

## ORIGINAL RESEARCH: EMPIRICAL RESEARCH – QUALITATIVE

# Supporting older people with cancer and life-limiting conditions dying at home: a qualitative study of patient and family caregiver experiences of Hospice at Home care

Barbara A. Jack, Tracy K. Mitchell, Louise C. Cope & Mary R. O'Brien

Accepted for publication 10 March 2016

Correspondence to B.A. Jack:  
e-mail: [jackb@edgehill.ac.uk](mailto:jackb@edgehill.ac.uk)

Barbara A. Jack MSc PhD RN  
Professor  
Evidence-based Practice Research Centre,  
Faculty of Health and Social Care, Edge  
Hill University, Ormskirk, Lancashire, UK

Tracy K. Mitchell BSc MA HCPC (Social  
Worker)  
Research Assistant  
Evidence-based Practice Research Centre,  
Faculty of Health and Social Care, Edge  
Hill University, Ormskirk, Lancashire, UK

Louise C. Cope BPharm MPhil  
Senior Lecturer  
Faculty of Health and Social Care, Edge  
Hill University, Ormskirk, Lancashire, UK

Mary R. O'Brien MA PhD RN  
Professor  
Evidence-based Practice Research Centre,  
Faculty of Health and Social Care, Edge  
Hill University, Ormskirk, Lancashire, UK

JACK B.A., MITCHELL T.K., COPE L.C. & O'BRIEN M.R. (2016) Supporting older people with cancer and life-limiting conditions dying at home: a qualitative study of patient and family caregiver experiences of Hospice at Home care. *Journal of Advanced Nursing* 00(0), 000–000. doi: 10.1111/jan.12983

### Abstract

**Aim.** To explore patients' and family caregivers' experiences and perceptions of Hospice at Home care.

**Background.** The public indicate a preference to be cared for and to die at home. This has inherent challenges, with a key factor being the family caregiver. Supporting end-of-life care at home has resulted in the expansion of Hospice at Home services. A wide configuration of services exists with a lack of robust evidence as to what is valued by recipients, particularly those who are older people.

**Design.** A prospective descriptive qualitative study.

**Methods.** Recruitment was purposive. Eligible participants were in receipt of Hospice at Home service on at least three occasions and were deemed to have a life expectancy measured in weeks rather than days. Digitally recorded semistructured interviews with 41 participants (16 patients and 25 family caregivers) were undertaken between October 2014 - July 2015. Data were analysed and organized thematically.

**Results.** Several subthemes: 'Talking about'; 'Knowing and Doing'; 'Caring for the Caregivers'; and 'Promoting Choice' contributed to the overall theme of Embracing Holism. A positive impact on emotional, psychological, social and physical well-being was apparent.

**Conclusions.** This study has provided additional insights as to the value of Hospice at Home care where Hospice Nurses are helping to bring Hospice care into the home. This is helping to support older people who are dying and their caregivers, to live as well as possible and facilitate their wish to be cared for and die in their own home.

**Keywords:** caregivers, Hospice at Home, nursing, older people, qualitative research, supportive and palliative care

#### Why is this research needed?

- Most people wish to be cared for and to die in their own home, a key factor in achieving home care and death is the support of a family caregiver, but there are recognized groups, including older people, at risk of not achieving this.
- Lack of evidence on patients' and caregivers' needs and what they perceive as valuable support.
- Limited prospective studies that include patients receiving end-of-life care.

#### What are the key findings?

- This Hospice at Home service, delivered by staff trained in the ethos of palliative care, is providing holistic care in the home and acting as a bridge from the hospice.
- Older people and those living alone, recognized as high risk of being unable to achieve home care and death, appear to be supported with targeted interventions.
- Both family caregivers and patients reported how supported they were by the service and recognized its value in promoting their quality of life.

#### How should the findings be used to influence policy/practice/research/education?

- Hospice at Home services with staff trained in the ethos of palliative care should be made widely available.
- Older caregivers are at a higher risk of caregiver burden, and targeted support for them is needed.
- There is a need for more research with patients receiving end-of-life care, to capture their views and experiences.

## Introduction

Over the past 50 years advances in medical knowledge and technology have resulted in hospitals being the preferred site for end-of-life care rather than the home. This is reflected in a fall in number of deaths in the home, which, for the UK, fell from 31% in 1974 to 18% in 2003. Although there was slight rise to 22% for home deaths, still 48% of deaths were in hospital in 2014 (Gomes *et al.* 2013, Public Health England 2014). Globally, death rates in hospitals vary enormously, ranging from 20% in China to 78% in Japan due to multiple cultural, societal and financial issues (Broad *et al.* 2012).

However, the last decade has seen the emergence of a societal shift away from death in hospital to the home (Exley & Allen 2007). When questioned during a population-wide survey in seven European countries about their preference for place of care and death, between 50% and

83% of people, if they had cancer, would they want to die at home (Gomes *et al.* 2012).

Promoting death at home moves the focus onto the care to be provided by families. Exley and Allen (2007) referred to this shift as 're-domestication of care' with the families being co-providers of services. However, this is not without its challenges as several interrelated factors can impact on a home death being achieved, for example, certain cancers, clinical symptoms, marital status, living alone, age and, vitally, having the support of the family caregiver (we refer to family caregivers to include people important to the person; these are not paid caregivers) (Gomes & Higginson 2006, Knighting *et al.* 2015).

