

## APPROACHES TO PATIENT CARE

**Supporting home care for the dying: an evaluation of healthcare professionals' perspectives of an individually tailored hospice at home service**

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**Aims and objectives.** To explore health care professionals' perspective of hospice at home service that has different components, individually tailored to meet the needs of patients.

**Background.** Over 50% of adults diagnosed with a terminal illness and the majority of people who have cancer, prefer to be cared for and to die in their own home. Despite this, most deaths occur in hospital. Increasing the options available for patients, including their place of care and death is central to current UK policy initiatives. Hospice at home services aim to support patients to remain at home, yet there are wide variations in the design of services and delivery. A hospice at home service was developed to provide various components (accompanied transfer home, crisis intervention and hospice aides) that could be tailored to meet the individual needs of patients.

**Design.** An evaluation study.

**Methods.** Data were collected from 75 health care professionals. District nurses participated in one focus group (13) and 31 completed an electronic survey. Palliative care specialist nurses participated in a focus group (9). One hospital discharge co-ordinator and two general practitioners participated in semi-structured interviews and a further 19 general practitioners completed the electronic survey.

**Results.** Health care professionals reported the impact and value of each of the components of the service, as helping to support patients to remain at home, by individually tailoring care. They also positively reported that support for family carers appeared to enable them to continue coping, rapid access to the service was suggested to contribute to faster hospital discharges and the crisis intervention service was identified as helping patients remain in their own home, where they wanted to be.

**Conclusions.** Health care professionals perceived that the additional individualised support provided by this service contributed to enabling patients to continue be cared for and to die at home in their place of choice.

**Relevance to clinical practice.** This service offers various components of a hospice at home service, enabling a tailor made package to meet individual and local area needs. Developing an individually tailored package of care appears to be able to meet specific needs.

**Key words:** focus groups, home-care services, palliative care, questionnaires

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## Introduction

Healthcare professionals and the general public have identified being able to remain at home and to die there, as the preferred option (Higginson 2003, Shepperd *et al.* 2011). Indeed, 59% of the public report they are frightened of dying in hospital (Dying Matters Coalition 2011). In the UK, although the majority of deaths are in hospital (Office of National Statistics 2009), there has been a slight improvement in the home deaths. In 2004, 18.3% of deaths occurred at home, and in 2010, this had risen to 20.8%, this rise was particularly noted for patients who had a cancer diagnosis (Gomes *et al.* 2012). However, this is not the case for other countries including Italy and Korea where hospital death remains prevalent (Costantini *et al.* 2000, Decker & Higginson 2006, Yun *et al.* 2006, Costantini 2008, Economist Intelligence Unit 2010, Gomes *et al.* 2012).

Increasing the options for patients with chronic and life-limiting illnesses has been central to numerous UK policy initiatives that are aiming to reshape community care and service provision. These have resulted in the development of the Department of Health (2008), which has helped to develop end-of-life services in the UK. These initiatives are underpinned by the desire to meet patients' preferences regarding place of care are met, wherever possible. Coupled with these initiatives is a rapidly ageing population that is likely to have increasingly complex comorbidities, which will increase the demand for services (Gomes & Higginson 2008).

Several studies have explored the issues that impact upon the feasibility of keeping terminally ill patients at home. These identify a variety of influencing factors, highlighting issues relating to informal carers, including the fact of the patient living alone and the ability of the carer to cope (Davies *et al.* 2006, Zapart *et al.* 2007, Bee *et al.* 2008, Jack & O'Brien 2010). A systematic review by Gomes and Higginson (2006) identified 17 issues that affected the place of death, including the illness trajectory, patients' preferences, level of available home care and social support, the presence of informal carers and consideration of the families' wish for a home death. Having multiple family members to provide informal care and sharing of responsibilities was identified as important. They concluded the network of factors that influence where patients with cancer die is complicated and stressed the need for continuing evaluation of policy initiatives.

