

# Receiving end of life care at home: experiences of the bereaved carers of cancer patients cared for by health care assistants -

Final Report January 2013

Dan Munday<sup>1</sup>, Melanie Lovatt<sup>2</sup>, Julie Roberts<sup>1</sup>, Veronica Nanton<sup>1</sup>,  
Bill Noble<sup>2</sup>, Christine Ingleton<sup>2</sup>, Elizabeth Pitt<sup>3</sup>, Kate Seers<sup>1</sup>

1. University of Warwick;    2. University of Sheffield;  
3. Coventry and Warwickshire Partnership NHS Trust

**Warwick**  
Medical School



The  
University  
Of  
Sheffield.



## **Acknowledgements**

**The team would like to thank all those who took part in the study.  
We are grateful to Dimbleby Cancer Care for funding the study.**

## Contents

<u>Title</u>	<u>Page Number</u>
Executive Summary	5-11
Background	12-15
Aims and Objectives	15-16
Method	16-17
Findings 1: NHS Care Service	17-19
<i>Hospice X</i>	19-2
<i>Supportive Care at Home Service</i>	22-24
Findings 2: Key Informant Interviews	24-26
Findings 3: Interview data	27-61
Theme 1: Bereaved carers' narratives of caring	
<i>Caring Trajectories</i>	27-29
<i>Decisions Regarding Place of Care</i>	29-31
<i>Motivation for Undertaking Care Role</i>	31-32
<i>Facilitators of Informal Caring</i>	32-36
<i>Reflections on experience of End of Life Caring at Home</i>	36-38
<i>Discussion</i>	38-40
Theme 2: The impact of Health care assistants on the experience of informal carers	
<i>The experience of caring</i>	40-42
<i>Health care assistants: involvement and contribution</i>	42-43
<i>Health care assistants: challenges experienced by informal carers</i>	44-46
<i>Multiple roles of the HCA</i>	46-47
<i>Balancing the relationship</i>	47-48
<i>Experience of the care package and how services worked together</i>	48-52
<i>Discussion</i>	52-54
Theme 3: Emotional support	
<i>The relationship which the HCAs developed with the patients</i>	54-55

<i>The relationship which the HCAs developed with the carers</i>	55-56
<i>The Sensitivity which the HCA's displayed in being able to fit into individual homes and situations</i>	56-58
<i>Giving carers a break</i>	58-50
<i>Discussion</i>	61-62
<b>Final Discussion</b>	62-66
<b>References</b>	66-71
<b>Appendices</b>	72
1 <i>Bereaved Carer Interview Schedule</i>	73-75
2 <i>Sample Characteristics</i>	76
3 <i>Sample Group by Setting</i>	76

# Executive Summary

## Introduction

Many terminally ill cancer patients and their families prefer for death to occur at home rather than in an institution where the majority of care falls to the patient's family and friends. As death approaches caring can become an increasing burden for the patient's informal carers. This issue has long been recognized by health care professionals and also in current policy for end of life care, with the End of Life Care Strategy for England (DH, 2008) highlighting the need for community services to enable home death by supporting both patient and their family carers. Basic nursing, social and respite home care has frequently been provided by basically trained, unqualified nursing staff, including auxiliary nurses and health care assistants (HCA). Whilst increasing research has been undertaken into the needs of family carers (Stajduhar et al, 2010; Funk et al 2010), relatively little has focused on the care HCAs deliver (Herber & Johnston 2012) and very few studies have explored the experience of bereaved family carers of patients who have received such services.

This study aimed to explore the experiences of bereaved carers who had received the services of HCAs. It explored the carer's own role, triggers for involving home care services provide by HCAs and their judgments as to the quality, benefits and drawbacks of receiving this care.

## Method

### *Setting for the research*

In order to increase the transferability of the results and to gain insights which could be applied widely within the UK, we undertook the research in three different settings:

- 1) A service provided by a NHS Trust in a City in the English Midlands of over 300,000 inhabitants, which employed its own HCA staff, coordinated a limited amount of care from Marie Curie and Crossroads and relied on agency staff to provide around 50% of the hours of care needed across the city. An experienced palliative care clinical nurse specialist managed the service.
- 2) A Hospice at Home service provided by an independent hospice in a small town in the English Midlands with a large rural hinterland and covering a population of 187,000 people. This service provided its own HCA staff and worked together with district nurses who also accessed care from Marie Curie and care from social services, including agency staff. This service was managed by two registered nurses.
- 3) A service jointly provided by a NHS Trust and Marie Curie Cancer Care in a town with a history of coal mining in Yorkshire. Unlike the other two services this service mainly operated at night-time. It provided its own staff but not agency staff. Patients in the area did received care from agency staff via social service.

### *Phase 1*

Following ethical approval for the study, phase one involved nine key informant semi-structured interviews with HCAs and other health service staff to enable a description of each service to emerge and for the nature of the role played by HCAs in each service to be explored. This enabled us to determine how HCA roles in these three settings compared to that described in recent research.

In phase1 we worked with a service lead from each service who gave access to documents relating to the services and assisted in developing the description of each service. The service lead representative was also given training in purposive sampling and was responsible for contacting bereaved carers for interview in phase 2.

### *Phase 2*

160 bereaved family carers between 3 and 9 months following the death of their family member were contacted by post and invited to take part in an interview. A total of 33 responded agreed to participate and were interviewed by a research fellow from University of Warwick or University of Sheffield. As this fell below the target of 36 interviews, all the bereaved carers who agreed to take part were interviewed. Interviews lasted between 45 minutes and one hour and were recorded verbatim and transcribed. Transcripts were analysed thematically using a constant comparison technique. A second researcher coded 20% of the transcripts and disconfirming examples for emerging themes were sought within transcripts to ensure rigor of the method.

Analysis was initially undertaken for the individual services and then comparisons were made across all three services and discussed by the project team to explore differences between the sites.

## **Results**

The three services differed in their organizational structure and in the type of staff they employed (as described above); however their aims for providing home nursing and domestic care were broadly similar. All services provided training, support and supervision for the staff whom they employed.

HCA interviews confirmed their role involved providing basic nursing and domestic care for patients and that they provided respite for home carers to enable them to take a break from caring. They described their role as including emotional as well as physical care, which included listening to the patient's and carer's concerns, giving reassurance and being a calming presence. They were aware of the sensitivity of their role in the patient's home and their need for flexibility. They described the skills they possessed and work they undertook in ensuring that they were able to meet the patient and carers needs and to do so in an appropriate manner. Whilst undertaking domestic tasks such as washing up, doing washing etc. was not in their job descriptions, they described how they never-the-less performed such tasks when they were needed.

The results from the bereaved carers interviews were found to fall into three major themes.

1) *Bereaved carers' narrative of caring:*

Carers described a wide range of trajectories that preceded the involvement of the HCAs in supporting the informal carer's role within the home. They reflected a diversity of circumstances which may impact directly or indirectly upon carer experience and response to this final caring phase.

Care-giving by family members sometimes took place over an extended period of time, sometimes as a result of multi-morbidity, allowing gradual adjustment and accommodation to their role. In these circumstances, continuing to care at home during the last stages of the patient's life occurred as an almost inevitable progression of what had gone before. However in this group, some carers were still be unprepared for, or overwhelmed by the physical and/or emotional challenges, of caring for a dying patient.

Where patients had been diagnosed with advanced aggressive cancer having been previously well, carers had relatively little time to accommodate and explicit decisions regarding place of end of life care became more evident. These decisions were often based on a simple response to the expressed wishes of their spouse or parent, or involved a more complex interaction between a sense of duty, love and a wish to reciprocate for care they themselves had received. In some instances, when the decision for the patient to be cared for at home had been made in hospital, the rapid organisation of a care package within which HCAs formed an integral part seemed to provide an important assurance to the family that their caring would be supported with professional help.