## Background

Approximately 6.5 million known family caregivers in the UK are acting in a caring role; half a million of those being cared for are expected to die within the year (National Council for Palliative Care 2012). Changes in household composition, increasing divorce rates, geographical mobility, more women working and rising retirement rates have reduced the availability of people to care family members (Leadbetter & Garber 2010). Consequently, many family caregivers are themselves ageing with an increasing number of older caregivers aged 85 +, a number which has grown by 128% in 10 years to 87,000 (Office for National Statistics (ONS) 2013). This trend is reflected globally with projected rises for the new European Union countries as well as India, Chile, Brazil and China over the coming decades (ONS 2010). Furthermore, most of these older caregivers are looking after someone who is also an older person, adding to the complexity of caring and increasing burden for the caregivers.

Supporting end-of-life care at home has seen the expansion of palliative care home services. However, there are wide configurations of services, including mixed health-care professional teams, rapid response teams for crisis intervention and out-of-hours services generally staffed by unqualified staff. Broadly, they can be defined as hospice care in the home setting (Stosz 2008). The evidence of the effectiveness of such services is generally positive, albeit meagre and limited by the lack of service consistency and the challenges inherent in undertaking robust trials (Shepherd *et al.* 2016). There is clearly a need to explore the impact of these services on those in receipt of them to identify exemplars of good practice and evidence to enable interventions to be appropriately targeted, particularly for the increasing numbers of older caregivers.

## The study

### Aim

The aim of the study was to explore patients' and family caregivers' experiences and perceptions of Hospice at Home care.

### Design

A prospective qualitative approach was undertaken drawing on a naturalistic interpretative design (Ritchie & Lewis 2003). This allowed us to gain an in-depth, rich understanding of the participants' experiences and perceptions of the service (Robbins 1998, Polit & Beck 2009).

#### *Setting and organizational model of the Hospice at Home service*

The service is located in North West England covering two counties. To complement the adult hospice inpatient and day service provision, the Hospice at Home service was developed to support people to remain at home and to die at home. The service is available for patients with life-limiting illnesses and cancer who are eligible for non-means-tested benefits at the end of life (within the UK, this is the DS1500 which is issued for a patient with a progressive disease where death is expected within 6 months). The patient would be receiving care from the community nursing team and other care agencies, such as social services and private agencies; the Hospice at Home service is an additional care (Baldry *et al.* 2011, Jack *et al.* 2013, 2014).

The Hospice at Home service is a mixed team of healthcare professionals providing three elements of a service. This comprises accompanied transfer home; medically led Hospice crisis intervention team providing crisis intervention in the home and Hospice Nurses, who are a combination of healthcare assistants (mainly with community experience) and Registered Nurses, who provide shifts of care and support for the patient and carer in their home. They are trained, supported, integrated with and debriefed by multiprofessional palliative care specialists, concentrating particularly on communication and conversations about the future; provide emotional, psychological and spiritual support; and care for the carer alongside practical physical care. Currently, the service is staffed by substantively employed staff including two senior Registered Nurses as service coordinators, administrative support, eight nurses who work 17 hours a week and a bank of 21 staff who are a mixture of healthcare assistants and Registered Nurses to support demand (Baldry *et al.* 2011).

We have previously reported the development of the service, healthcare professionals' views and bereaved family caregivers' perceptions (Baldry *et al.* 2011, Jack *et al.* 2013, 2014). However, there was a clear gap and a need to understand the experience of people currently in receipt of the core element of the service, namely the Hospice at Home Nurses (now referred to as Nurses).

### Participants

A purposive sampling approach was adopted with the inclusion criteria being: participants aged over 18 years, in receipt of the service on a minimum of three occasions (to allow them to become familiar with the service) and English speaking. Exclusion criteria: patients deemed to have a life expectancy measured in days (to avoid intrusion on the families at this time); inability to communicate even with the use of aids and inability to provide informed consent.

Sixteen patients and 25 caregivers were interviewed ( $n = 41$ ) (Tables 1–3 for participant and recruitment details). The majority of patients had a cancer diagnosis and were, in the main, older people with 88% (14) aged over 71 years; additionally, 37% (6) lived alone (factors recognized as challenges in providing a home death). Seventy-eight per cent (7) of patients who had died at the end of the study died at home. Participants were assigned an ID code by the research team P indicating patient and C indicating carers followed by a number, as the interviews were undertaken. Where there is more than one carer for a patient, they are assigned the letters a, b, c, etc.

### Data collection

A topic guide was developed from the previous elements of the evaluation of the service. We adopted a conversational style with semistructured digitally recorded interviews to enable relevant issues to be covered, but which provided flexibility for pursuing appropriate elements of inquiry raised by the participants. Interviews mostly took place in the participant's home (one was undertaken at the hospice when the patient was attending day therapy and one family caregiver requested a telephone interview). Individual or joint interviews were offered to patients and family caregivers and only two had individual interviews. Some patients had more than one family caregiver participate, for example, where several family members shared the care. Data were collected from October 2014 - July 2015 (we suspended collection over the Christmas and Easter seasons).