## Background

### Developments to support end-of-life care at home

Over the last two decades, the expansion of palliative care has resulted in a growth of specialist hospital palliative care

services and the number of hospices. Additionally, to meet the increasing request for home care, there has been a growth of palliative care home care services. This has included countries where resource constraints and cultural values focus on home care (for example, Uganda and Kerala in India) (Economist Intelligence Unit 2010). In the UK, approximately 140,000 patients were supported by hospice home care teams in 2006–2007 (England, Wales, Northern Ireland) [The National Council for Palliative Care (NCPC) 2007].

A review of the literature to establish the evidence base for hospice at home services found multiple descriptions of hospice at home services and also what that service comprised. Variations in services included: 'out-of-hours palliative care, hospital at home, community specialist palliative care, crisis intervention and rapid response teams' (Stosz 2008, p. 8). Generally, a broad definition was adopted for the review that included 'hospice style care that is provided in the home environment' (Stosz 2008, p. 7).

There is variation in the UK as to what hospice at home services comprise, generally they may be categorised to include nursing and sitting services, teams to support medical emergencies and transfer home support. More recently, Marie Curie Cancer Care has developed a 'Delivering Choice Programme' (<http://deliveringchoice.mariecurie.org.uk>) comprising out of hours specialist palliative care nursing response programme, care coordinating roles, a discharge link nurse, dedicated transport services, and health and personal care assistants. However, there is limited robust evidence on the

**Table 1** Composition of the hospice at home service (Jack *et al.* 2010, Baldry *et al.* 2011)

Hospice aides	These are nurses both registered and healthcare assistants who have had training to care and support patients and their families at end of life. There is a core team as well as a cadre of bank staff to draw upon. They can provide services in the patients' home
Accompanied transfer home	To support the discharge home of frail patients and enabling a seamless transition a hospice aide will accompany the patient, with or without a family member, on their journey from hospice/hospital to home. They will remain with the patient providing support until the district nurse or other carer arrives
Crisis intervention	For complex cases or where palliative care input is urgently needed, a multi-professional team (doctor/nurse/physiotherapist/occupational therapist/pharmacist) undertake an assessment visit and plan ongoing management to be undertaken, usually by the primary healthcare team. If necessary, they will perform short-term management and then hand care back

effectiveness and interrelationships of the different service elements (King *et al.* 2000, Grady & Traverse 2003).

The wide variation in hospice at home care services, along with the challenges of conducting robust clinical trials with patients who are at the end of life, has resulted in limited evidence of their effectiveness (Stosz 2008, Shepperd *et al.* 2011). In a recent revised Cochrane review, only four trials met the criteria for inclusion (Shepperd *et al.* 2011). However, studies that have obtained healthcare professionals' views and past carers' experiences have generally reported positively on the overall impact of services (Lucas *et al.* 2008).

### The hospice at home service

The hospice is located in the north-west of England and provides ten inpatient beds and day care services in a region with a population of approximately 235,000. It comprises a mixed population encompassing both a rural (market town and farming area) and urban (holiday/retirement). It was recognised that a hospice at home service would be a useful addition to the services the hospice offered (the development of the service, including planning, design, implementation and a summary of steps to develop a hospice at home service are reported elsewhere) (Baldry *et al.* 2011).

The service comprises of *hospice aides* (registered nurses and healthcare assistants), *accompanied transfer home* and *crisis intervention* (see Table 1). Specific referral from a healthcare professional for patients with 'advanced progressive disease, who are on the Gold Standards Framework Register, have a DS1500 form (which entitles the patient to non means tested benefits at end of life) and who wishes to remain at home. The patient will already be receiving

**Table 2** Data on patients who received the service (Jack *et al.* 2010, Baldry *et al.* 2011)

Demographic data
Referred to service – 245 (several patients were admitted to hospital, had died or declined service)
Received service – 201
41 crisis intervention visits, 30 accompanied transfers, 1330 hospice aides shifts
Gender – 97 (48%) male:104 (52%) female
Living situation – 57 (28%) lived alone:144 (72%) did not live alone
Diagnosis – 184 (92%) cancer:17 (8%) noncancer
Age in years – 25–60 = 12%, 60–79 = 51%, 80–97 = 36% (range 25–97 years)
Source of referral – primary care 91 (45%):palliative care 100 (50%):hospital 10 (5%)

care from the district nursing services and other available agencies (social services, private agencies)' (Jack *et al.* 2010, p. 3).

