



ORIGINAL PRACTICE DEVELOPMENT AND RESEARCH

Establishing a hospice at home service: lessons to share

Catherine R Baldry, Barbara A Jack*, Karen E Groves, Helen Birch and Ann Shard

*Corresponding author: Faculty of Health and Social Care, Edge Hill University, England. Email address: jackb@edgehill.ac.uk

Submitted for publication: 1st July 2011

Accepted for publication: 4th October 2011

Abstract

Background: Promoting the choice to die at home is central to UK policies and strategies and supporting this are hospice at home services of which there are variations in service composition and intervention. A bespoke hospice at home service comprising three elements: accompanied transfer home; a multi-disciplinary (including doctors) crisis intervention team and a flexible sitting service was established in the North West of England and piloted for one year. The aim of this study was to evaluate the impact of the service including its establishment.

Methodology: The retrospective cohort study and stakeholder evaluation undertaken of the pilot phase, found that of the 201 patients who received the service, 73% (132) died at home. 75 healthcare professionals (general practitioners, district nurses, community specialist palliative care nurses and hospital discharge co-ordinator) participated in semi-structured interviews, focus groups and electronic open ended questionnaires to identify their views on the service, its establishment and impact.

Results: In regard to the establishment of the service, the healthcare professionals reported that they had initially been fearful of the new service and how it could take over their role with terminally ill patients. However, this fear was unfounded and they found the service to compliment the care they could provide. This paper describes the phases of planning and designing the service, introducing the service and the pilot evaluation. Examples of good practice and lessons learnt are discussed including the importance of good lines of communication.

Conclusions: This bespoke service provides different elements of a hospice at home service, provides a tailor made package to meet individual and local area needs. The approach taken by the hospice in the establishment of the service appears to have played a key factor in its success.

Implications for practice:

- The lessons from setting up this service could be transferred to other new services not just hospice at home
- Communication with all key stakeholders is vital at all stages of the design of the service
- Developing services that meet local needs is important

Key words: hospice at home, palliative care, dying, service development

Introduction

In the UK the last twenty years has seen the development and expansion of palliative care services to enable the hospice model of care to be more widely available. Policy initiatives such as the End of Life Care Strategy (2008) have driven the development of palliative care services. Key developments such as the Gold Standards Framework and the Liverpool Care Pathway have helped to ensure that the best available evidence is informing care of the dying (Department of Health, 2008). Underpinning these policies and development is the importance of considering the patient's wishes regarding their preferences on the place of their care, including being cared for and dying at home if they so wish.

Studies that have explored caring for terminally ill patients at home, have identified that there are multiple factors that impact upon whether a home death can be achieved including the amount of available support, patient and families preferences and the ability of the carer to cope (Gomes and Higginson, 2006; Caress et al., 2009; Jack and O'Brien, 2010). Additionally Grande et al., (2004) found that home deaths were associated with both better bereavement response and better physical health post-bereavement than were inpatient deaths

The development of models of palliative care to support the patient in their home have emerged particularly in the last decade and the revision of the Palliative Care Minimum Data Set in 2006 incorporated a revised section to measure this activity (Jack et al., 2009). What was apparent was the wide variety of terms encompassing the phrase 'hospice at home', with elements of services including out of hours services, rapid response teams, crisis intervention etc. Furthermore the remit and composition of the teams varied from those that were generally nurse led to multidisciplinary teams.

A literature review of the evidence base for a hospice at home service (Stosz, 2008), (that was undertaken prior to the stakeholder meetings) drew some key recommendations as to what a successful intervention should comprise. This included: that it operated in addition to community services and is available throughout the course of the illness; rapid access to specialist input (at all hours), providing access to medication and equipment as needed and viewing the informal carer as integral to the care team but recognising carer burden.