Women out-numbered men in all three sites in which the study took place, reflecting both demographics and traditional caring role characteristics. While our study did not seek to explore the characteristics of male carers as such, it was notable that several of the male carers described an upbringing involving caring or past experience that enabled them to cope with the terminal care of their spouse. Since limited attention has been given to male end of life carers in previous research, further exploration of informal male end of life carers may be valuable in the development of strategies to support and enable more men to take on this role.

2) *The impact of Health care assistants on the experience of informal carers*

The carer's accounts indicated the intense difficulties involved with caring for someone who is dying at home. Carers invariably indicated that they had not realized the extent of the burden of caring before they had got to the terminal stage. The work was physically as well as emotionally demanding and took place in the context of facing up to the death of a loved-one.

Many carers, however, had been reluctant to access a home care service from HCAs, with the uncertainty about having a stranger in their house and it seemed that accepting a HCA to provide “sits” within the home can be seen as an invasion of the patient and carers’ private space which has potential and uncertain costs for them. However, despite initial reluctance, all participants expressed a positive assessment of the care that HCAs had provided in the strongest possible terms, admitting that they could not have continued caring without the help they received.

This positive assessment was clearly influenced by the skill the HCAs showed in being unobtrusive, flexible in working together with informal carers in providing care as well as in providing emotional support (see below). Carers tried to normalize life within the home by accepting the HCA as being “like a family member” and reciprocating for the HCA’s work in offering hospitality. When the attributes necessary for this negotiation of roles was lacking in HCAs, the carers expressed dissatisfaction with individual care assistants. This seemed to invariably implicate staff from agencies, rather than employed HCAs from the services hosting the study.

The carers accounts of the tasks the HCAs undertook corroborated remarkably well with HCAs own accounts: nursing tasks - mouth care, toileting, changing bed linen and domestic chores - ironing, washing up, making drinks. Carers occasionally expressed surprise at the wide range of tasks which were undertaken by HCAs, particularly domestic tasks. Offering respite so that the carer could take a break or have a night’s sleep was a major benefit of having HCA sitters within the house; carers being able to benefit from this needed to have confidence in the HCA providing the service.

One area in which HCAs needed to display bility was in delivering personal care to patients. A number of wives were keen to retain that function for their husbands, whilst children were happy for HCAs to perform that role for their parents.

Concerns which carers expressed about the services they received suggested that lack of availability of care at certain times and lack of flexibility regarding the time at which care was provided was problematic, as was lack of information about services. Carers sometimes indicated it had been difficult to find out what services were available. These concerns were however very much balanced by high levels of satisfaction with the work of the HCAs by bereaved carers.

Participants frequently indicated that care had been provided by a wide range of HCAs. However, we found that this lack of continuity of care was not frequently cited as a problem; we had expected it to be more of a concern. It seemed that HCAs’ displaying good communication skills, friendliness and flexibility mitigated for this lack. Lack of information about changes in times at which care was being offered, however, did lead to dissatisfaction for the carers. It seems therefore that most of the concerns carers expressed were related to systematic issue regarding how services are configured, rather than being within the control of HCAs.



The work of caring and the indignity of the dying process affected some carers' views about their own management if they found themselves in need of end of life care. Some had decided that they would not want to pass that burden onto their family members and had determined not to request a home death. The duty, love and altruism which they displayed for their dying loved ones seemed to have a reverse effect in considering what they would want for family carers called to look after them. This is an aspect of the caring experience that we believe merits further exploration.

### 3) *Emotional support provided by HCAs*

Health care assistants demonstrated emotional support through their relationships with the patients and carers, their ability to sensitively enter and work within private, domestic homes at a time of great difficulty and stress, and their skill in giving carers a break from caring, whilst not excluding them.

Previous research has noted the ambiguity of the health care assistant's status and the lack of an in-depth understanding of their role in palliative care. The findings from this study suggest that, rather than this necessarily being a problem, this ambiguity helped the HCAs to negotiate relational, spatial and temporal 'boundaries' in their work, and provided them with the agency to skilfully provide emotional support in complex situations.

The emotional awareness and sensitivity of HCAs was crucial in allowing them to negotiate 'relational boundaries'. As paid care workers, HCAs were distinct from carers, yet their unqualified status distinguished them from nurses and other health professionals. Many carers welcomed this 'in-between' status occupied by HCAs, with some carers regarding the HCAs as helpful liaisons who were able to facilitate communication between themselves and health professionals.

HCAs were also able to sensitively negotiate spatial boundaries. Regular, often daily visits by nurses, doctors, and other health and social care staff, together with equipment such as hospital beds, drips and syringe drivers, contrast with the more usual concept of the domestic home as being a private, non-clinical environment. The HCAs in this study were able to 'fit in' to homes and were welcomed by carers, who in some cases came to regard the HCAs as members of the family. The unobtrusive and trusted presence of the HCA not only meant that the carers did not have to worry about a stranger in the house, but also allowed the carers to retain a sense of control and autonomy in their own home that may have been threatened by the constant visits of health professionals. HCAs were very much aware of their need to successfully negotiate their access to, and presence in the home. Therefore, while the HCAs' presence in the home may have been regarded as 'natural' by the carers, this was something that the HCAs were conscious of and had to work to achieve.

HCAs identify emotional support as a key aspect of their work, and it was clear that this was recognised and appreciated by many bereaved carers. Emotional support was not distinct from the

physical support which HCAs provided, such as lifting, turning and feeding. Rather, emotional support underpinned and informed all aspects of the HCAs' role, and indeed *allowed* them to perform other tasks. Some carers reported being unhappy with the attitude shown by health professionals and social care agency staff, and on occasion requested that certain personnel did not return to the home. The carers' unhappiness was not necessarily because of any technical incompetence on the part of staff, but more because of the manner in which they performed their work. Therefore, when participants often spoke of HCAs as being 'compassionate', 'lovely' or 'friendly', these characteristics weren't merely seen as being 'bonus' personal qualities. Instead, the display of such emotions was crucial in allowing the HCA to be in the home and successfully conduct all aspects of their work.

The flexibility and ambiguity of their role allowed HCAs a great deal of agency in supporting the patients and carers. Our study shows that HCAs successfully negotiated a number of boundaries - relational, spatial and temporal - and demonstrated considerable skill in providing the patients and carers with emotional support.

## **Discussion**

This study has enabled us to explore the experiences of bereaved carers three to nine months after the death of a family member for whom they had cared with the assistance of HCAs. Participants had had experience of one of three separate services in the English Midlands and Yorkshire. We believe this is the first and largest study to specifically explore bereaved carers experiences of HCA working in the home at the end of life that has taken an in-depth qualitative approach.

The study has provided insights into the challenges of caring for a dying family member in the home and how HCAs can help family carers to continue with caring, enabling the patient to die at home, in their place of choice. A number of previous studies have explored the role of HCAs in providing home care, indicating that they perform a wide range of tasks: nursing and domestic, providing respite and offering emotional support. Bereaved carers accounts of their experience of having HCAs within the home corresponded remarkably with HCAs own accounts.

Areas of concern for bereaved carers included the occasional experience with HCAs who did not display good interpersonal or caring skills. These criticisms were aimed almost entirely at agency staff rather than staff directly employed by the services in which we conducted the study. It was remarkable how consistent bereaved carer description of the work of HCAs was between the services in the study.

Another area of concern was lack of information about services, particularly their availability and information about service changes when they happened. Participants also were concerned about a lack of flexibility as to the times at which care was provided and some thought that patients and their needs should be matched more closely with the age and experience of individual HCAs. These

issues are systemic and relate to how services are organised rather than being a criticism of the work of HCAs themselves.

This study focused on the care provided by HCAs and not trained health care staff working in the community. Comments in the interviews about these staff were limited and we therefore do not present them in this report.