### The use of the service

The hospice at home service recorded information regarding all the patients who were referred to the service during the first year from February 2009. Demographic data are as follows: gender and who they lived with; clinical diagnosis and who referred them; service use including which elements, the number of days used and place of death. In the first year, 201 patients received the service of which 132 (73%) died at home (Jack *et al.* 2010, p. 4), Baldry *et al.* (2011) (Table 2).

### Methods

#### Aim

The aim of this study was to explore healthcare professionals' perceptions and experiences of the hospice at home service.

#### Design

A stakeholder-based evaluation research approach was adopted for the study; as the purpose was to explore stakeholders' (in this case, the healthcare professionals) perceptions and experiences of the new hospice at home service

**Table 3** Data collection and sample

Role	Data collection	Number invited (approx)	Participants
Specialist palliative care nurses	Focus group	9	9
District nurses	Focus group	20	13
Discharge coordinators	Interviews	2	1
GP	Interviews	20	2
GP	Survey	90	19
		88 (included in survey)	
District nurses	Survey	70	31
		57 (included in survey)	
Total			75

NB staff who had participated in the interviews and focus groups were not sent the survey (Jack *et al.* 2010, Baldry *et al.* 2011).

(Robbins 1998, Patton 2002). Evaluation research was appropriate for this study, as its focus and aim was to produce information about the programme under evaluation, in this case the new service. Evaluation research does not have a specific methodology, but draws upon both quantitative and qualitative approaches, enabling an evaluation to be specifically designed to meet the needs of the study (Patton 2002). This study was a mixed methods design, including a retrospective analysis of all referrals made to the service in its first year (Baldry *et al.* 2011), as well as qualitative data from healthcare professionals, which is the focus of this paper.

### Data collection

Data collection included a variety of tools (interviews, focus groups, open-ended electronic surveys) (see Table 3 that describes the tool used and response rates). In the first phase of data collection, qualitative interviews and focus groups were undertaken, to enable an exploration of the experiences of the service by community healthcare professionals (Polit & Beck 2009, Todres & Holloway 2010, Topping 2010). Focus groups are widely used to facilitate group discussion and are valuable in obtaining a broader perspective (Kitzinger 1996, Vaughn *et al.* 1996, Hudson 2003, O'Brien & Jack 2010). Interviews were also used to capture the views of the discharge coordinator team (based in the acute hospital) and general practitioners.

To reach the wider population, a second phase of data collection was introduced, which comprised a confidential electronic survey, comprising mainly open-ended questions. Electronic surveys are becoming increasingly popular in health service research as they are inexpensive to administer, can be completed in the respondents' choice of time and can reach a wide geographical area (Oppenheim 1992, Jones & Rattray 2010, McKenna *et al.* 2010).

### Interview and survey schedule

A semi-structured interview schedule to guide the discussion was developed, drawing upon the available literature. Questions focused around the participants' experiences of the hospice at home service, the different elements and its impact. Generally, questions were open ended, and participants were encouraged to elaborate on points and supplement with clinical examples if appropriate. This was adapted for the survey that contained similarly open-ended questions. Piloting of all data collection tools was performed with healthcare professionals, who were not part of the study and minor modifications made to the phrasing of some questions.

### Participants

The specialist palliative care nurses, district nurses (registered nurses) and general practitioners who (from the patient referral data) had been actively involved in at least three cases who had the hospice at home service were invited to participate in the focus groups. (Unfortunately, a focus group was not feasible for the general practitioners as practical constraints could not be overcome, and therefore, interviews were offered as an alternative). The views of the hospital discharge coordinators were also sought, owing to their active involvement in planning discharges home (owing to the low numbers in post, interviews were offered).