Initiatives to achieve care at home at the end of life

Various models of palliative care home teams have emerged both in the UK, western world and more recently developing countries. Hospice at home is an umbrella term with no one clear term to describe the service, its composition or availability. A literature review of the evidence base for hospice at home services found several terms used, along with additional elements including: out-of-hours palliative care, hospital at home, community specialist palliative care, crisis intervention and rapid response teams (Stosz, 2008). Generally, a broad definition encompasses a palliative care service that is provided in the home environment. Within the UK, models vary from teams that only provide crisis interventions (rapid response teams), sitting services, nursing and medical care. It is estimated that approximately 140,000 patients were seen at home by hospice home care teams in 2006-7 in the UK (figures do not relate to Scotland) (NCPC, 2007).

Development of service

The area that the hospice covers (West Lancashire and Southport and Formby) is a mixed urban and rural area comprising a seaside resort with a high elderly population and transient holiday influx, as well as rural market town and a 1960s new town. In anticipation of the publication of the Department of Health End of Life Care Strategy (2008), the hospice senior clinical and education team held stakeholder meetings (patients, family carers and healthcare professionals) to discuss what gaps were evident for those who wanted to be cared for and to die at home. The

overwhelming theme of this discussion, particularly from district nurses, was the lack of sufficient, suitably trained, reliable, competent, qualified and unqualified, home carer support to care and provide confidence for patients and families. They also identified that discharges home from hospital or hospice could result in immediate readmission without really good support and that the confidence of someone accompanying the transfer would make a difference. Additionally, they recognised that sometimes a crisis at home could result in admission when in fact a multi-professional assessment and a management plan, by a team used to managing such situations at home, could in fact keep the patient there. Paramount was that any service was flexible and bespoke.

Queenscourt at home

The service comprises Queenscourt aides (health care assistants and registered nurses), accompanied transfer home and crisis intervention (see Box 1). The service is available if criteria are met that include referral from a healthcare professional for patients who have: advanced progressive disease, are on the Gold Standards Framework Register, have had a DS1500 form (which entitles the patient to non means tested benefits at end of life) and whose preferred place of care is home. The patient will already be receiving care from the district nursing services and other available agencies (social services, private agencies).

Box 1. Composition of the hospice at home service

Queenscourt at Home Service

Queenscourt aides – a mixture of substantively employed and bank healthcare assistants and registered nurses, trained to provide care and support for patients and their families at the end of life, for periods of hours at home.

Accompanied transfer home - where physical, psychological, and family dynamics are complex and perhaps unstable, an aide will accompany the patient, with or without a family member, on their journey from hospice/hospital to home, smoothing the transition from one environment to another at a time of high anxiety and distress. The aide will remain with the patient and family and continue care until the district nurse or other carer arrives, to handover.

Crisis intervention - when the issues which threaten staying at home are more complex than care alone, a multi-professional team of people e.g. doctor/nurse/physiotherapist/occupational therapist/pharmacist etc. may be dispatched to make an assessment visit and plan ongoing management to be undertaken, usually by the primary healthcare team but if this poses problems, they will carry out the short term management and then hand care back.

Developing the workforce

Following the identification of the elements of the service drawn from the three main gaps identified by the stakeholders, the core team was appointed consisting one full time equivalent clinical coordinator (two part time band six registered nurses with extensive district nursing experience), one full time administrative assistant and six aides, who are healthcare assistants with community and end of life care experience, substantively employed for 17 hours a week. In addition a bank of healthcare assistants and registered nurses were engaged.

An intensive period of training took place during the first three months of the service. That included both palliative care education and practical clinical experience within the hospice, ensuring that all hospice at home staff would be educated to the same high standard expected of any member of the

hospice team. An important part of the training was to replicate the good care that the hospice was renowned for providing. It was quickly apparent that a strong team ethos was developing with a shared vision and willingness to make this hospice at home service a success. On-going education was provided via Moodle™ (an open source virtual learning environment) which was available on the netbooks (with mobile broadband) that the staff carried with them whilst on duty. In addition all staff are required to attend regular in-service training sessions in the education centre several times a year.

All new staff work on the inpatient unit when first employed as part of their induction training. This is then followed up by 'double up' shifts with experienced staff until they are competent and confident to work alone. Additionally, with new staff the co-ordinator will ring patients and families after a shift to assess if there have been any problems. Also the co-ordinator will randomly visit the patients' home to observe staff performance. All hospice at home staff are required to work an occasional shift each year on the inpatient unit so that their performance can be observed. This also provides an opportunity for them to update their skills.