### *Strengths and limitations*

This study exploring in depth the experience of bereaved carers who have received the services of HCAs caring for their dying relatives provides a valuable addition to the evidence base around end of life care in the community in the UK. This is particularly topical given the aims of the End of Life Care Strategy to enable people to die at home, the commonest place of choice. Undertaking the study in three varied services has enabled us to provide insights which we believe are potentially applicable for practice in the UK.

We interviewed fewer bereaved carers than we had planned. For two of the services we interviewed 15 and 14 bereaved carers as planned and we are confident that the data in these areas reached saturation, with no new themes emerging. However in the third service only four bereaved carers responded despite 40 being invited. It is unclear whether the experience of these four interviewees was representative of bereaved carers in general for this service.

We had planned to recruit a purposive sample of bereaved carers for interview, but in the end we interviewed all those who were invited who responded positively and agreed to be interviewed. We did achieve a reasonable spread of bereaved carers in terms of gender, age and which relative they cared for; so we believe we have captured a diverse range of perspectives.

### **Conclusion**

HCAs provide a valuable service in the view of bereaved carers which enables them to continue in their caring role. HCAs show considerable skill in negotiating ambiguous spatial, relational and temporal boundaries which is important to enable them to care in a way which is sensitive and acceptable to family carers. HCAs who work within services where training, support and supervision are given, seemed to at times provide better care than those from agencies, as reported by some bereaved carers. It is important that service providers and commissioners ensure that services that provide home care are fit for purpose and that appropriate training and support of HCAs is provided and that their skilful contribution to care is properly valued.

# Background

## Introduction

Many terminally ill cancer patients and their families prefer for death to occur at home rather than in an institution. Here the majority of care falls to the patient's family and friends and as death approaches caring can become an increasing burden for the patient's informal carers (Wilkinson 2010). This issue has long been recognized by health care professionals (Baines 2010) and also in current policy for end of life care, with the End of Life Care Strategy for England (DH, 2008) highlighting the need for community services to enable home death by supporting both patient and their family carers. Some patients require support at home, either continuously or for periods of respite and this care has normally been provided by basically trained nursing staff, for instance auxiliary nurses or latterly health care assistants (HCA). Whilst increasing research has been undertaken into the needs of family carers (Funk et al 2010), relatively little has focused on the care HCAs deliver (Herber & Johnston 2012) and very few studies have explored the experience of bereaved family carers of patients who have received such services.

This study aimed to explore the experiences of bereaved carers who had received the services of HCAs and their judgments as to the quality, benefits and drawbacks of receiving this care. It aimed also to explore their experiences in general of caring for a family member who was dying at home and how the care provided by HCAs had influenced this.

## Summary of relevant literature

### *Caring at home*

Caring at home for a patient who is dying is frequently hugely demanding on their family carers. A recent comprehensive review of family based caregiving, highlighted how providing such care produces stress and a variety of conflicting emotions. The situation can be intensified by a lack of professional support and information about the patient's likely illness course and services available, compounded by the uncertainty inherent in the dying process (Funk et al 2010). They conclude that "the caregiving experience at end of life has been conceptualized as involving uncertainty, powerlessness, insufficiency, vulnerability, and turmoil" p 602.

Family carers have been identified as needing practical and emotional support and information from community health service (Bee, Barnes & Luker, 2009). When services are made available to patients they are reported to be frequently reactive rather than planned in advance (Hudson & Payne 2011). This is probably partly related to the ambivalence which carers may feel about accepting help, which may be related to an implicit belief that this represents a failure in fulfilling their role (Harding & Higginson 2001).

Research has illustrated how varied carers' experiences and needs are, but it has been identified that more exploration of the specific caring needs of different groups is required (Funk et al 2010).

#### *Health Care Assistants (HCAs) and end of life care*

HCAs were introduced in the NHS and Community Care Act (1990) as a grade to support qualified nurses, to enable them to spend more time with the patient rather than on ancillary duties (McKenna et al., 2004). Over the twenty years since their introduction, HCAs have become a central part of the workforce within the NHS and other healthcare organisations and now make up around 25% of the NHS workforce (NHS 2012). Their role has evolved so that they provide direct patient care often taking on roles previously undertaken by their qualified colleagues (McKenna et al., 2004).

No formal training is required before a worker can be employed as a HCA, apart from a good general education (NHS Careers 2012). Training modules in the Qualification Credit Framework (successor to National Vocational Qualifications - NVQ) are available (SFC 2012), however, these are not mandatory and in the past HCAs have found it difficult to access training through lack of protected time and funding (Thornley, 2005). Evidence remains that this continues to be an on-going issue (SFC 2012). There is no registration or regulation system for HCAs despite calls for this over a number of years<sup>1</sup> and they have a variety of work titles, many of which are trust specific, making comparative surveys of their roles and the work they undertake problematic (McKenna et al., 2004).

For years HCAs have made up an important part of the workforce caring for patients with advanced cancer in a variety of settings: hospital, hospice (James, 1992), care home (Davies and Seymour, 2002) and the community (Clark et al., 2000). Those working in the community might work for a range of organisations including: NHS, hospice charities, voluntary organisations such as Marie Curie Cancer Care and private healthcare agencies, with a lack of standardisation in the training and support provided for them. In 2008 core competencies for HCAs, providing end of life care were developed ([www.endoflifecare.nhs](http://www.endoflifecare.nhs)) and these have continued to be refined (SFC 2012), but it is still unclear whether these competencies are being met. Although there is a lack of in-depth understanding of the role of HCAs in palliative care as only five studies from the UK have been reported (Herber & Johnston 2012). These studies have consistently shown that HCAs are involved in undertaking personal care, performing social tasks and caring for patients who are dying. Several studies have also indicated how emotional support is an important aspect of their work (James, 1992, Clark et al., 2000, Munday, 2007., Ingleton, Chatwin, Seymour & Payne 2011)

---

<sup>1</sup> For example see: <http://www.nmc-uk.org/Press-and-media/Latest-news/Future-Forum-calls-for-review-of-HCA-regulation/>

### *Home Care Respite Services.*

Providing support for the carers of patients dying of cancer in the community has a long history in the UK. The 1943 “Queen’s Nursing Handbook” suggests that community nurses should seek “reliable women who will sit up at night with a patient and carry out orders intelligently”<sup>p28</sup> (Wilmshurst, 1943). Later more formal caring services emerged with Marie Curie Cancer Care establishing its home care nursing service in 1958 and St Christopher’s Hospice setting up its hospice at home service 10 years later (Baines, 2010). Since these early developments, a variety of models of home care respite for patients at the end of life have emerged, some provided by hospices and other voluntary organisations; others by community trusts, social services or nursing agencies. The model of care provided varies between areas, with some having formally organized services (e.g. hospice at home) and others relying on more ad hoc arrangements where community staff access a range of services as required.

Most studies of home care respite services for terminally ill cancer patients have been descriptive with few presenting rigorous evaluations; whilst the evaluations which have been undertaken have frequently not given a detailed description of services or their local context (Ingleton et al., 2003). A systematic review of home care respite services (Harding and Higginson, 2003) identified only two sitting respite services using untrained staff which had been evaluated. One study used a questionnaire administered to bereaved family carers which revealed that satisfaction with the service was high, carers felt able to leave the patient with the HCA and reported that without the service they would not have coped well (Clark et al 2000). Similarly a recent questionnaire study of bereaved carers who had received a home care service also reported high levels of satisfaction (McLaughlin et al., 2007).

Marie Curie Cancer Care introduced a major programme, “Delivering Choice” providing community care to enable more patients to die at home. This was a complex intervention part of which was to provide rapid response teams to visit patients at a time of crisis to prevent hospital admission. The evaluation shows that the programme was well received, however there were mixed results as to whether it achieved its aims of preventing admissions. Family carers did report high levels of satisfaction, either from receiving the service or from the awareness that it was present as a backup should it become necessary (Payne, Seymour, Ingleton, Sargeant & Kidd 2008)

### *Emotional support*

In a seminal study of hospices, James(1992) identified that experienced Nursing Auxiliaries (a grade similar to, but predating the introduction of HCAs) had a key role in providing emotional support for patients, such that younger trained nursing staff relied on their expertise in this area. Clark et al (2000) in an evaluation of a community carer scheme also reported that HCAs provided emotional support for patients and their families. Similarly in a recent interview study with HCAs employed by a community trust, participants described emotional support as being a central aspect of their role,

including: active listening to patient and family carers' concerns, support as they came to terms with the illness and prognosis, reassurance as the patient's condition changed and even help in funeral planning with patients (Munday, 2007). No studies have explored the experiences of bereaved carers regarding emotional support delivered by HCAs to patients or themselves.

