Optimum models of hospice at home services for end-of-life care in England: a realist-informed mixed-methods evaluation

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Scientific summary

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Scientific summary

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Background

The UK is a world leader in end-of-life care (EOLC), which has evolved from the hospice movement since the 1960s. Hospice at home (HAH) services aim to offer the quality and ethos of hospice care at home to support dying patients to have a 'good death' and to provide patients with a choice about where they receive their care at the end of life, which is central to UK policy. The majority of patients who express a preference state that they wish to die at home (although many do not express a preference for place), and the evidence indicates that the number of people expressing this wish is increasing. Establishing how care can be delivered and maintained at home was identified as a top 10 research priority by the James Lind Alliance in 2015. Future projections demonstrate that the number of older people in the UK will increase over the next few decades and that the number of deaths every year will rise. The provision of HAH services will be important to help meet this demand.

Prior to this study, the evidence about HAH services was mixed and demonstrated wide variation in service provision and the settings in which they operated. Published reports described individual services without comparators and reported a range of different outcome measures. Lack of clarity about what aspects of services produce which outcomes made sharing good practice between HAH services difficult and stifled efficient service development. It was therefore important to understand how best to deliver effective HAH services, in a cost-effective manner, to achieve the outcomes desired.

Objectives

The study's aim was to investigate the impact of different models of HAH on patient and carer outcomes and experiences of EOLC. The overarching research question was as follows: what are the features of HAH models that work, for whom and under what circumstances?

The objectives to address the primary research question were as follows:

- identify the range and variation of HAH models operating across England in terms of patient criteria, organisation and delivery of services
- categorise the models by type, setting and key features
- select case studies of each model to enable an assessment of the impact of model type on patient and carer outcomes
- investigate the resource implications and economic costs of patient care in each model
- explore the experiences of patients, family carers, providers and commissioners of the different HAH models
- identify the enablers of and barriers to embedding HAH models as part of service delivery for EOLC.

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Methods

Hospice at home is a complex intervention and part of a whole system of health and social care delivery. The research design was informed by realist evaluation, a theory-driven methodology increasingly used to evaluate complex interventions, including services for EOLC.

The study had three phases.

Phase 1: national telephone survey

Hospice at home services across England were approached to provide data to enable the development of a typology of service models (categorising the services into types) in terms of service size, setting, staffing, funding, patient eligibility and service operations.

Phase 2: case studies

Representative services from the different service types identified in phase 1 were recruited to allow in-depth exploration of context–mechanism–outcome (CMO) configurations. At each site, patient and carer dyads were recruited on admission to HAH. A mixed-methods approach collected quantitative data, comprising information about the patient and the informal/family carer on admission to HAH and outcome measures from carers post bereavement [i.e. Quality of Dying and Death questionnaire (QODD), achievement of preferred place of death (PPOD), service satisfaction]. Qualitative interview data were also collected (from carers post bereavement, service providers and commissioners) and analysed by repeated refinement through research team consensus meetings over an 18-month period. In addition, health economics data, comprising carer-reported patient service use data using the Ambulatory and Home Care Record, which was administered by telephone interview every 2 weeks between recruitment to the study and death, were collected.

Phase 3: stakeholder consensus

Two national consensus workshops were held in London and Leeds in early 2020. Participants included service providers, commissioners, researchers and members of the public. Emerging findings from the study and relationships between contexts, mechanisms and outcomes were presented to the stakeholders in a variety of workshops and formats, for discussion, refinement and validation.

Findings

Phase 1

Seventy (55% response rate) HAH services in England reported varied settings, activity, staffing configurations and patient criteria. Although almost all HAH services provided personal care, psychosocial support and symptom management, not all provided this 24 hours per day, 7 days per week (24/7). Most services provided care for between 1 week and 2 months from referral to death and reported using more health-care assistants (HCAs) than registered nurses (RNs). Two-thirds of services reported that they were financed mostly from charitable sources.