At the same time information was developed for health professionals, patients and families. The clinical co-ordinators visited general practitioners' surgeries and district nursing teams to inform them of the service and to explore how the service would work alongside the existing community services. It was important to make sure that the pilot project was recognised as an additional service to fill gaps and to allay fears that it would 'take over' palliative care. District nurses were informed that 'Queenscourt at Home' staff would work to their care plans, contacting them first when the patient required their assistance and community staff were encouraged to feedback their views and experiences of the service.

The hospice at home staff were provided with mobile phones plus tracker badges to safeguard them as lone workers. To provide on-going support, the staff commenced and ended their shifts at the hospice. This provided opportunities for support for the staff especially if they had experienced a difficult or distressing shift.

Evaluating the service

In order to assess the impact of the service, the hospice collaborated with their local university with whom they have a long established relationship, and formed a steering group to oversee the evaluation. This group included the hospice clinical medical director, head of education and a university professor. It was agreed that the evaluation element would be an opportunity for research capacity building for both the hospice and university. Therefore novice researchers were attached to the evaluation team. Although the research team included members from the hospice staff (who had no daily input into the hospice at home service), sampling strategy, recruitment, data collection and analysis were undertaken by people who were unknown to the participants. All members of the team were involved in the design of the evaluation, literature review, data collection tools, and writing of the report.

The planning of the evaluation was constrained by several factors, which directly impacted upon the study. Firstly the issue of time as the service was only funded for a year in the first instance, and there was a need for a formal report to be available for the trustees at the end of the financial year. Secondly, funding, as there was no specific funding for the evaluation element. These factors resulted in it not being possible to collect data from the carers on this occasion and to undertake an observational study of care in the last few days of life as this would have ethical implications as well as financial costs. Similarly undertaking interviews with bereaved relatives would have been valuable, but the 'cool off' time of approximately three months post bereavement that appears to be adopted by the majority of research ethics committees would have resulted in limited access to

carers within the timeframe. Lastly an economic evaluation would have been useful, but for the reasons discussed above, was not undertaken.

Research ethics

Liverpool Research Ethics Committee reviewed the study and accordance to the National Research Ethics Service guidance; the chair considered the study to be service evaluation and therefore did not require ethical review by an NHS Research Ethics Committee. Standard procedures for recruitment and obtaining informed consent were followed throughout the study. The Primary Care Trusts' research governance approval was obtained and their procedures were adhered to throughout the study.

Design

A standard programme evaluation methodology encompassing both quantitative and qualitative approaches was adopted (Robbins, 1998; Patton, 2002). In addition to a retrospective analysis of all referrals to the service, the inclusion of a qualitative element allowed the exploration of stakeholder i.e. health professionals experiences and expectations (Polit and Beck, 2009; Todres and Holloway, 2010; Topping, 2010). Complementary data collection tools (focus groups, interviews, surveys) enabled a plurality of perspectives to be obtained and increased the range and quantity of information available (Polit and Beck, 2009). All healthcare professionals' data was collected between October 2009 and January 2010, to allow them to have had experience of the service when it had been established for eight months. All referrals to the service during the pilot year were included in the evaluation.

Patients who were referred to the service

A total population sampling approach was adopted for all patients who were referred to the service during the first year of operation. Data was routinely collected on the cohort of referrals to the service during the pilot year by the hospice at home service as part of their normal practice. This included patient demographic details including age, sex, if they lived alone, diagnosis, aspect of the service used, length of time that the service was used for and place of death (if died during the pilot). This data was anonymised and retrospectively analysed by the research team.

The service was piloted for one year from February 2009, during which time 245 patients who expressed a wish to be cared for at home were referred to the service of which 201 received the service (several patients were admitted to hospital, had died, or declined the offer of the service). This comprised 41 crisis intervention visits (85% included a doctor), 30 accompanied transfers, 1330 Queenscourt aides shifts of which 86% were by healthcare assistants. Of the patients who received the service, 132 (73%) died at home (72% were patients with cancer). 51 patients lived alone, of which 35 (69%) died at home.

