings of symptom severity during final 2 weeks, patients at home only

	District nurse				GP				Informal carer			
	Control mean (SD)	Total n	CHAH mean (SD)	Total n	Control mean (SD)	Total n	CHAH mean (SD)	Total n	Control mean (SD)	Total n	CHAH mean (SD)	Total n
Pain	2.26 (0.86)	31	2.02 (0.78)	140	2.35 (0.95)	31	2.03 (0.73)	130	3.12 (1.05)*	17	2.49 (0.92)	84
Nausea/vomiting	1.85 (0.87)	33	1.79 (0.85)	140	2.00 (1.02)	30	1.78 (0.82)	129	2.47 (1.07)*	17	1.91 (0.87)	87
Constipation	1.82 (0.77)	33	1.66 (0.83)	137	1.97 (0.94)	29	1.81 (0.78)	127	2.50 (0.97)	16	2.32 (1.09)	82
Diarrhoea	1.30 (0.60)	30	1.37 (0.74)	136	1.36 (0.73)	28	1.17 (0.49)	125	1.60 (0.98)	15	1.49 (0.88)	81
Breathlessness	1.88 (1.07)	32	1.89 (0.99)	136	1.66 (0.93)	29	1.82 (1.01)	129	2.21 (1.19)	14	2.39 (1.17)	87
Anxiety	2.48 (0.88)	31	2.20 (0.96)	138	2.50 (0.97)*	30	2.10 (0.95)	127	2.50 (1.10)	16	2.45 (1.05)	80
Depression	1.76 (0.69)	29	1.79 (0.87)	129	2.19 (1.08)**	27	1.62 (0.76)	125	1.93 (1.14)	14	2.08 (0.97)	84

\*P < 0.05, \*\*P < 0.01.

There was no difference in daytime visits or in night and evening visits in the last week of life ( $P > 0.05$ ) (Table 2). The same pattern of significant differences had previously been found when comparing control patients with patients receiving CHAH in their final 2 weeks of life.<sup>36</sup> Past analysis has also shown that the CHAH and control groups did not differ in the amount of input from any other primary or secondary care service in the final 2 weeks of life.<sup>38</sup>

#### Comparison 2: Results relating to patients at home during the final 2 weeks

If the patient was actually at home during the final 2 weeks of his/her life, district nurses were significantly more likely to report that the control group should have had more help with night nursing (mean 2.03 versus 1.43) and more help for the carer (mean 1.81 versus 1.36) compared to the CHAH group ( $Z = 4.012$ ,  $P = 0.0001$  and  $Z = 2.838$ ,  $P = 0.005$ , respectively). GPs were significantly more likely to give the control group high ratings of anxiety (mean 2.50 versus 2.10) and depression (mean 2.19 versus 1.62) compared to the CHAH group ( $Z = 2.101$ ,  $P = 0.036$  and  $Z = 2.603$ ,  $P = 0.009$ , respectively). Ratings did not otherwise differ significantly between CHAH and controls ( $P > 0.05$ ). Tables 3 and 4 give an overview of ratings. The same pattern of significant differences had previously been found when comparing control patients with patients receiving CHAH in their final 2 weeks of life,<sup>36</sup> except that GPs in addition were significantly more likely to report that the control group should have had more psychological support compared to the CHAH group (mean 1.50 versus 1.22,  $Z = 2.083$ ,  $P = 0.037$ ).

In order to consider how carer ratings may compare with district nurse and GP assessments, carer ratings were re-analysed for the subsample of patients who spent time at home during their final 2 weeks (Tables 3 and 4). In this analysis carers again gave control patients higher ratings of pain than the CHAH group (mean 3.12 versus 2.49,  $Z = 2.315$ ,  $P = 0.021$ ). They also gave the control patients higher ratings of nausea than CHAH patients (mean 2.47 versus 1.91;  $Z = 2.120$ ,  $P = 0.034$ ). Previous analyses comparing control patients with patients receiving CHAH in their final 2 weeks of life showed the same pattern of significant differences.<sup>36</sup>

## Discussion

Previous RCTs of palliative home care differ from the current study in that they recruited patients considerably earlier and thus further from death, and provided far less intensive care interventions. A RCT of a hospital at home service, able to offer 24-h 'hands on' nursing care, at such a late stage of terminal illness has not previously been reported. However, an evaluation at such close proximity to death could only be carried out at the cost of losing the views of patients themselves, since very few were able to complete even brief rating scales at this point.