**Table 1** Demographic data – patients.

|  |           |
|--|-----------|
| Patients who expressed initial interest in participating | 35        |
| Total number of patient participants                     | 16        |
| Reason for 19 patients not participating                 |           |
| Withdrew pre-interview                                   | 2         |
| Condition deteriorated                                   | 7         |
| Stratified purposive sampling 81-90 age group            | 4         |
| Asleep during joint interview with carer                 | 6         |
| Ethnicity  |           |
| All White British patients                               | 16 (100%) |
| Gender   |           |
| Male   | 10 (63%)  |
| Female   | 6 (37%)   |
| Age in years   |           |
| 81-90  | 11 (69%)  |
| 71-80  | 3 (19%)   |
| 61-70  | 2 (12%)   |
| Diagnosis  |           |
| Cancer   | 12 (75%)  |
| Non-cancer   | 4 (25%)   |
| Resides  |           |
| Alone  | 6 (37%)   |
| Not alone  | 10 (63%)  |
| Patient status at end of evaluation                      |           |
| Died   | 9 (56%)   |
| Still receiving the service                              | 5 (31%)   |
| Discharged and alive                                     | 2 (13%)   |
| Place of death   |           |
| Home   | 7 (78%)   |
| Care home  | 1 (11%)   |
| Another hospice  | 1 (11%)   |
| Reason for discharge from service                        |           |
| Condition stabilized                                     | 1 (50%)   |
| Family carer declined service                            | 1 (50%)   |
| Interviewed  |           |
| Alone  | 3 (19%)   |
| With one family carer                                    | 11 (69%)  |
| With two family carers                                   | 2 (12%)   |

### Ethical considerations

Approval was granted by the Hospice Council of Trustees and University Faculty Research Ethics Committee. All standard ethical and data storage processes were adopted. Consent included the use of direct anonymized quotations. All participants were provided with a contact at the Hospice, if they wanted any support after the interview. A flyer advertising the project was given to patients and family caregivers who met the inclusion criteria by Hospice staff and those interested were given a project information sheet. Those who wished to participate agreed for their details to be passed to the research team who contacted them to arrange a convenient time for the interview.

**Table 2** Demographic data – family caregivers.

|  |          |
|--|----------|
| Total number of family caregiver participants                                  | 25       |
| Interviewed  |          |
| With, or in the presence of, a patient   | 23 (92%) |
| Alone (without patient, i.e. telephone interview or conducted in carer's home) | 2 (8%)   |
| Relationship to patient  |          |
| Spouse   | 12 (48%) |
| Husband  | 4 (33%)  |
| Wife   | 8 (67%)  |
| Daughter   | 11 (44%) |
| Son  | 2 (8%)   |
| Caring for patient aged in years   |          |
| 81-90  | 17 (68%) |
| 71-80  | 6 (24%)  |
| 61-70  | 1 (4%)   |
| 41-50  | 1 (4%)   |

### Data analysis

Interviews were transcribed verbatim with identifying features, or names, removed to preserve participants' anonymity. Data were subjected to a thematic analysis approach involving key stages of organization, reduction and refinement (Braun & Clarke 2006). Familiarization with the data was achieved through reading and re-reading each transcript to ensure a thorough understanding of the content. Any similarities, or disparities, in the data were noted as potential themes (Green & Thorogood 2004). The analysis continued as these themes were defined and redefined ensuring all data were represented (Miles & Huberman 1994).

### Validity and reliability/rigour

To establish an element of rigour and reduce the likelihood of introducing bias at the analysis stage (Saks & Allsop 2007), three researchers (TM, MOB and LC) independently analysed and coded transcripts before identifying and comparing initial descriptive codes. Subsequently, a meeting with the fourth researcher (BJ) enabled consensus to be reached on the final coding frame which was then applied across all transcripts to support the initial conclusions from the data.

### Findings

#### Embracing Holism

Thematic analysis identified two main themes: 'Embracing Holism and Service Organization. Our focus here is on Embracing Holism'. Several subthemes contributed to the