An evaluation of the service included exploring the views of 75 healthcare professionals using focus groups, individual interviews and an electronic survey (19 general practitioners and 31 registered district nurses completed the questionnaire; 13 district nurses and 9 palliative care nurse specialists participated in two focus groups; interviews were held with one hospital discharge co-ordinator and two general practitioners). Full details of the methodology, sample etc. are contained in a main report (Jack et al., 2010).

Data collection

For the focus groups a semi-structured interview schedule to guide the discussion was developed by the steering group and based upon the literature. Questions were focused around the hospice at home service and its components and the experiences of the staff of using the service. Questions were generally open ended and participants were prompted to expand on points and to give clinical examples from their practice where possible. For the survey element of the study the questions

were based upon the focus group responses. Piloting of all data collection tools were performed with healthcare professionals who were not part of the study and minor modifications made to the phrasing of some questions.

Data analysis

The qualitative data was analysed using a thematic analysis approach that included the four stages of organisation, familiarisation, reduction and analysis (Miles and Huberman, 1994; Polit and Beck, 2009). Each interview was analysed independently by three researchers to enhance the credibility of the findings. The reduction phase included the coding of the data where categories under each question were identified and subsequently coded. The analysis stage comprised the defining of theme descriptors until all data was fully represented (Miles and Huberman, 1994; May, 1998). The final themes were discussed by the research team and a consensus reached. Survey data was analysed using descriptive statistics where appropriate. The open ended free text questions were subject to content thematic analysis and compared to the theme descriptors. Congruence was generally found with the themes raised in the interviews and focus groups and the results are presented as a complete data set.

The evaluation resulted in a large amount of data regarding the patients who were referred to the service as well as the views of the healthcare professionals of the value and impact of the service both on patients and carers and interestingly on themselves in the provision of additional support (see main report, Jack et al., 2010). Additionally, the evaluation focused on the establishment of the service and with regards to this element three themes emerged that are relevant to setting up the service: the initial fears and how these were overcome, teething problems and local issues regarding care agencies. The verbatim quotations presented are the best exemplars and represent a cross section of the respondents.

Health care professionals' fears

One of the themes that emerged from the data was the initial fears surrounding the establishment of the service and how these had been handled which is presented here. One general practitioner stated:

'I think there was an initial concern that the Hospice at Home would not be sensitive to who's really in charge, and in fact they were very sensitive and handled it very well I thought' (general practitioner respondent 1)

One of the clinical nurse specialists also referred to this issue:

'I think there were some issues initially about what role Queenscourt at Home were going to play and I think there was some issues around that with the district nurses and how it would impact on them, and I think that Queenscourt at Home were very aware of that and very sensitive towards it and they will always ask the question 'are the district nurses involved and have you gone through them first of all'' (palliative care nurse specialist respondent 3)

Additionally one district nurse commented:

'I think that the service have been very careful to ensure that they are seen as an extra support and not as a threat, making sure they communicate well with district nurse team, this has been appreciated' (district nurse survey respondent 7)

Teething problems

No new service is without initial teething problems and there appeared to have been some initial problems with relatives getting confused as to who was actually coming to sit with them. This

appeared to be relating to night visits and was generally confined to the start of the service. One palliative clinical nurse specialist said:

'On a negative point, I know they've had problems because there has been times where there's been some confusion between the sitting services, because I think sometimes there's problems with double booking and some problems with communication between you know the hospice, the district nurses and then the patient, the carer about who's actually coming in' (palliative clinical nurse specialist respondent 5)

Local issues - care agencies

One interesting finding was the impact of the service on other agencies which was referred to by several respondents:

'They are so pleased with the staff from Queenscourt at Home, that it's actually had a bit of knock-on effect for other carer services. Well like the agency carers who go in and that I suppose has highlighted some issues maybe around their carers, their standard of carers, their education of carers' (palliative clinical nurse specialist respondent 6)

'We've had a couple of incidences with a couple of our patients where the agency night sitters fell asleep, so the family have just been distraught because these patients have been like very, very poorly' (district nurse respondent 12)