Categorising the hospice at home services/the typology

Based on phase 1 findings and study team discussions, four service models were defined by size (large vs. small services, with a cut-off rate of 365 referrals per year) and provision (or not) of 24/7 care.

Case study sites and recruitment

Twelve case study sites were recruited across the four models. Services were selected to represent a range of other factors: different areas of England, admission criteria, urban/rural setting, deprived/affluent demographic and staffing mix (RNs and HCAs). A total of 339 patient–carer dyads entered the study. Interviews were conducted with 76 service providers, nine commissioners and 76 bereaved carers.

Patient and carer data

Most patients recruited to the study had a diagnosis of cancer (76.8%); most informal/family carers were female (70.2%) and the spouse/partner of the patient (60.4%). Patients varied considerably on admission to HAH: 48.0% had a modified Karnofsky performance status score of $\geq$ 50% [range 0% (dead) to 100% (normal function)]. Participants in model 1 (larger, 24/7 services) differed from those in other models: they were in the study longer (accepted by the HAH service further from death) and had better health status at recruitment. The duration of time in the HAH service varied from a few hours to > 1 year, and services commonly struggled to achieve discharge or transfer of care to other providers.

Qualitative interview data

The qualitative interview evidence was used to refine programme theories into CMO configurations; six main themes emerged that significantly affected patient and carer outcomes: sustainability (of the HAH service); volunteers (use of, in the HAH service); integration and co-ordination (with the wider health and social care system, including commissioners); marketing and referral (of the HAH service); knowledge, skills and ethos (of HAH staff); and support directed at the carer or patient–carer dyad at home.

Primary quantitative outcome measure: Quality of Dying and Death questionnaire findings

- The median QODD score was 70.7 (range 0–100, with 70 indicating a good death).
- Higher (i.e. better) QODD scores were elicited from female carers, from university-educated carers, from patients who had known they were dying for a longer time, and especially when patients had died at home or in a hospice.
- When all items were adjusted for, smaller services (models 2 and 4, with and without 24/7 services) delivered significantly higher (≈12) QODD scores.

Other quantitative measures

- A total of 73% of patients achieved their PPOD, with no statistically significant difference between the four service models; this proportion was 82.3% in model 2 (smaller, 24/7 services).
- Nine per cent of patients who had been admitted to HAH died in hospital.
- Most participants reported that they received as much support from health and social care services as they needed; female patients reported a lower level of support; carers in model 2 were eight times more likely to report receiving all of the support they needed.
- Carers overall rated the help and support they received as excellent. Better ratings were associated with university-educated carers; worse ratings were associated with patients dying in hospital. There was a trend for carers in model 2 to report a better quality of support.

Health economics findings

Home nursing and personal caring were the services most frequently accessed by participants. Service use increased closer to death. In the last 2 weeks of life, the median number of nursing and personal caring visits was 1.76 per day, and informal/family carers provided an average of 20 hours of caring per day. Service use and costs were lower in model 1 (larger, 24/7 services) than in the other models, but reasons for this could not be identified. Costs of informal care (valued by replacement cost methods) exceeded formal care costs in all models. More intensive in-home nursing and personal caring in model 2 (smaller, 24/7 services) coincided with better QODD scores, more patients dying in their preferred place (not significant) and higher carer satisfaction scores than in other models.

Synthesis of findings from the mixed-methods data

Achieving preferred place of death and reducing the number of hospital admissions

Hospice at home enabled the majority of patients to achieve their PPOD and patients who had been in HAH services had a very low chance of dying in the acute hospital setting compared with the national average.

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Time to care and expertise

Family/informal carers placed a high value on HAH staff in comparison with others (care agency staff, community nursing staff). HAH staff made them feel that they had 'time to care' and that they were clearly experienced in and comfortable with dying and death.