## **Aims and objectives.**

The main aim of this study was to explore in depth the experiences of bereaved carers who have received home care respite services from HCAs.

The study included three principle objectives

- 1) To explore the bereaved carer's narrative of caring, including their relationship to the deceased, the length of time they had been in the caring role, the support they had received from family, friends and the wider community and the services they had received in helping them to care for the deceased. The purpose of this objective was to understand what it is that leads informal carers to receive care from HCAs, the triggers to the HCAs service becoming involved with patients and their informal carers and factors that may play a role in determining carers' response to HCA involvement (Results section 1) . We consider both positive and negative aspects of carer experience and variation in perceptions of carer burden in relation to carer family role (partner, son, daughter), gender and age. We discuss further factors that appear to impact upon carer response to their caring role relating to both health care provision and broader social context
- 2) To explore bereaved carers' experiences of having HCAs working in their homes. Did their accounts of the HCAs' activities corroborate with those of HCAs themselves in terms of the role of HCAs? What activities did the HCAs undertake? Were there any issues such as lack of continuity, poor communication and lack of training which led to problems in the HCAs work? What were the benefits and burdens of receiving such a service? (Results Section 2)
- 3) To explore the extent to which bereaved carers were aware of emotional support being delivered to the patient and themselves by the HCA. Did they recognise emotional support as being an aspect of the HCAs' work? (Results Section 3).

In order to increase the transferability of the results we undertook the study in three different settings:

- 1) A city in the English Midlands with a dedicated NHS home care service for terminally ill patients led by an experienced community Macmillan clinical nurse specialist. The service employs its own HCAs, but also arranges for care from other providers including voluntary organisations and nursing agencies.
- 2) A hospice at home service provided by a voluntary hospice based in a small town with a large rural hinterland in the English Midlands.

- 3) An urban area in Yorkshire with a palliative care home care service provided and coordinated by an NHS trust together with a national charity.

## **Method**

Phase 1 a: An in-depth exploration of the local context for each of the three services was undertaken in order to provide the background to the findings from the bereaved carer interviews. An overview of each service was undertaken through the collection of documentary evidence. At each site a key member of staff was invited to join the project team to assist the researcher in collecting this information and by providing details about the service.

Phase 1b: 16 semi-structured interviews with key informants: service managers, Macmillan and district nurses and HCAs were undertaken to complete the contextual exploration of each area. Findings from the analysis of these data informed the development of the topic guides for semi structured interviews to be undertaken in Phase 2 of the study (see appendix 1).

Phase 2: The sampling strategy was discussed with each of the service leads employing the health care assistants. Bereaved carers were identified 3-9 months post bereavement by the service lead. It had been intended to use a purposive sampling frame at each site to enable a spread of carers to be interviewed, but it became apparent during phase 1 that the numbers were relatively small.. Invitations were therefore sent to all bereaved carers unless there was a specific reason not to do so. Bereaved carers were only contacted once by post. They were sent an information sheet and covering letter from the service lead explaining the nature of the study and requesting their participation in an interview lasting 45 minutes to one hour.

In total 160 invitations over the three services were sent out, and thirty three bereaved carers responded indicating that they were happy to be interviewed (21% response rate). All of these family carers were recruited. Interviews were undertaken with each of these by one of three researchers undertaking data collection. Interviews lasted from forty five minutes up to an hour and a half.

All interviews were audio-recorded and transcribed verbatim

### **Analysis**

#### **1. Documentary evidence**

Any operational policy documents, annual reports or other written evidence from each service was read and notes taken to enable a description of the service to be made. In addition, key informant interviews with the service lead, HCAs and other professionals with knowledge of the service provided additional information to enable a full description to be made. (see Findings 1 below)



## 2. Interviews with HCAs and bereaved carer interviews

Transcripts of the nine interviews undertaken with the HCAs and 33 interviews with bereaved carers were analysed for emergent themes using a constant comparative technique. The results of the HCA interviews were discussed by the project group who from them and results from a previous study of HCAs' experience undertaken at site 1 (the NHS service) (Munday, 2007) developed the interview schedule with the assistance of a carer "user" representative.

For the bereaved carer interviews, initial analysis was undertaken with the set of interviews for each site individually, For each site disconfirming examples were sought to test the robustness of emergent themes. All interviews were analysed by a single researcher with 20% analysed by a second researcher as a further method of ensuring rigor. Comparison of emergent themes across all three sites was made by the whole research team thus enabling patterns of cross cutting themes to be identified.

## Findings

### NHS Care Service

#### *Background of the Service*

This service is situated in a City in the English Midlands with a population of over 300,000. It is provided by a mental health and community NHS trust and commissioned by the local PCT having been established in 1992. From 2000 it had been incorporated into intermediate care services within the trust but was reorganised in 2007 following an evaluation project that highlighted the need for enhanced support for HCAs working within the service (Munday, 2007). The focus of the service is on providing good quality care for the patient as well as supporting family members and informal carers. HCAs provide practical and psychological support. The service is tailored to meet the needs of each individual patient and can adapt as their needs change.

#### *Staff and Training*

The service is coordinated by a dedicated home care facilitator (a Clinical Nurse Specialist in Palliative Care) and two service administrators. Care is provided primarily by health care assistants (HCAs). The service employs 20 contracted HCAs as well as 30 bank staff. They also deploy Marie Curie nurses and Crossroads carers supplemented by carers from a local agency. Agency staff do not specialise in end of life care and so may not have received training in this area specifically. Table Z1 shows a breakdown of the amount of care delivered by each service. As the service has become busier, agency hours have increased so that almost the same amount of care is provided by agency workers as by directly employed staff.

**Table 1 - Activity April 2011 - March 2012 for the NHS Care Service - Sitting Services, showing the proportion of care delivered by each provider**

Total Hours	PCT employed staff (contract+ bank)	Marie Curie hours	Agency hours	Crossroads hours
87,391	33,228.5	8,917	32,646	12,599.5

HCA's employed by the service must have experience of end of life care and ideally NVQ level 2 or 3. New staff have a class room based induction based in End of Life Care provided by the home care facilitator, which includes how to recognise / manage end of life symptoms and the important principles of effective communication. They then spend a period shadowing more experienced staff as they care within patients' homes. They receive additional appropriate training including moving and handling, food hygiene, equality and diversity. Staff are invited to attend a team meeting every 6 weeks. This includes an education session delivered by the home care facilitator and time to reflect on particular patients, situations and challenges. Staff undergo an annual performance review. They are encouraged to drop into the office or to contact the home care facilitator for support or to discuss specific issues whenever they need to do so.

#### *Aims and Provision of care*

According to the service specification, the service 'aims to give timely, practical and empathetic support to individuals nearing the end of life, irrespective of their diagnosis to enable them to live and die in their preferred place of care.' This will normally be the patients' own homes. In 2011/12, 44.5% of patients referred to the service died at home. This relatively low rate probably reflects the fact that patients are referred earlier in their diagnosis - up to 12 weeks before death - and the service is withdrawn if patients are admitted to hospital, hospice or care home. These patients may also subsequently be discharged and die at home.

The place of death data for area 2 presented in Table 3 indicates that cancer deaths at home are around the national average, unlike those in area 1 which were much higher. Hospice beds are available in the area on two sites, one within the city and the other in a market town 10 miles away.