**Table 3** Sample details.

| ID *1            | Sex *2 | Age in years | Individual/joint interview | Diagnosis *3 | Lives alone | Carer relationship *4      | Status at end of data collection | Place of death/discharge reason |
|------------------|--------|--------------|----------------------------|--------------|-------------|----------------------------|----------------------------------|---------------------------------|
| P1<br>C1         | F      | 71-80        | Joint                      | NC           | No          | Husband                    | Discharged Alive                 | Stabilized                      |
| P2<br>C2         | M      | 61-70        | Joint                      | C            | No          | Wife                       | Died                             | Another hospice                 |
| C3               | F      | 81-90        | Individual                 | NC           | No          | Husband                    | Discharged Alive                 | Carer declined service          |
| P4<br>C4         | M      | 81-90        | Joint                      | C            | No          | Daughter                   | Discharged Alive                 | Stabilized                      |
| P5<br>C5         | M      | 81-90        | Joint                      | NC           | No          | Wife                       | Died                             | Home                            |
| P6<br>C6         | F      | 81-90        | Individual<br>Individual   | C            | Yes         | Son NR                     | Died                             | Nursing home                    |
| P7<br>C7a<br>C7b | M      | 81-90        | Joint                      | C            | No          | Wife<br>Daughter           | Died                             | Home                            |
| C8a<br>C8b       | M      | 71-80        | Joint                      | C            | No          | Wife<br>Daughter           | Died                             | Home                            |
| P9<br>C9a<br>C9b | F      | 81-90        | Joint                      | C            | No          | Husband<br>Son             | Died                             | Home                            |
| P10<br>C10       | M      | 81-90        | Joint                      | C            | No          | Wife                       | Died                             | Home                            |
| P11<br>C11       | F      | 81-90        | Joint                      | C            | No          | Daughter                   | Died                             | Home                            |
| C12a<br>C12b     | M      | 71-80        | Joint                      | NC           | No          | Wife<br>Daughter NR        | Alive                            | Ongoing                         |
| P13<br>C13       | F      | 81-90        | Joint                      | C            | Yes         | Daughter                   | Died                             | Home                            |
| C14              | F      | 41-50        | Individual                 | C            | No          | Husband                    | Died                             | Home                            |
| C15              | M      | 81-90        | Individual                 | C            | No          | Daughter NR                | Discharged Alive                 | Nursing home admission          |
| P16<br>C16       | M      | 81-90        | Joint                      | C            | No          | Wife                       | Died                             | Home                            |
| P17              | F      | 71-80        | Individual                 | C            | Yes         | N/A                        | Alive                            | Ongoing                         |
| P18<br>C18       | M      | 71-80        | Joint                      | NC           | No          | Wife                       | Alive                            | Ongoing                         |
| P19<br>C19       | M      | 81-90        | Joint                      | C            | Yes         | Daughter NR                | Alive                            | Ongoing                         |
| C20a<br>C20b     | M      | 81-90        | Joint                      | C            | No          | Daughter NR<br>Daughter NR | Alive                            | Ongoing                         |
| P21              | M      | 61-70        | Individual                 | NC           | Yes         | N/A                        | Alive                            | Ongoing                         |
| P22<br>C22       | M      | 81-90        | Joint                      | C            | Yes         | Daughter NR                | Alive                            | Ongoing                         |

\*1 P = patient, C = carer; \*2 M = male, F = female; \*3 C = cancer, non-cancer; \*4 NR = non-resident.

overall concept. These demonstrate how the skills and expertise of the Nurses impact on the quality of care received and the confidence felt by patients and caregivers that their decisions would be respected and their choices supported. This inevitably had a positive impact on emotional, psychological, social and physical well-being.

### Talking about

There was a clear consensus among participants that the Nurses were skilled communicators able to engage patients and caregivers in often difficult discussions about death and dying. One participant explained:

They [Nurses] approach you and talk about cancer. . . a lot of people hide their emotions, they can't cope with it. All of the staff have approached it . . . in the manner that I would have liked to have been approached . . . Because of the nature of their work, you have the confidence in speaking to them, speaking about what's going to happen to you, where you're going and what's the by-product, the future, without any of the silliness (P2, 61- to 70-year-old male patient).

As a result of being able to have such sensitive conversations, relationships with the nurses were established which were evidently very important to both patients and caregivers. There was a sense that the Nurses can, holistically, understand an individual's situation which ensures that the patient's needs and wishes remain central. One participant stated:

[Nurse's] very understanding and when you're talking about understanding in this day and age, it's not easy to get people to understand your needs or your way of life . . . [Nurses] always put your needs first (P4, 81- to 90-year-old male patient).

Additionally, caregivers highlighted the importance of interaction between Nurses and patients as a means of providing social and intellectual stimulation:

When I come back he's [patient] . . . always very happy, very cheerful, . . . it's nice for him to have social interaction as well . . . he comes out of himself, otherwise he can sit there quite quiet (C4, daughter of 81- to 90-year-old male patient).

This notion was echoed in comments suggesting that patient and caregiver psychological well-being is improved through having such a good relationship with Nurses. One patient summed up what others implied:

The very presence of somebody being there. You know, physical presence, it makes a difference. Psychologically it's a boost. . . what I'm saying [is that I feel safe]. Yes. Psychologically you feel that you've had a boost (P22, 81- to 90-year-old male patient, lives alone).

### Knowing and doing

Nurses' medical knowledge and understanding of the trajectory of conditions means that they are able to monitor the patient's condition and ensure symptoms are managed. Using their expertise, it was apparent that Nurses can reduce the likelihood of having to involve other professionals for minor issues. Additionally, they have the ability to anticipate signs of deterioration as well as signpost to medication or equipment that impacts on quality of life; one participant elaborated:

[Nurses] knowing I needed the artificial saliva for night time use. It was very, very practical and I'd never heard of it before. . . And it's invaluable . . . [and] the bed itself, although we thought they were a little bit premature. . . they were absolutely right [about needing this hospital bed] (P2, 61- to 70-year-old male patient).

In addition, Nurses were able to assist patients and caregivers to traverse the complexities of care provision and direct them towards appropriate services:

You're trying to navigate it and you're dealing with so many agencies and you don't know which way to go sometimes. They're very good in that particular sphere in that they'll try and help you as much as possible, but it's so – I didn't realize it was so complicated to die, I didn't, honestly. I thought it'd be a fairly simple job, but it's not, it's not (P2, 61- to 70-year-old male patient).

It was clear that participants perceived that the Nurses' level of training and expertise resulted in the provision of a fundamentally different service to that provided by other health professionals and staff from care agencies, engendering confidence in the care provided. Comments suggested that without appropriate training or experience, people such as agency carers or volunteers may not understand the patient's needs, or how best to handle any anticipated or unexpected complications:

It is good to have somebody who has obviously had some training with issues involved with cancer. . . I don't need to worry about mum when they're here because they would know what to do (C9b, resident son of 81- to 90-year-old female patient and her spouse).