Participants for the second phase of the study (electronic survey) included all permanent general practitioners and qualified district nurses in the locality who were invited to participate in the study (staff who had participated in the initial phase of focus groups and interviews were not included in the survey). Locum general practitioners, specialist trainee general practitioners, student nurses and bank nursing staff were excluded from the study, as we could not ensure they had any experience of the service (Table 3).

### Procedure

Semi-structured interviews were held at the hospice or via telephone, took between 30 minutes and an hour and were conducted by one member of the research team (BJ). The research team were mindful of the differing roles held by the specialist palliative care nurses and generalist staff (district nurses) regarding end-of-life care, and therefore, separate focus groups were held (Jack & O'Brien 2010). The focus groups were run by two of the research team, one who acted as moderator (BJ) and the other as note taker (AW). Only participants and researchers were present during the focus group interviews. As group members knew each other professionally, the researchers agreed the ground rules of confidentiality and respect with all participants at the start of the focus group. At the conclusion of the interview, to ensure key issues were verified with respondents and additionally to enhance the trustworthiness of the results, a summary of issues was verbally reported on by the moderator/interviewer (Jones 2003, Goodman & Evans 2010). Participants were invited to comment on the transcription, but all declined. The confidential electronic survey was distributed by the research governance department, in accordance with the trust data protection policy, with a reminder sent after two weeks. Data from healthcare

practitioners were collected between October 2009–January 2010 so that at least eight months experience of the service was possible.

### Data analysis

The data analysis drew upon a thematic analysis approach owing to the flexibility that it offers (Braun & Clarke 2006). The process adopted included the following steps; all recordings from the focus groups and interviews were listened to. This enabled the initial ideas and potential themes to be identified. Following the verbatim transcribing of the digital recording, additional analysis was performed. The identification of categories was made and data subsequently coded. This process carried on until all data were analysed. The preliminary analysis of the open-ended electronic survey was performed via survey monkey which has been used to distribute the survey. The same procedure was then used as for the analysis as for the focus groups and surveys. This process was undertaken independently by three members of the research team (BJ, AW, KyG) and an agreement on the key themes made (Miles & Huberman 1994, Polit & Beck 2009). Congruence was generally found with the themes raised in the interviews, focus groups and open-ended electronic survey, and the results are presented as a complete data set.

### Ethics

The study was reviewed by the Liverpool Research Ethics Committee who considered it to be service evaluation. Standard procedures for recruitment, consent and participant information (including confidentiality) were adhered to. Research governance approval was gained from the Primary Care Trust, and appropriate guidelines followed. Participants were informed that identifying data would be removed at transcription stage. All data collection and analysis were performed by the academic members of the research team.

### Results

Several themes emerged from the study including the development of the service and impact on healthcare professionals, which are reported elsewhere (Baldry *et al.* 2011). We focus here on the elements of the service and issues reported by the participants that related to patients, including those who lived alone and carers. The verbatim quotations presented are the best exemplars for the theme and represent a cross-section of the respondents.

### The elements of the service

The different elements of the services were referred to by all groups of respondents; the accompanied transfer home service was particularly commented upon by the discharge coordinator and palliative care nurse specialists who had more experienced of this service. The discharge coordinator referred to the practical value of this service, which had been used on 30 occasions during the year, as an additional resource in helping to get patients discharged home:

I think it's just given us more tools to try and help, where we could see a problem, where we would have struggled with the person who we thought was vulnerable in an ambulance, that you felt secure that they were being looked after appropriately. (Discharge Coordinator, interview)

The palliative care nurse specialists' (PCNS) focus group discussed the accompanied transfer home service and the case of a patient dying in the ambulance. Although the patient had not died at home the value of the effort and ongoing support for the family was noted:

— didn't make it home (alive), but the 'hospice at home' service were there with the family when they got him home, they were able to spend time with them and she was very supportive and the family mentioned that afterwards. That that was a great of comfort to them that there was somebody there. (PCNS respondent 5, focus group)

The impact of the crisis intervention service was particularly highlighted by the palliative care nurse specialists and general practitioners. It was stressed that the added input from a multi-professional specialist palliative care service was fundamental to enabling some patients to remain at home. This element of the service had been used in 41 cases in the year (approximately 20% of cases). Examples were given in the focus group and one illustration included:

I had a situation where there was a gentleman who became acutely unwell with a brain tumour and his wife was caring for him at home and quite a youngish family and clearly the hospice admission would have been very appropriate for this gentleman, but he didn't want to go into the hospice and certainly couldn't be moved because of his symptoms anyway. And his wife wanted him to be at home, – I had a consultation with the GP on the phone and it was agreed that hospice at home (Crisis Intervention Team) would come out. (PCNS respondent 4, focus group)

A general practitioner also had experience of this element of the service where the team were able to respond to that avoided a hospital admission:

there was somebody with lung secondaries who became very very breathless, and that created, – a crisis, breathlessness. (GP respondent 1, interview)

The hospice aides element of the service was widely reported by all respondents. This was discussed in the context of the impact upon the patients and the carers including enabling the increased speed of discharge from the hospice and hospital and the impact on the carers. In particular, the palliative care nurse specialists and the discharge coordinator, referred to the overall service allowing speedier discharges, due to the additional support it can provide, examples included:

I think from the hospital point of view as well, I'm pretty sure that we've been able to get more people home because of this that we wouldn't have done. (PCNS respondent 3, focus group)

And often it can be a stop gap as well, if things have changed or carers are struggling, you can offer care immediately, you're not waiting for things to go to panel and forms to be filled in, it can happen quite quickly while those other systems happen, so it just fills that gap. (District nurse respondent 8, focus group)

### Impact on patients and carers

All respondents stated that the hospice at home service appeared to support patients remaining at home, and several respondents illustrated their responses with clinical examples such as the quotation from one general practitioner and a district nurse:

One patient who lived alone, who had, – widespread carcinomatosis and was gradually deteriorating over a period of months, who wanted to stay at home, who was able to do so because of the input of the sitting service, I don't think there would have been any other option for him at the time and that went very well at the end, he died at home. (GP respondent 2, interview)

We also had a lady that actually lived on her own and she was able to stay at home because of the 'hospice at home' service. (District nurse respondent 6, focus group)

Similarly, the added support the service could offer for those who live alone including providing an overnight sitting service was noted by one respondent:

I've just used it for an elderly gentleman that lives by himself and his daughter in law actually came in the day time, but at night time they have the reassurance that there was somebody. (PCNS respondent 7, focus group)

### Impact on carers

There was a consensus from all respondents of the value for the carers for providing respite for the carer, one general practitioner commented:

I think it allows carers to have some time and space, I think it gives them a breathing space – to be able to recharge their batteries to be able to cope and I think that's essential to have that, to be able to rely on people who they can trust and have experience as well rather than family member—I think I find carers can off-load to them as well and get some support from them. I think that's a good thing. (GP respondent 2, interview)

Furthermore, by providing this sitting service enabled the carers to have some space for themselves and to carry on with their lives:

I had a situation where again it was quite a young man and all his wife wanted to do was to be able to take the young children to football on a Saturday and Sunday, so we used them for a Saturday and Sunday morning, but it's having that confidence now to say that that service is available. (PCNS respondent 7, focus group)

I had a situation as well where somebody wanted to go to church, you know it was like every Sunday, she went to church and we actually got hospice at home in whilst she could go to church and that was a big thing for her. (District nurse respondent 2, focus group)

### Discussion

This study reports on the introduction of an additional hospice at home service, comprising discrete elements to support care of the dying at home, and the findings suggest that each the element is seen as valuable by the healthcare professionals. First, the accompanied transfer home element, which can be arranged quickly, appears to be helping speedier discharges. This finding is similar to the Marie Curie Delivering Choice Programme (Ingleton *et al.* 2009). Interestingly, the rapid access to the hospice aides element of the service was also reported as contributing to a faster hospital discharge as care could be put in place quickly. This is clearly an important point surrounding discharge planning for policy makers who in the UK are focusing on reducing hospital in patient length of stay (Torjesen 2011).