**Table 2 Overall place of death rates for the local authority area of NHS Care Service (2008-2010) - National averages in parentheses**

Place of Death	Home	Hospital	Hospice	Care Home
	28% (27%)	44% (43%)	11% (17%)	15% (12%)

The service provides sitting services - day or night-time care - by HCAs, staying with the patient for 7-10 hours and since 2010 it has also provided a domiciliary care service which delivers short episodes of care (up to four home visits per day), assisting patients with personal care, dressing, diet etc.

### *Referrals*

Referrals to the service can be made Monday - Friday 8:30 to 16:00. Care outside these hours in an emergency can be arranged via the trusts community fast response team, which provides generic nursing care for patients for periods of up to 48 hours. At the beginning of the week, new referrals pick up by fast response may be transferred to the service.

Patients are referred to the service by district nursing teams, by the continuing healthcare team or end of life care facilitators at the local hospital and occasionally by GPs or Macmillan Nurses. Needs assessments are carried out by the district nurse to determine what level of care is required. The PCT defines end of life as applicable to patients who have been given a prognosis of 12 weeks or less and therefore referrals must meet this criterion i.e. patients must qualify to access NHS fully funded continuing healthcare. In the year 1<sup>st</sup> April 2011- 31<sup>st</sup> March 2012, the service received 497 referrals: 353 for the sitting service and 207 for domiciliary care.

### *Challenges*

The service sometimes faces challenges when agency staff have to be used. When coordinating the package of care, every effort is made to place directly employed staff or Marie Curie nurses with those patients who are imminently dying and to use agency to cover shift with those who are less dependent on carers. The rationale for this is that those with the greatest need should receive the care of those who are most skilled in end of life care. Although agency staff are expected to be appropriately skilled in caring for patients at the end of life at home, experience has indicated to managers of the service, that the quality of agency staff is not consistently high.

Demand for the service is growing year on year and the service is facing an "overspend". Demand is unpredictable and because defining when a particular patient has reached the end of life can be challenging, patients with a life expectancy of 12 weeks or less can sometimes live much longer. Occasionally there is a need to withdraw the service if the patient improves or circumstances change. This can be a very difficult situation for the service to negotiate with family members and informal carers.

## **Hospice X**

### *Background of the Service*

Hospice X is situated in an ex-industrial town, with former textile and other manufacturing industries with a coal-mining hinterland. In recent years it has retained its service industrial status and has become a commuter town for a number of conurbations in the English Midlands. The area

covered by the hospice includes a population of around 187,000. The hospice was opened was launched in 1988 by a Mayoral appeal to raise funds for a non-bedded hospice unit. Care is provided for anyone in the local area diagnosed with a life limiting illness. A range of services are provided including: day hospice, hospice at home, lymphoedema service, a bereavement service and a support group for survivors of cancer. All services are provided free of charge to patients. The hospice is a registered charity and receives some NHS funding (28%) but the remaining costs are raised through donations, fundraising events and charity shops.

### *Staff and Training*

District nurses act as key workers to the patients cared for by hospice at home carers and they have responsibility for planning and organising services. The Hospice at Home service is staffed by two part-time nurses (1.13 WTE) and eight healthcare assistants (HCAs). HCAs are required to have a minimum qualification of NVQ level 2 and should be willing to work towards level 3. They must have experience of working in a healthcare environment and preferably experience of palliative care. They need to demonstrate that they can show empathy towards patients being cared for and commitment to the service and its principles.

HCAs employed to work in the service receive mandatory training in areas such as manual handling, record keeping and infection control. Other training is also provided as the need arises, including training about dressings, syringe drivers, lymphoedema, equality and diversity. HCAs can attend any training which is being provide by hospice staff and they also have access to training DVDs. The HCAs have daily meetings with their team leader and the staff nurse.

Some nursing agencies in the area are involved in providing support respite services to patients and their carers. Marie Curie do night support visits although the hospice X service does provide some. Whilst the hospice is not directly involved in planning or coordinating care delivered by these other organisations it does have contact with them.

More recently the service has been involved in providing care within a county wide pilot project to enable home death. Patients are referred to the service for urgent care if they are estimated to be in the last two weeks of life. The volume of work has meant that the service is unable to provide care for patients earlier in their diagnosis as before. Should a patient be referred and the service is unable to provide care when requested, it has the responsibility to contact another provider, normally Marie Curie to request them to take on the care.

HCAs working through the night will ring the hospice in the mornings to say how the night has been and report any issues with patient care. All staff undergo an annual appraisal at which competency levels are assessed. The hospice at home trained staff on occasions also accompany HCAs to patients' homes and assess their work through direct observation

### *Aims and Provision of care*

The hospice at home service is able to achieve its aim of enabling most patients to die at home (see Table 1). A number of patients however are admitted to hospice or hospital to die. The average yearly number of cancer deaths (End of Life Care Intelligence Network 2008/2010) for the area covered by the service was 496, suggesting the hospice at home service cared for around 30% of patients dying from cancer in the area.

The nearest hospice beds are 9 miles from the hospice base and patients may have to travel up to 25 miles to access a hospice bed. Death rates from cancer in the area served by the hospice are given in table 3. The high home death rate for cancer patients (36%) as well as the high hospital cancer death rate compared to the national average may be related to the relative lack of availability of hospice beds in the locality and the availability of hospice at home, although there may also be other socio-geographical factors involved.

**Table 3 Place of Death 2010/11 - Hospice at Home service - Hospice X**

Number of patients	Deaths at home	Hospice	Hospital
145	119 (82%)	14	12

**Table 4 Overall place of death rates for the local authority area of Hospice x (2008-2010) - National averages in parentheses**

Place of Death	Home	Hospital	Hospice	Care Home
	36% (27%)	49% (43%)	6% (17%)	9% (12%)

The Hospice at Home service provides respite care (visits of 3-4 hours), personal care, night support visits (10pm - 7am) and a bereavement service. The service aims to enable patients to be cared for at home when that is their preferred place of care and to assist their informal carers to achieve that aim.

### *Referrals*

Referrals can be received 7 days per week 9-5pm and although the office is unmanned at weekends the telephone answer machine is checked regularly. Referrals are dealt with on the same day.

Prior to the county wide pilot project commencing in September 2011, the service accepted patients who were in the palliative stages of their illness for respite and in an acute episode would provide personal care for a period of 2 weeks, after which it would be reviewed and a referral made back to the District Nursing Service. Latterly the service has received referrals for patients at end of life whatever the diagnosis, the emphasis being on need. Theoretically it is in the last few weeks of life but sometimes patients can be receiving the service for a 2-3 months.

The criteria of the Hospice at Home service for accepting patients is:

- Adult who has a diagnosis of a life limiting illness
- Has palliative/terminal care needs
- Has personal care needs during the terminal phase (last few weeks of life)
- Requires personal care during an acute episode whilst awaiting a formal package of care to be provided

### *Challenges*

The challenges of the service include a lack of funds which restricts the number of patients who can be supported. Difficulties sometimes arise when it is unclear whether a patient qualifies for fully funded Health Care from the NHS. The hospice can only provide care for patients for whom this assessment has been made. In emergency situations it will provide care before an assessment is made although this can lead to difficulties, when care then needs to be withdrawn

## **Supportive Care at Home Service**

### *Background of the Service*

In 2002 following Government recommendations for the NHS a group of local professionals came together to form a working party looking at the provision of end of life care at home. The development of this group had a multi-agency approach and members included representatives from Hospital, Hospice, Social Services and Community based services. Whilst a good standard of community based care was being provided to patients in the terminal phase of life, it was recognized there was a gap in meeting the needs of those requiring more intensive support at home.

Current service provision at this time was provided by the Marie Curie Service, funded by the local PCT and Marie Curie Cancer Care. This service provided qualified and unqualified nursing staff to stay with patients in their own homes, either by day or throughout the night. The service operated on a bank type rota, where staff would telephone the Coordinator and inform when they would be available to work. Although the Marie Curie Service was very well supported by staff, availability was unknown and on an ad hoc basis.