The notion of professionalism was commented on by participants suggesting that it provided reassurance. No matter what might occur during a shift, the Nurses would know how to respond, especially, as highlighted here, when the patient is at end-of-life:

I am quite convinced that when the day comes if there's a crisis, they'll deal with it. They won't be running round like a headless chicken; I don't think that will happen (P2, 61- to 70-year-old male patient).

On occasion, caregivers also picked up useful techniques from observing the Nurses in action with the patient, meaning that the patient then responds better to the caregiver, or the caregiver gains confidence in using equipment:

They've shown us how to use the [slider] sheet. . . definitely they give you the confidence (C20a, non-resident daughter of 81- to 90-year-old male patient and his spouse).

In addition to medically related aspects of care, it was clearly apparent that Nurses providing more domestically

related support was highly valued by caregivers. Not only does it enable caregivers to relax, but providing practical household support appeared to relieve the burden on caregivers of the additional day-to-day chores, such as laundry, which often result from the patient's condition.

### Caring for caregivers

It was apparent from what participants told us that caregivers find it difficult to hand over the patient's care to others, putting the needs of the patient above their own. Having the Hospice at Home service gave caregivers the confidence to let go of caring responsibilities, even if only for a short period of time, knowing the patient would be well cared for:

I can go to bed and I can sleep ... it does make a difference when you know that there's somebody here ... you do feel that bit better (C7a, wife of 81- to 90-year-old patient).

Additionally, knowing that someone had their best interests in mind was reassuring to caregivers who felt that their needs and their health were clearly regarded as important:

Whenever they come they always ask how I'm doing, am I coping alright, do I need any more help, is there anything else they can do. ... they always keep me aware of what's available, that's reassuring, too, that somebody's watching out for me (C4, daughter of 81- to 90-year-old male patient).

Impact on the wider family was also reported. Caregivers explained that Nurses' shifts enable them to attend to caring responsibilities for other family members and attempt to achieve some sense of normality with their own families:

[The service has] given us more time to keep our homes going as normal as possible (C12b, non-resident daughter of 71- to 80-year-old male patient).

### Promoting choice

Several participants discussed how the Hospice at Home service had enabled needs to be met in the home and thus prevented unwanted hospital admissions; as a result of the holistic understanding that the Nurses have, patients expressed confidence that their wish to die at home will be respected:

The declaration for do not resuscitate... I know in my own mind that they [Nurses] would respect that and they would understand that – understand what I mean. It is important to me, 'cause the last thing I would want is for them to have any outside agencies to

start imposing on things when it reaches the stage where I can't really do it myself, which is outside of my scope, my wish (P2, 61- to 70-year-old male patient).

There was a clear sense that patient choice should be respected and that the service was fundamental in ensuring that such wishes were realized. It was apparent that some participants felt that without the Hospice at Home service their choices about where they were cared for and where they would ultimately die would not have been valued:

I want to die at home. I desperately want to die at home ... but without this [Hospice at Home service] I'd have probably ended up in some nursing home somewhere, or hospital, or some totally undesirable place which I don't want to go to (P2, 61- to 70-year-old male patient).

The convenience of receiving hospice care in their own homes was clearly appreciated by participants, many of whom described tortuous journeys to and from hospital when visiting patients; the service was seen as a *bridge* from the hospice to the home:

Whoever thought that up [the Hospice at Home service] – brilliant idea. That's all I say. It is, to bring the hospice here – we've got all the benefits of the hospice but in our own home. (C8a, wife of 71- to 80-year-old male patient).

## Discussion

This study has reported on the views and experiences of patients and caregivers as they received the Hospice at Home service, focusing on the provision of the core element, the Hospice at Home Nurses. Including the voices of the terminally ill is recognized to be challenging and the design of this study clearly went some way to address the practical and ethical issues to successfully meet its overall aim.

The 41 participants included a variety of relationships including living with the spouse as main caregiver, living with a family member as main caregiver and family caregiver living elsewhere, which is fairly typical of the population. Those living alone were also represented. All participants had a diagnosis of cancer or life-limiting condition.

The overarching key finding was the enormous value all participants gained from the service. No negative comments or reports of poor care or criticisms were made about the service. What was evident from the study was the level of *holistic care* that was being provided by the Nurses. It is known that increased caring roles puts caregivers at risk of

physical and psychological distress (Knighting *et al.* 2015) and fear of not being able to cope (Funk *et al.* 2010, Stajduhar *et al.* 2010). Our findings reflect this and also emphasize the benefits to both patients and caregivers of taking a holistic view of their needs. The provision of a service based on the underpinning philosophy of palliative care was shown throughout the findings, with examples of physical, psychological, practical and social needs being met. Additionally, there was a clear emphasis on achieving the best quality of life for the patients and their caregivers and a goal of letting the patients live as well as they could. What was highly visible to the patients and caregivers was the level of skill and expertise that the Nurses had to *Embrace Holism*. This was coupled with a resulting confidence in the care that was provided. This was similar to that identified by bereaved caregivers in a previous study where they felt they were 'in good hands' (Jack *et al.* 2014).