Second, the input of the hospice aides in supporting both the patients and carers was reported as valuable, particularly the additional support for the carers was seen as

clearly beneficial. This is a similar finding to other studies reported in the literature (Stosz 2008). However, for this particular service, it is important to consider that the hospice aides had additional training in palliative care, including communication skills, whereas other social care agencies that provide sitting services for terminally ill patients, staff may not have had. How relevant this additional training is remains unclear but is worthy of further research.

Third, the novel component of this hospice at home service was the crisis intervention element that included a specialist palliative care physician, and this is suggested as instrumental in keeping patients at home. Clinical examples of where patients would have been admitted to the hospital indicated this element of the service seems to be having a positive impact. Increasing the options for patients who wish to remain and die at home is clearly going to result in more complex cases being cared for in the community. Therefore, ready access to specialist palliative care teams, who can support the general community healthcare teams, is worthy of consideration for the future development of hospice at home services.

### Limitations of the study

A potential sample bias exists as it was not possible to compare a sample of patients who were not referred to the service with this group. This coupled with a lack of observational data, means the results have to be cautiously interpreted. However, the wide range of data from different groups of healthcare professionals does suggest confidence in the findings. Owing to the time constraints, the views of patients or carers of the service were not able to be obtained. Further research with both patients and carers is undoubtedly required along with an economic evaluation which is important, to confirm financial benefit of the service.

The organisation of this hospice at home service is a model that has not been evaluated in other locations, but it is currently being used to inform the development of other services within the north-west region of the UK to be operational this year. Although the transferability of the findings has to be considered with caution, in a similar way to the 'Marie Curie Delivering Choice Programme' rolled out across the UK, it can be proposed this hospice model could also be transferred. Although this is a local study, the findings are important, as they are helping to identify what models and elements of hospice at home services are potentially effective.

### Conclusion

The flexible hospice at home service, comprising different elements that can be selected and implemented in a timely fashion, is perceived by healthcare professionals as having a positive impact on patients and carers. Particularly with the added input of a medically led crisis intervention team appears to be preventing hospital admissions. This along with the additional support from the hospice aides supporting patients and their families are elements contributing to helping patients being discharged from hospital and also remaining at home. With an increasingly ageing population, there are likely to be more patients who are living alone or where family carers may also be frail. Having specialist services, such as hospice at home that can provide additional care and support and can be tailored for the changing needs of patients (and carers) during the end-of-life journey, seems to be an option for increasing patient choice for a home death.

### Relevance to practice

Supporting patients to be cared for and to die at home if it is their choice is currently being promoted. With an increasingly ageing population, it is clear that many carers will be older and potentially have their own health problems. Therefore, it is important to consider the additional support the carers need to help care for the patient at home. Additionally, there are likely to be more patients with complex palliative care needs being cared for in the community, and services are required that provide rapid support and intervention, including a palliative care physician (where necessary) is important to support the general community care teams. The development of hospice at home services need to consider the complexities of caring for the dying and the changing journey for the patients and carers. Having a model that provides a menu of services that can be individually tailored for the patients need is clearly worth considering.

### Contributions

Study design: BAJ, KEG, CRB, KG, AW; data collection and analysis: BAJ, AW, KG and manuscript preparation: BAJ, CRB, KEG, AW, JS, KG.

### Conflict of interest

The authors, KEG, CRB and JS are employed at the hospice where the service was developed. No other conflict of interest is declared.

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