'I've had a negative experience quite recently from one of the services (care agency)....., they sent quite an inexperienced member of staff to a patient and it was for a night sit and this particular member of staff couldn't even use a bed pan, she didn't know how to use a bed pan. --- So I think, I worry that a lot of the staff in these agencies are not experienced enough' (district nurse respondent 13)

The impact of the service on other agencies was widely reported by the district nurses. Examples of suggested sub optimal care from agency carers was noted (the research team were assured that in one particular case action had been taken and the particular carer no longer worked at the agency). This issue appears to be widespread and clearly further exploration into what training agency staff provide for their staff is undoubtedly needed.

Conclusion

Helping to provide choice in care at the end of life is central to UK policy, and developing services that can help to promote this choice to die at home, if wished, is the goal. Providing additional support in the form of a hospice at home service is suggested as one method of promoting choice. But the wide variation in what a hospice at home service comprises indicates the need for careful planning in establishing the service to ensure it meets the needs of the local population. This paper reports on some general lessons that can be considered in the development of a bespoke hospice at home service, stressing the importance of a local consultation with all stakeholders that clearly identified what is actually needed.

Implications for practice: lessons to share in developing a hospice at home service

Introducing any new service has to be carefully planned and the time that should be allowed for this stage cannot be underestimated. The hospice team undertook a benchmarking exercise to explore other models of hospice at home services, and as is indicated in the literature there are a variety of models that can be used or adapted. The key message from this exercise was the consultation with the stakeholders to find out what was needed in the locality. Pertinently, this was a service that was provided by staff who had specific training and education in palliative care. The additional on-going

support via Moodle™ was found to be beneficial judging from the informal comments by the hospice at home team. All these factors were taken into account (see Box 2) coupled with clear leadership of the hospice at home service by staff who were cognisant with the current district nursing service provision within the locality.

Box 2. Steps to develop an effective hospice at home service

1. *Preparation:* speak to stakeholders (patients, family carers and healthcare professionals) to find out exactly what services are already available in your locality and the gaps in current services
2. *Be clear about what you can offer:* assess if you are the right service to fill the gap
3. *Clinical leadership:* ensure the clinical co-ordinator is fully cognisant with the district nursing service and how it works
4. *Team staffing:* ensure the staff have either community experience (lone working) or palliative care experience or both
5. *Comprehensive induction programme:* with placement at the hospice essential
6. *Support:* ensure lines of support are in place for the staff including regular clinical supervision as well as lines of adhoc support 24/7 via the hospice in – patient unit
7. *Communication:* ensure good lines of communication with the primary care teams are set up including in the planning, launch and development of the service
8. *Reassurance:* to the healthcare professionals that this is an additional service and that you are not taking over care
9. *Referral criteria:* ensure clear and agreed by all stakeholders
10. *Publicity for the public:* advertise the service in the local paper and distribute flyers to health centres etc.

What was very clear from the consultation exercise was the importance of the patient remaining under the care of the district nursing service and that the hospice at home was not taking over the care of the patients, but providing additional care and support. This was possibly one of the biggest challenges faced in the establishment of the service as some district nurses were fearful of losing the palliative care patients. Although there was some resistance to use the service in some areas, this was short lived, helped possibly by good communication and feedback to the district nursing service. This was a point constantly reinforced by the hospice at home co-ordinators and clearly this was achieved as reported in the feedback from the healthcare professionals.

The evaluation element of the project that had a perhaps more novel approach of capacity building for novice researchers, generally worked well. The main challenges were developing novices where there was a tight time frame, which was addressed by clearly defined role and responsibilities, a closely monitored time frame and regular reporting. There was a problem with poor recruitment of district nurses into the focus groups due to high levels of staff sickness. To overcome this, the research team developed an on line survey in order to give them the opportunity to share their views and experiences.