The communication skills demonstrated by the Nurses were widely reported, including being prepared to discuss end-of-life issues. The skills of listening, putting people at their ease, treating them with dignity and providing opportunities for open and honest conversations were valued by patients and caregivers. Indeed, several respondents reported on the efforts the Nurses made to get to know the 'whole' patient. Additionally, the skills of the Nurses to observe and assess both the patients and caregivers were noted. This support for the caregivers is vital, as it is known that they often neglect their own health and well-being and miss their own health appointments (Knighting *et al.* 2015).

Furthermore, the Nurses were valued for their knowledge of the healthcare system and being able to help the patient and caregiver navigate complex processes, a finding also reported by Morris *et al.* (2015). It is well known that caregivers experience increased social isolation and many who have other responsibilities become removed from their 'normal' family lives (Social Care Institute for Excellence (SCIE) 2013). What is apparent is that the service enables caregivers to retain some sense of 'normality' by providing cover for them to interact with their own families or engage with social activities that are important to them. Such activities may often appear to be mundane, such as shopping, but without the service would be impossible. It is not the extravagance of the activity that is important to caregivers; it is the opportunity to have a break from the demands of caring that is priceless to them.

The value to the caregivers, both those with additional caring and employment commitments and those who have a single caring role, particularly of having day and night shifts (to support them to sleep), was widely reported and

is a factor associated with achieving preferred place of care and death supported in other studies (Ewing & Grande 2013, Jack *et al.* 2014). The value of the service to enable the caregiver to go out of the home was also noted by the patients, knowing their caregiver was having some time for themselves, as well as by the caregivers and wider family members. The support for the caregiver is clearly a vital aspect of the service and particularly so when we consider the age group of the caregivers in this study where many were frail themselves; this targeted intervention is clearly paramount in addressing their needs.

*Embracing Holism*, by bringing Hospice care into the home and acting as a *bridge* from the Hospice, is clearly promoting patient choice in being able to be cared for and to die in their own home. This reflects the notion that providing holistic support in the community will lessen the likelihood that patients will receive expensive hospital admissions and futile treatment at the end of their lives (Murray *et al.* 2004). This holistic-based community care is also supported by the recent findings of Gomes *et al.* (2015) in a mortality follow-up study of 352 patients with cancer, which identified four factors that help to indicate a home death. These include the patient's and carer's choice, the input of community/district nursing and being in receipt of home palliative care. The availability of resources, including home palliative care, was also recognized by Pollock (2015), not only to ensure a home death (where wished for) but also to support symptom control. Consequently, there is a need for such services to be made adequately available.

In this qualitative study, we have reported on the value of being in receipt of a Hospice at Home service, as perceived by the patients and family caregivers. It was apparent that this additional service demonstrated the ethos and philosophy of palliative care, with the overarching emphasis on the holistic care being provided. It can be suggested that this model, co-ordinated and supported by an experienced team at the Hospice, is pivotal to the success of the service and care delivered. Indeed, participants reported how they could see a difference in the care provided by hospice Nurses compared with that provided by other agencies.

The participants in this study were generally older people and some of whom were being cared for by older family caregivers. Older age is identified as a risk factor for patients with cancer in not being able to achieve a home death (Lock & Higginson 2005, Cohen *et al.* 2010). This is an important point to consider when assessing the findings for their transferability, in the development of other services and long-term planning, with the predicted rise in the population of older people (ONS 2012).



Additionally, the study included participants who lived on their own, which is also a reported risk factor for achieving home death. Several patients spoke how without the service, they knew that they could not have remained at home. Of the patients who had died at the end of the study, 78% died at home, this is higher than the average in 2014 of 44.5% (NHS England 2014). It can be suggested that this may be due to the preparatory ground work and consultation with community healthcare teams in the setting up of the service (Baldry *et al.* 2011). This increased awareness of the services available may have resulted in earlier referrals and intervention, although further research would be required to explore this further.

### Limitations

The study is limited through being based on one service, but the element evaluated, that of Hospice Nurses are probably the common denominator of most Hospice at Home services globally. Furthermore, other services are being developed that have adopted this model demonstrating its potential transferability. However, the access to the medical team and flexibility of the service cannot be ignored and are acknowledged as a possible influencing factor. Joint interviews are noted as a potential weakness due to a lack of 'privacy' of accounts. However, this is outweighed by the fact that this was a prospective study and participants' preferences took precedent. A randomized controlled trial comparing different models of services would be of value, although undertaking prospective trials with patients at the end of their lives is particularly challenging.

### Conclusion

This study has provided additional insights as to the value of a Hospice at Home service where Hospice Nurses are helping to bring Hospice-standard care into the home. This holistic care is clearly supporting the patient and older caregivers to live as well as they can, helping to promote and achieve the option of remaining in their home. The prospective study design has enabled us to obtain the real-time experience of the participants, including the voices of the terminally ill who are often a forgotten population in research studies. The experiences of the participants as to what they valued about the service and, importantly, what helped them are factors to consider in the design of Hospice at Home services, in particular, for the increasingly older caregivers who may need targeted support due to their own increasing frailty.

### Acknowledgements

We thank all the participants for the willingness to share their experiences at such a challenging time for them.

### Funding

This research was supported by the Cheshire and Merseyside Palliative and End-of-life Care Network.

### Conflict of interest

None.