In January 2002 'Supportive Care at Home Service' was developed. The service was reflective of identified local need, but was also in line with a national approach. Its aim would be to support patients who are at the end of their life to remain at home, therefore having a choice of where they could be cared for. The service would work closely with District Nursing, Social Services, and the existing bank Marie Curie Service. The service began taking patients in 2003. The service works in partnership with other health and social care colleagues to deliver high quality care to people in their own homes. Recognizing how difficult it is to care for someone at home who has a progressive life limiting illness, the service provides practical, emotional and physical support for patients and their carers/family, particularly as the end of life draws near.

### *Staff and Training*

The team consists of: Three qualified nurses (and 1 vacant post), 11 auxiliaries (HCAs) (1 vacant post), the service coordinator and 2 secretarial staff. The service also has the option of Bank Qualified Nursing. All the team are employed on a permanent basis on an annualized hours contract, working a variety of hours and shift patterns. When recruited, healthcare assistants (auxiliaries / nursing assistants) must have at least one year's experience as an auxiliary or carer of caring for people in a health and/or social care setting. Emphasis is on a 'caring person'. The supportive care at home service does not employ agency staff itself (but works closely with the local social services who do employ agencies - so agency staff will often be part of the care package, but not employed by the supportive care at home service).

All staff follow a robust training programme, which includes both mandatory and ad hoc training. They spend time with colleagues from District Nursing Service and attend courses relating to palliative and end of life care.

### *Aims and Provision of care*

The main aim is to care for the patient and the primary carer. Duties might include personal care for the patient (washing, mouth care, helping them with drinks, prompting - though not administering - medication, getting the patient comfortable, talking to the patient and providing emotional support. HCAs might help out around the house, for instance washing up, ironing, and making light meals, even though these aren't in the job description.

The care packages provided are created and tailored to meet the individualised needs of patients and their carers/families, enabling them to be supported in their choice to be cared for at home or to be discharged home from another care setting.

As well as the provision of the important 'hands on' practical assistance such as personal care, hygiene needs, washing, dressing, making meals and drinks, a key part of the service is the provision of a friendly, reassuring and supporting presence.

**Table 5 Overall place of death rates for the local authority area of Supportive Care at Home Service (2008-2010) - National averages in parentheses**

Place of Death	Home	Hospital	Hospice	Care Home
	32% (27%)	41% (43%)	14% (17%)	13% (12%)

In 2009/2010, 277 patients were referred to the service and the local hospice has only ten beds. The service provides care to support those dying at home 24 hours per day, seven days per week. Care could consist of all night 22.00 to 07.000, daytime and evening hours. The service takes a

flexible approach to the hours/times of availability to patients. The service works closely with Social Services and colleagues from District Nursing Service.

### *Referrals*

Referrals are received seven days per week between the hours of 9.00 to 17.00. This ensures patient referrals can be accepted at weekends and on bank holidays.

The services uses a standard referral form, however in the first instance and to provide a quick response the referral is taken over the phone. All referrals are responded to on the same working day. The initial response is by telephone to either the patient/family or the referrer. Further information relating to the needs of both the patient and their family/carers is established with visits to the home and a patient centred package of care is developed.

### *Challenges*

It can be challenging to spend hours putting a care package into place, only to have to change it if the circumstances of the patient or carer change. Establishing and monitoring a care package involves liaising with many different individuals and services. Demand is increasing as more people want to die at home, and more resources are needed to be able to meet that demand.

For all of the services involved in the study, all patients remain under the care of their own GP and District Nurse with the District Nursing Sister being the Key Worker in the patient's care. The specialist element of cancer and palliative care would continue to be provided by the Macmillan Clinical Nurse Specialist team.

## Findings 2: Key Informant interviews

### **Interviews with HCAs**

We undertook 9 interviews with HCAs in phase one of the study principally to explore whether their own description of the role they undertook was similar to or whether it differed in any way from that which is reported in the literature or from their description in the study which DM had previously undertaken in one of the services (Munday 2007). The roles they described were similar between the three services and also did not differ from previous research. A summary of the themes emerging from the HCA interviews is now presented.

HCAs listed in interviews with them the following duties which they regularly undertook:

- Personal care
- Help with daily living - eating and drinking
- Being there



- Calling for assistance from other professionals when needed
- Recognising pain and trying to alleviate it e.g. by changing position
- Calming the patient
- Giving family members a break
- Supporting the family especially by providing information and reassurance
- Talking with patients and family members - just chatting.

Several challenges arose around duties:

HCA's were very aware of the boundaries of their role but sometimes found it difficult or uncomfortable to stay within these. In particular, it is sometimes difficult to refuse to do housework (although they sometimes use their discretion on this). Declining to discuss diagnosis or prognosis with the patient or family can also be difficult. One HCA talked at length about the issues around medication, especially defining the line between administering medication and prompting the patient to take medication.

HCA's aim to be responsive to patients but not all patients are able to communicate what they want the HCA's to do.

Caring alongside family members can be challenging. HCA's have to judge whether family members want to/are capable of performing certain tasks. Relationships with family members can be challenging - either because they are stressed/difficult or because they lack knowledge about end of life care and the HCA needs to explain, for example, that the patient may not eat/drink.

HCA's work in a small team and share information as well as providing emotional support to one another but working with other professionals can be problematic. Making contact with a district nurse when needed can be difficult. Communication between HCA's and other professionals is largely through the notes kept at the patient's home but DNs don't always read the notes written by HCA's. HCA's feel quite powerless when other aspects of the care needed (e.g. drugs, equipment) are beyond their control and they have to rely on the DNs and Macmillan nurses to agree with their assessment of what is needed and then put it in place. HCA's sometimes feel that their lower professional status means that DNs don't listen to them. One HCA reported difficulties with providing advice/input when a patient was already living in a care home with full time carers. She found it difficult to assert her expertise in end of life care.

Managing their time can be a challenge since HCA's never know how long each patient will need them. They often have to travel quite long distances between patients.

HCA's must manage their own emotions, especially when a patient dies but also manage family members' emotions. Two HCA's mentioned that some deaths stayed with them for some time after the event.

HCA's mentioned a range of positives of the services:

- Providing patients with choice about place of death
- Enabling death at home
- Providing constant care where needed - unlike hospital where staff have a lot of patients to look after
- The service is very flexible
- The service is responsive - carers can be put in place very quickly
- The service provides patients and families with a sense of security
- Continuity of care means that the patient isn't cared for by 'strangers'

HCA's formed different kinds of relationships with different patients. They mentioned a variety of roles from acting as advocate for the patient with other healthcare professionals, becoming confidants to the patient, especially to talk about things that the patient is uncomfortable discussing with family members, and becoming part of the family. HCA's do form attachments with some patients - especially those they care for over a longer period, or those they particularly get on well with. Building up trust from the patient is important but patients don't always cooperate with HCA's and this can make the relationship difficult.

Relationships with family members are equally varied with HCA's becoming advocates, providing emotional support and offering guidance and reassurance to family members.

In some cases, the HCA's become like friends to family members. Some HCA's visit some families after the patient has died. Others bump into them in the street and so have an on-going relationship of sorts

<b><u>Organisation Identifier</u></b>	<b><u>Key Informants Role</u></b>	<b><u>How many Interviewed</u></b>
<b>A Hospice</b>	Service Lead	2
	Health Care Assistants	2
	District nurse	1
<b>B NHS Service</b>	Home Care Facilitator	1
	Health Care Assistants	4
	Macmillan Nurse	1
<b>C Supportive Care at Home</b>	Coordinator of Supportive Care at Home Service	1
	End of Life Clinical Lead	1
	Health Care Assistants	2
	District Nurse	1
	Staff Nurse ( Supportive Care at Home Service)	1

## Findings 3: Interview data

### Theme 1: Bereaved carers' narratives of caring

Our analysis aimed to identify the circumstances and events that lead to the patient being cared for and dying at home. We sought to understand whether varying types of experience were related to differences in the way family members coped and responded to the particular demands of caring at the end of life.