The results of this study do not allow us to conclude that CHAH permitted increased numbers of patients to spend time at home during their final 2 weeks. Furthermore, previous analysis did not show clear evidence that CHAH increased the proportion of patients dying at home.<sup>31</sup> This appears in contrast to past studies, which show home care patients to be most likely to die at home or have reduction in inpatient days. However, all of these studies but one<sup>6</sup> were either comparative studies<sup>12-14</sup> in which home care recipients may have been the patients already best able to remain at home, or studies of hospital at home for nonpalliative patients, of which all but one<sup>27</sup> were discharge schemes.<sup>23-26</sup>

CHAH was associated with reduced out-of-hours GP visits in the penultimate week of life. Such out-of-hours visits are often associated with urgent problems, and CHAH may confer greater sense of security and better opportunity to 'nip problems in the bud' than standard care. It may also be that care of these patients was better co-ordinated and planned overall, thus preventing problems occurring.

Results relating to the CHAH and control groups as a whole showed that carers rated pain to have been more severe for the control group than the CHAH group (Table 2). We should, however, note that this difference was no longer significant when comparing controls with patients who received CHAH in their final 2 weeks of life. When considering only CHAH and control patients who spent time at home in their final 2 weeks (Tables 3 and 4), carers reported that controls had suffered significantly more pain and nausea, GPs that they had suffered more anxiety and depression and

district nurses that they were more likely to have received insufficient night care and support for the carer. Thus CHAH came out favourably in the assessments by all three respondent groups, but on different parameters, depending on the type of respondent. When assessing packages of care it may be difficult to pin down exactly what aspect of care worked well. Respondents may be left with a very general impression that the patient's final weeks worked out well or badly, but when trying to assess in retrospect which specific components were good or bad, each group may focus on different components, according to their particular concerns (e.g. the district nurse as a key organizer of care, is likely to be concerned about adequacy of care, while carers may be particularly distressed by patient suffering, and hence focus on symptoms). The differences found between the different groups emphasize the importance of gathering data from more than one source, particularly when obtaining data from patients themselves proves impossible. However, developing methods to collect such data from patients themselves should remain a priority.

Several methodological issues were highlighted by the study. Due to the unpredictability of terminal illness, many patients in the CHAH group failed to receive their allocated treatment. This led to a dilution of the experimental effect.<sup>30</sup> Furthermore, it meant that a high number of patients had to be allocated to the service to ensure that CHAH places were filled, yielding a randomization ratio of 4:1 CHAH to standard care. Even then 8% of patients had to be excluded from randomization and thus the study, to ensure that the service ran at capacity. Ensuring that CHAH operated at or near full capacity was an important precondition for conducting an RCT, but led to loss of statistical power. Denying services to patients, even if their value has not been proven, is often contentious, particularly in terminal care.<sup>30</sup>

The timing of the CHAH intervention could not be controlled. Most CHAH care took place in the patient's final 2 weeks of life, and survey assessments were therefore made for this period. However, not all patients had their care during this time, further diluting the treatment effect.

CHAH could furthermore not be compared with a single, homogenous package of care. Standard care involved acute hospital care, hospice care and alternative home care packages. The small size of

this control group prevented subanalyses being made. In addition, there would often be other services working alongside CHAH. The level of variance within the groups resulting from such multiple care options may have made any real between-group differences more difficult to detect. When comparing only patients at home during their final 2 weeks, the setting was at least held constant between the CHAH and the control group. The above factors may have made the study prone to type II error, i.e. failing to detect real differences between the CHAH and control group.

Another concern was that it was not possible to blind respondents to the fact that CHAH care had been delivered. However, survey respondents were not made aware that they were evaluating CHAH care in particular, and were only asked to evaluate care provision in general. Finally, as patients were referred at a median of 11 days before death, it proved impossible to obtain the views of the most important people in such a study – the patients themselves.

In spite of the above difficulties, the RCT was nevertheless able to demonstrate that care was perceived by GPs, nurses and lay carers to be better under CHAH than standard care. That significant effects were found despite loss of power attests to the positive impact of the service. Furthermore, the RCT provides more convincing evidence for this than could be obtained through other research methodology. We cannot conclude that CHAH enabled more patients to remain at home during their final 2 weeks, nor to die at home.<sup>31</sup> However, while the service may not affect place of death, it clearly seems to be associated with improved quality of dying.

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