### Author contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (<http://www.icmje.org/recommendations/>)]:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

### References

- Baldry C.R., Jack B.A., Groves K., Birch H. & Shard A. (2011) Establishing a hospice at home service: lessons to share. *FoNS International Practice Development Journal* 1(2), 5. Retrieved from [http://www.fons.org/resources/documents/journal/vol1no2/ipdj\\_0102\\_05.pdf](http://www.fons.org/resources/documents/journal/vol1no2/ipdj_0102_05.pdf) on 2 November 2015.
- Braun V. & Clarke V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2), 77–101. doi:10.1191/1478088706qp063oa.
- Broad J.B., Gott M., Kim H., Boyd M., Chen H. & Connolly M.J. (2012) Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *International Journal of Public Health* 58(2), 257–267. doi:10.1007/s00038-012-0394-5.
- Cohen J., Dirk Houttekier D., Bregje Onwuteaka-Philipsen B., Guido Miccinesi G., Addington-Hall J., Kaasa S.S., Johan Bilsen J. & Deliens L. (2010) Which patients with cancer die at home? A study of six European countries using death certificate data. *Journal of Clinical Oncology* 28, 2267–2273. doi:10.1200/JCO.2009.23.2850.
- Ewing G. & Grande G.E. (2013) Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: a qualitative study. *Palliative Medicine* 27(3), 244–256. doi:10.1177/0269216312440607.
- Exley C. & Allen D. (2007) A critical examination of home care: end of life care as an illustrative case. *Social Science and*

- Medicine* 65(11), 2317–2327. doi:10.1016/j.socscimed.2007.07.006.
- Funk L., Stajduhar K., Toye C., Aoun S., Grande G.E. & Todd C. (2010) Part 2: home-based family caregiving at the end-of-life: a comprehensive review of published qualitative research (1998–2008). *Palliative Medicine* 24(6), 594–607. doi:10.1177/0269216310371411.
- Gomes B. & Higginson I. (2006) Factors influencing death at home in terminally ill patients with cancer: systematic review. *British Medical Journal* 332(7540), 515–521. doi:10.1136/bmj.38740.614954.55.
- Gomes B., Higginson I.J., Calanzani N., Cohen J., Deliens L., Daveson B.A., Bechinger-English D., Bausewein C., Ferreira P.L., Toscani F., Menaca A., Gysels M., Ceulemans L., Simon S.T., Pasman H.R.W., Albers G., Hall S., Murtagh F.E.M., Haugen D.F., Downing J., Koffman J., Pettenati F., Finetti S., Antunes B. & Harding R. (2012) Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Annals of Oncology* 23(8), 2006–2015. doi:10.1093/annonc/mdr602.
- Gomes B., Calanzani N., Gysels M., Hall S. & Higginson I.J. (2013) Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care* 12(1), 7. doi:10.1186/1472-684X-12-7.
- Gomes B., Calanzani N., Koffman J. & Higginson I.J. (2015) Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study. *BMC Medicine* 13, 235. doi:10.1186/s12916-015-0466-5. Retrieved from <http://www.biomedcentral.com/1741-7015/13/235/> on 27 October 2015.
- Green J. & Thorogood N. (2004) *Qualitative Methods for Health Research* Sage, London.
- Higginson I.J., Sarmiento V.P., Calanzani N., Benalia H. & Gomes B. (2013) Dying at home is it better: a narrative appraisal of the state of the science. *Palliative Medicine* 27(10), 918–924. doi:10.1177/0269216313487940.
- Jack B.A., Baldry C.R., Groves K.E., Whelan A., Sephton J. & Gaunt K. (2013) Supporting home care for the dying: an evaluation of healthcare professionals' perspectives of an individually tailored hospice at home service. *Journal of Clinical Nursing* 22(19–20), 2778–2789. doi:10.1111/j.1365-2702.2012.04301.x.
- Jack B.A., O'Brien M.R., Scrutton J., Baldry C.R. & Groves K.E. (2014) Supporting family carers providing end-of-life home care: a qualitative study on the impact of a hospice at home service. *Journal of Clinical Nursing* 24(1–2), 131–140. doi:10.1111/jocn.12695. Retrieved from <http://onlinelibrary.wiley.com/doi/10.1111/jocn.12695/pdf> on 27 October 2015.
- Knighting K., O'Brien M.R., Roe B., Nolan M., Lloyd-Williams M., Gandy R. & Jack B. (2015) Development of the Carers' Alert Thermometer (CAT) to identify family carers struggling with caring for someone dying at home: a mixed method consensus study. *BMC Palliative Care* 13(14), 22. doi:10.1186/s12904-015-0010-6.
- Leadbetter C. & Garber J. (2010) *Dying for Change*. Demos, London. Retrieved from [http://www.demos.co.uk/files/Dying\\_for\\_change\\_-\\_web\\_-\\_final\\_1\\_.pdf](http://www.demos.co.uk/files/Dying_for_change_-_web_-_final_1_.pdf) on 27 October 2015.
- Lock A. & Higginson I. (2005) Patterns and predictors of place of cancer death for the oldest old. *BMC Palliative Care* 4, 6. doi:10.1186/1472-684X-4-6.
- Miles M.B. & Huberman A.M. (1994) *Qualitative Data Analysis: An Expanded Sourcebook*, 2nd edn. Sage Publications, California.
- Morris S.M., King C., Turner M. & Payne S. (2015) Family carers providing support to a person dying in the home setting: a narrative literature review. *Palliative Medicine* 1–9, doi:10.1177/0269216314565706.
- Murray S.A., Boyd K., Thomas K. & Higginson I.J. (2004) Developing primary palliative care: people with terminal conditions should be able to die at home with dignity. *British Medical Journal* 329(7474), 1056–1057. doi:10.1136/bmj.329.7474.1056. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC526105/> on 27 October 2015.
- National Council for Palliative Care (2012) *Who Cares? Support for Carers of People Approaching the End-of-life*. Conference Report. The National Council for Palliative Care, London.
- NHS England (2014) *Actions for End of Life Care: 2014-16*. 11 November. NHS England, Leeds.
- Office for National Statistics (2010) *Population Trends*. Winter 2010. 142. Chris W. Smith, ONS, Newport. Retrieved from <http://www.ons.gov.uk/ons/rel/population-trends-rd/population-trends/no-142-winter-2010/population-trends-no-142.pdf> on 27 October 2015.
- Office for National Statistics (2012) *Population Ageing in the United Kingdom, its Constituent Countries and the European Union*. 2 March. Retrieved from [http://www.ons.gov.uk/ons/dcp171776\\_258607.pdf](http://www.ons.gov.uk/ons/dcp171776_258607.pdf) on 27 October 2015.
- Office for National Statistics (2013) *2011 Census Analysis: Unpaid care in England and Wales, 2011 and comparison with 2001* Chris White, ONS, Newport. Retrieved from [http://www.ons.gov.uk/ons/dcp171766\\_300039.pdf](http://www.ons.gov.uk/ons/dcp171766_300039.pdf) on 27 October 2015.
- Polit D.F. & Beck C. (2009) *Essentials of Nursing Research Appraising Evidence for Nursing Practice*, 7th edn. Lippincott Williams and Wilkins, Philadelphia, PA.
- Pollock K. (2015) Is home always the best and preferred place of death? *British Medical Journal* 351, h4855. doi:10.1136/bmj.h4855. Retrieved from <http://www.bmj.com/content/351/bmj.h4855> on 27 October 2015.
- Public Health England (2014) *National Cancer Intelligence Network. Older People and Cancer*. 2014538. Public Health England/National Cancer Intelligence Network, London.
- Ritchie J. & Lewis J. (2003) *Qualitative Research Practice: A Guide for Social Scientists*. Sage, London.
- Robbins M. (1998) *Evaluating Palliative Care – Establishing the Evidence Base*. Oxford University Press, Oxford.
- Saks M. & Allsop J. (2007) *Researching Health: Qualitative, Quantitative and Mixed Methods*. Sage Publications, London.
- Shepperd S., Gonçalves-Bradley D.C., Straus S.E. & Wee B. (2016) Hospital at home: home-based end-of-life care. *Cochrane Database of Systematic Reviews* 6(2), CD009231. DOI: 10.1002/14651858.CD009231.pub2. Retrieved from <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD009231/full> on 27 October 2015.