#### 1. Caring trajectories

Marked contrasts were seen within the sample group with respect to the length of time that family members had become 'carers.' In most cases this role had been assumed because of cancer but in over one third of the group other significant morbidities had preceded the cancer diagnosis.

##### Continuation of caring role lasting more than 12 months: patients with a single diagnosis of cancer

Carers described the impact of diagnosis and treatment and their subsequent lives. In some instances cancer treatment had been curative, requiring adjustment by patient and carer but nevertheless allowing many of the routines of their previous lives such as work, holidays and social activities to continue for a time prior to recurrence. In other instances a downward trajectory had been inevitable from the outset thus bringing about a major reorientation.

*he showed me the scan so I knew it wasn't good, and I had to go back in and pretend everything was okay. So for a couple of days.....because I didn't want him to get too upset....then he had the operation and that's how we went on. It wasn't when he was going to die, it was how he was going to live. .... I haven't slept properly for 6 years. (BYF26) Husband of patient*

##### Continuation of caring role lasting more than 12 months: carers of patients with multi-morbidity

Thirteen of the patients had suffered multi-morbidity with cancer as the last of a range of severe conditions including: diabetes, ulcerative colitis, peripheral neuropathy and heart disease.

The caring partner confidently and knowledgeably enumerated the various illnesses suffered by their spouse or parent.

*she had a lot of illness throughout her life. She was pretty much... she was partially disabled because she couldn't walk very far because she had a cardiovascular problem. she had stents in her legs to try and improve the blood flow, she even was going to have her main one done but when they opened her up the veins and the arteries were so calcified that it was too*

*dangerous to do it. it didn't stop us from going to America and doing things, but I had to push her round in a wheelchair all the time we was there, so... (BYM20) Husband of patient.*

*Well she (A) was always on medicines obviously for different things, because she'd got diabetes, took two tablets for diabetes, um and she had a bad heart anyway, she'd got a dodgy heart valve, and she was taking water tablets, well loads of tablets. (BYM14) Husband of patient.*

Carers described the complex roles they undertook in managing the various aspects of the illnesses including physical care, accompanying the patient to appointments, managing medicines and communication with health care professionals. These carers had become used to their wide ranging roles minimising the impact of these responsibilities upon themselves.

*I've looked after him as a carer more or less all me married life really...But he were no bother when I were caring for him, no bother. (CYF11) Wife of patient.*

*Yes, I had five years of... yes, good days, bad days, you know, plus she still had the pain in her ribs and I had to rub the cream in her back every night and it was... you know, not that it mattered. (BYM12) Husband of patient.*

For some of the respondents who had cared long term, death had appeared imminent at various points in time when crises had occurred and been averted. For others it had appeared more gradually, its inevitability becoming increasingly apparent. For all these respondents there had been a transition over an extended period from caring for a spouse or parent with growing physical needs to the role of caring for the dying.

#### Carers of patients with cancer diagnosis of less than 12 months

Where cancer had been diagnosed within 12 months of the patient's death and there was no co-morbidity the transition to a caring role was necessarily rapid. Carers described in detail a progression from onset of symptoms to the terminal phase of the illness.

*Anyway it began with him complaining that he'd got a water infection and that sort of went on for a couple of months really. And round about March last year he woke up in great pain and he couldn't go to the loo, and when he sort of tried to go he was passing blood.....  
I gave him a jolly good wash and took him back to bed and they decided that they would perform the cystoscopy on the Thursday morning, which they did. And we didn't get the results of that for at least three weeks.....  
And he told him that he had cancer in his bladder and they couldn't discover to what extent and they couldn't do another rigid cystoscopy for several more weeks because his bladder would be very inflamed.....*

*So we went home; we went back again about 2-3 weeks later and he decided to book him in - it was the 7<sup>th</sup> June - he had another cystoscopy and this time... on the first time they said it was a tumour in his bladder, but this time they just said, you know, they used the word cancer very clearly to him, and he was very, very distressed. (AYF 27) Wife of patient.*

## **2. Decisions regarding place of care**

The process of decision making regarding place of care showed some variation depending on whether caring had taken place long term or because of a relatively recent cancer diagnosis. In some instances where patients had been ill for an extended period, their previous experience of hospitals or that of other family members influenced the decision for continuing care at home.

*The alternative for her to have been in a care home, um it's unthinkable because when my wife was in hospital we had a 24-hour vigil. I know they're there and there's care, but um I just wouldn't have left her there and neither would the rest of the family. So there was no choice really, there wasn't a choice of, well do you want to be going to a care home to visit your wife all the time, or do you want her at home - there's no choice, you know. Given the option, you know, given the option there's no choice, you always go for the care at home. (BYM21) Husband of patient.*

*A had this fear of hospitals, I mean she'd watched her mum die in hospital and her dad and then her sister, and her sister got some abysmal treatment in the hospital and um, and so we, we discussed it and there was no way we was going to let that happen. (BYM20) Husband of patient.*

In others, no moment of decision is apparent. In these instances carers were apparently struggling to look after increasingly frail relatives and either relatives or health care professionals or in a minority of cases they themselves, had taken the initiative in requesting help and bringing in HCAs to alleviate the increasing strain on the carer.

*yes we go onto the last three months when they said three months. They got it organised that a nurse came in to see her. Yes, J, the district nurse came in. And um, and then it got... what happened after that? Yes, she was deteriorating a bit so we had... we had a couple of carers came and I was showering her every morning anyway, but they came to make sure she was alright, dressed and downstairs. (BYM24) Husband of patient.*

*Well with it being just before Christmas, silly me I didn't do anything about it, I waited until the holidays were Over because I was thinking there perhaps won't be anybody available. And I rang the doctor, it was a fortnight after Christmas and I asked if somebody would come down and see him. (BYF17) Wife and Daughter in law of male patient.*

*Well it was to give... to be quite honest they brought the carers in then and they... my GP, our friends next door, he said you need someone to help you because it was just too much for me to cope with. And um and it was so that I could sort of get out and that's when we had the help from that. (BYF16) Wife of patient.*

Where cancer had been diagnosed within 12 months of the patient's death and there was no co-morbidity the transition to a caring role was necessarily rapid. Carers described in detail a progression from onset of symptoms to the terminal phase of the illness.

*Anyway it began with him complaining that he'd got a water infection and that sort of went on for a couple of months really. And round about March last year he woke up in great pain and he couldn't go to the loo, and when he sort of tried to go he was passing blood..... I gave him a jolly good wash and took him back to bed and they decided that they would perform the cystoscopy on the Thursday morning, which they did. And we didn't get the results of that for at least three weeks.....*

*And he told him that he had cancer in his bladder and they couldn't discover to what extent and they couldn't do another rigid cystoscopy for several more weeks because his bladder would be very inflamed.....*

*So we went home; we went back again about 2-3 weeks later and he decided to book him in - it was the 7<sup>th</sup> June - he had another cystoscopy and this time... on the first time they said it was a tumour in his bladder, but this time they just said, you know, they used the word cancer very clearly to him, and he was very, very distressed. (AYF 27) Wife of patient.*

In these instances a decision point was generally apparent. Several carers described a response to partners stated wishes or knowing that their partner or parent was anxious to remain at home.

*He was diagnosed in the October and he died in March and he desperately wanted to Um be kept at home. The nurses at one point asked if he'd like to go to... asked me if he'd like to go to Hospice X and I just said, no, because he... he was... he was paranoid about going to the doctor anyway, and to go into hospital again, well he couldn't have done it. (BYF 11) Wife of patient.*

*And um I said, well if he has the blood it won't make him better will it? They said no, which I knew very well it wouldn't. So I said, well he doesn't want to go to the hospital, and I promised that he won't have to go. (BYF17) Wife and Daughter in Law of male patient.*

In several instances the patient had been in hospital and a decision had been made for discharge home. In these cases care had been arranged and was in place from the outset.