Caring for the carer

Successful care at home depends heavily on the informal/family care set-up. Services providing assessment, care and support directed at the family carer and taking into account the needs of the 'home dyad' were highly valued. HAH services could usefully review their bereavement services as current provision was, on the whole, not providing what bereaved carers wanted, which was support from staff who had been directly involved in the care.

Hands-on care

One way of understanding different models of HAH services that emerged was to place them on a spectrum from 'medical' (higher grades of skilled, registered staff giving advice and prescribing medications) to 'social' (focus on hands-on care). Hands-on, relational care was particularly valued by carers in the period close to death.

Hospice at home integration with health and social care systems: balancing internal and external investment

In terms of HAH service sustainability (of both funding and workforce), it emerged that the direction in which HAH tended to have a predominant focus was important: either internally focused (on staff support and development) or externally focused (on external relations, reputation, educating others). A significant investment in either direction to the detriment of the other was unfavourable to service sustainability.

Service size and outcomes

Smaller services tended to deliver better outcomes, but the key features that any service could replicate were the speed of response to need, the intensity of care provided and working closely with other services. Larger services provided other benefits worth imitating, in terms of earlier interventions and breadth of services. However, making early contact and then placing the responsibility for seeking further help onto carers was not found to be supportive.

Utilising volunteers

Although the enormous contribution of volunteers to wider hospice services was recognised, volunteers were an underutilised resource in HAH. Most organisations were reluctant to use volunteers to support patients at home who were close to death and suffering significant physical disability; linked to this were worries about safety and accountability. However, volunteers could be utilised in different ways: to provide support with domestic tasks in the home (as in the COVID-19 pandemic), to provide direct patient care when the volunteer has a professional background or in a looser model whereby hospices facilitate an approach more along the lines of Compassionate Communities and neighbourliness, rather than 'professionalising' volunteers and overbureaucratising the arrangements.

Limitations

The data collection for the study relied heavily on informal/family carers both before and after a patient's death, and we were therefore unable to recruit patients who did not have such a carer involved on a daily basis. We were not able to provide translation services and could not therefore recruit participants unable to complete questionnaires in English. We omitted to gather data on the ethnicity of patients and carers, which was a significant oversight and one that was highlighted at the consensus meetings.

A significant number of patients admitted to HAH services lived for longer than we had anticipated when the study was designed. As a result, not as many patients as estimated died during the study, and thus post-bereavement data are missing; in addition, the post-bereavement response rate was lower than predicted. The QODD proved difficult and arduous for carers to complete, resulting in missing items. This also had an impact on the recruitment rate for post-bereavement interviews, which was lower than expected.

Recruitment was slower than expected, and more HAH services had to be included in the study to achieve the target patient sample size. As a result, there was heterogeneity of services within each model (except model 3: larger, not 24/7 services) and also variation in the numbers of recruits from different services. These factors meant that summed or averaged descriptors from each model (e.g. case-mix descriptors or costs) were difficult to interpret. Services contributing a lot of recruits to a model tended to dominate in the quantitative and health economic analyses. The precision of estimates of service model effects was impeded by missing data, including on service use. The allocation algorithm used to allocate service use reported by carers to time periods before death may have introduced some inaccuracies.

Conclusion and implications

For people approaching the end of their lives who wanted to die at home, HAH services provided care that was likely to deliver 'a good death' and was highly valued by its recipients. Patients admitted to HAH services were likely to achieve their PPOD and unlikely to die in hospital. Learning from different models of HAH could be utilised to develop and improve services. Carers in one model (model 2: smaller, 24/7 services) reported receiving more 'in-home' services and better outcomes. There was evidence that commissioners could improve the quality of EOLC for their populations by engaging with HAH services in future funding and development plans.

Research recommendations

The study indicated areas for further research: HAH bereavement services; HAH utilisation of volunteers; timing and intensity of HAH input; and further development of the QODD, which to our knowledge, was used for the first time in large numbers in the UK in this study.

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