Social Care Institute for Excellence (2013) *Dying Well at Home: Research Evidence*. SCIE, London.

Stajduhar K., Funk L., Toye C., Grande G., Aoun S. & Todd C. (2010) Part 1: home-based family caregiving at the end-of-life: a comprehensive review of published quantitative research (1998–2008). *Palliative Medicine* 24(6), 573–593. doi:10.1177/0269216310371412.

Stosz L. (2008) *Literature Review of the Evidence Base for a Hospice at Home Service*. Centre for Health Services Studies. Centre for Health Services Studies, University of Kent. Retrieved from [http://kar.kent.ac.uk/24789/1/hospice\\_at\\_home\\_literature\\_review.pdf](http://kar.kent.ac.uk/24789/1/hospice_at_home_literature_review.pdf) on 27 October 2015.

The *Journal of Advanced Nursing (JAN)* is an international, peer-reviewed, scientific journal. *JAN* contributes to the advancement of evidence-based nursing, midwifery and health care by disseminating high quality research and scholarship of contemporary relevance and with potential to advance knowledge for practice, education, management or policy. *JAN* publishes research reviews, original research reports and methodological and theoretical papers.

For further information, please visit *JAN* on the Wiley Online Library website: [www.wileyonlinelibrary.com/journal/jan](http://www.wileyonlinelibrary.com/journal/jan)

**Reasons to publish your work in *JAN*:**

- **High-impact forum:** the world's most cited nursing journal, with an Impact Factor of 1.527 – ranked 14/101 in the 2012 ISI Journal Citation Reports © (Nursing (Social Science)).
- **Most read nursing journal in the world:** over 3 million articles downloaded online per year and accessible in over 10,000 libraries worldwide (including over 3,500 in developing countries with free or low cost access).
- **Fast and easy online submission:** online submission at <http://mc.manuscriptcentral.com/jan>.
- **Positive publishing experience:** rapid double-blind peer review with constructive feedback.
- **Rapid online publication in five weeks:** average time from final manuscript arriving in production to online publication.
- **Online Open:** the option to pay to make your article freely and openly accessible to non-subscribers upon publication on Wiley Online Library, as well as the option to deposit the article in your own or your funding agency's preferred archive (e.g. PubMed).