Overall the key to the success of the establishment of the service, was the careful planning and listening to the stakeholders, and focusing on providing an additional tailor made service to meet the needs of patients and families. Keeping the district nurse as the key care provider coupled with clear referral criteria and developing lines of good communication with all agencies are suggested as vital for the implementation of the service. Although there is no formal evaluation from patients and family carers at this point in time, informal anecdotal feedback from health professionals, and family carers including letters and thank you cards; inform us that the staff appear to be 'doing a good job.'

References

- Caress, A., Luker, K.A. and Chalmers, K.I. (2009) A narrative review of interventions to support family carers who provide physical care to family members with cancer. *International Journal of Nursing Studies*. Vol. 46. No. 11. pp 1516-1527.
- Department of Health (2008) *End of Life Care Strategy – promoting high quality care for all adults at the end of life*. London: HMSO.
- Gomes, B. and Higginson, I. (2006) Factors influencing death at home in terminally ill patients with cancer: systematic review. *British Medical Journal*. Vol. 332. No. 7540. pp 515-521.
- Grande, G., Farquhar, M., Barclay, S. and Todd, C. (2004) Caregiver bereavement outcome: relationship with hospice at home, satisfaction with care, and home death. *Journal of Palliative Care*. Vol. 20. No. 2. pp 69-77.
- Jack, B.A., Groves, K., Baldry, C., Gaunt, K., Sephton, J., Whelan, A. and Whomersley, S.J. (2010) *Evaluation of the Queenscourt at Home Pilot Service*. Evidence-based Practice Research Centre, Edge Hill University. (www.edgehill.ac.uk/eprc/reports)
- Jack, B. and O'Brien, M. (2010) Dying at home: community nurses' views on the impact of informal carers on cancer patients' place of death. *European Journal of Cancer Care*. Vol. 19. No. 5. pp 636–642.
- Jack, B.A., Littlewood, C., Eve, A., Murphy, D., Khatri, A. and Ellershaw, J.E. (2009) Reflecting the scope and work of palliative care teams today: an action research project to modernise a national minimum data set. *Palliative Medicine*. Vol. 23. No. 1. pp 80-86.
- Miles, M.B. and Huberman, A.M. (1994) *Qualitative data analysis: an expanded sourcebook* (2nd edition). California: Sage Publications.
- Patton, M.Q. (2002) *Qualitative Research and Evaluation Methods*. California: Sage Publications.
- Polit, D.F. and Beck, C. (2009) *Essentials of Nursing Research Appraising Evidence for Nursing Practice* (7th edition). Philadelphia: Lippincott William and Wilkins.
- Robbins, M. (1998) *Evaluating Palliative Care – Establishing the Evidence Base*. Oxford: Oxford University Press.
- Stosz, L. (2008) *Literature Review of the Evidence Base for a Hospice at Home Service*. Centre for Health Services Studies, University of Kent. Available at: http://www.kent.ac.uk/chss/researchcentre/docs/hospice_at_home_literature_review.pdf (Last accessed 1st November)
- The National Council for Palliative Care (NCPC) (2007) *National Survey of Patient Activity Data for Specialist Palliative Care Services-MDS*. Full report for the year 2006-7. NCPC.
- Todres, L. and Holloway, I. (2010) Phenomenological Research. Chapter 15 in Gerrish, K. and Lacey, A. (Eds) (2010) *The Research Process in Nursing* (6th edition) Oxford: Wiley- Blackwell Publishing. pp 177-187.
- Topping, A. (2010) The Quantitative-Qualitative Continuum. Chapter 11 in Gerrish, K. and Lacey, A. (Eds) (2010) *The Research Process in Nursing* (6th edition) Oxford: Wiley-Blackwell Publishing. pp 129-141.

Catherine R Baldry (MA, RN), Director of Nursing and Education, Queenscourt Hospice, England.

Barbara A Jack (PhD, MSc, BSc econ, RN, RNT, PGDE), Head of Research and Director Evidence-based Practice Research Centre, Faculty of Health, Edge Hill University, England.

Karen E Groves (MRCGP, FRCP, MSc), Consultant in Palliative Medicine, Queenscourt Hospice, England.

Helen Birch (RN), Staff Nurse, Queenscourt Hospice, England.

Ann Shard (RN), Staff Nurse, Queenscourt Hospice, England.