*when they... they did finally say, you know, look there's just nothing we can do, and he said, "I want to come home" And I said, "Yes we'll take you home". So he came home at 9:30. The la-... the nurse, I presume she was a nurse, I don't know who she was, um went through everything and within two hours she'd organised a bed and the care staff, the Macmillan and Marie Curie nurses, and everything just took off. (BYF09) Wife of patient.*

### **3. Motivation for undertaking caring role**

A sense of duty or of caring as an unquestioned part of their role was expressed by several of the wives as an explanation for how they had come to take on the care of their husbands at home during the terminal phase of their illness.

*one of his aunties came up at the funeral and said to me "I admire you for taking him home" and I said "what do you mean?" and she said "well, you took him home" and I said "he's my husband, I love him, why wouldn't I take him home. (BYF26) Wife of patient.*

Associated with this sense of duty, (or an insistence that caring was the "natural thing to do") was a marked reluctance by several of the wives to accept outside help.

*When Macmillan came, you know she had always said you know there is plenty of help out there, and then I think when she came one day I probably broke down and she said, "I think you're getting tired and you need somebody to come overnight". They did ring and I kept putting them off, "no" you know "it's, it's my job" (CYF15) Wife of patient.*

In some cases too, wives felt they should have done more.

*I thought I hadn't done enough for him but everybody said I had, you feel as though you want to do a lot more. (BYF16) Wife of patient.*

For men by contrast, expressions of duty and responsibility were less apparent. For some it appeared as a challenge they were happy to take on, expressing a determination to give their wives the best possible care sometimes involving an 'active' approach to caring that involved either modifying equipment or engaging the patient cognitively or physically.

*I'd got it into my head that, well if we were going to give her the best care that we could and the best quality of life, to lie here in bed all the time wasn't acceptable. (BYM21) Husband of patient.*

Help when offered to men or suggested by others was generally readily accepted.

For the inter-generational carers, a continuing close relationship with a parent or other relative (in several instances widowed) who lived nearby, was characterised by a history of frequent and regular contact and underpinned the transition or led apparently seamlessly in to the assumption of the caring role.

*I live about half a mile away so I used to visit most days and take her shopping and pay the bills and do things like that. (BYF22) Daughter of female patient.*

*Since my mum died....as I said its 27 years since my Mum died and Dad has always been with us. Literally, he was up here every day but he was one of these he liked to go home to his own front door at night and he liked his own bed. (BYF27) Daughter of male patient.*

#### **4. Facilitators of informal caring**

A number of factors appeared to be important in enabling carers to care for their relatives during the last few weeks of life

##### Relationship with the patient

Carers described close, loving and in many instances very long relationships with the patient, lasting 50 years and above. This bond appeared important in helping carers carry out their role through reinforcing motivation, knowing the patient and their particular likes and dislikes and responding positively to their needs even when these might appear unreasonable.

*Quite and kind and he never raised his voice to anybody. .... he never raised his voice to anybody and everybody loved him and he didn't want a lot out of life just him and his family to be happy. And er he were lovely, he were the most perfect husband, anybody could wish for. And I've known him since I was sixteen, and I'm now nearly seventy. And er, you know we did everything together we were just joined at the hip. (CYF11) Wife of patient.*

*Well he was 86 he never thought he would reach 86 but he did. And yes we had a good retirement. We've been in this house 25 years (BYF23) Wife and daughter of male patient.*

The need for increasing compromise by the carer in the face of the illness of the spouse was expressed by one husband.

*Um, because like all couples, you clash don't you occasionally, and like when it came to sort of getting her to bed from the... I'd got an electric bed in that room there for her and I was off to a single bed myself but sleep in the same room to make sure if she needed me in the night, you know, she could get me. And um, but it was like she didn't probably want to go bed at 10 or 11 o'clock and I did, so I'd say, come Anne, it's time for bed. No I don't want to go. And I kept*



*thinking, well I'm tired. But then you give in don't you, you know. I mean when you're okay I mean you just say, oh I'm going to bed and you say, okay I'll just watch this and then I'll come, or vice versa you know.. But it gets a bit difficult towards... Well you give in don't you [laughs], if you're the carer.* (BYM14) Husband of patient.

Relationships, however, had necessarily changed from one of mutuality and reciprocity in the case of couples to dependence. Wives particularly felt grief on behalf of their husbands and reflected on how hard this loss was for them to bear.

*But it were just awful watching, its awful watching somebody you love die slowly...there's no dignity in taking someone to the toilet for any of you.* (CYF17) Wife of patient.

Appreciation of the character and of the close relationship with the older relative was also evident in the accounts of inter-generational carers and contributed to the sense of value they experienced through the caring undertaking.

*I know I sat too long in the chair, I know that but I wasn't going to give that up. As long as I could do it....and then as [husband] used to say "you go and lie on the bed, I'll call you if there's anything" and he was down here on the sofa. But yes I suppose when we look back at it....we didn't sort of look at it like that because he was Dad.* (BYF27) Daughter of male patient.

*...As I say communication wasn't that good..... well it was my Mum. (previous CVA) It was just nice to spend that time together.* (BYF23) Wife and daughter of male patient.

#### Knowing what to expect, knowing how to care

A number of carers had had previous experience of cancer and thus felt better prepared than they would otherwise for the course of events that ensued.

*Mind you I knew what to expect because my father had cancer and I knew how he went. I sort of saw the same thing happening again with my husband. I mean its life and death and you just carry on really.* (BF17) Wife and daughter in law of male patient.

One carer had been particularly praised by the GP for the skill with which she cared for her husband.

*"You've been absolutely magnificent", but I did what I could. I mean I've never been put down as a nurse, but I did it. And even my family's amazed. ...* (BYF10) Wife of patient.

As well as her willingness to undertake the task, this wife identified her family history as an important factor in her coping.

*I've come across cancer before, I mean my gran had it, my aunty had it badly and my mum ended up with pancreatic cancer. I have gone all through that.* (BYF10) Wife of patient.

Several male carers explained their ability to care for their wives by their experience of looking after other relatives or by an upbringing that had involved learning how to carry out household tasks and looking after siblings.

*I just did it you know because I come from a large family and I was brought up that way you know I could do everything. Yes I have got 8 sisters and 2 brothers.* (BYM 24) Husband of patient.

*And her mum died the year before. Her mum died 13 months before L and she lived next door. And I was... I had to do a lot of the donkey work if you like there because L couldn't do it.* (BYM20) Husband of patient.

Where carers lacked experience or knowledge their confidence in their capacity to care was frequently low. Even retrospectively, in some instances, carers felt their efforts were inadequate.

*I am not a nurse. I understand a lot of people are quite good at it. Er, and happy to do it, I was happy to do it, but I wasn't, I don't feel as if I was good at it, despite what people said* (CYF07) Wife of patient.

#### Carer and patient response to terminal illness.

A minority of carers identified aspects of their own and the patient's personality as enabling them to cope with whatever might occur.

*I think because we are the sort of people we are it definitely helped. I think our need to understand what is going on made everybody's life easier. I mean we don't panic we don't worry about stuff, our ability to accept help.* (CYM 20) Son of male patient

Some remembered moments of humour, at times initiated by patients themselves, that arose during the visits of various health care professionals. These exchanges were important in diffusing the emotional intensity of the situation and as a welcome reminder that the patient retained their individuality despite their declining physical condition.

*. ... And he said, if I was a bit younger, he said, I'd take you out for the day for your birthday, he said, I'd take you to the races. And she said, oh I'll hold you to that, she said, I'll come back and I'll let you take me.* (BYF23) Wife and daughter of patient.

### Family support

Almost all of the carers described receiving some support from their families. The level of support varied in frequency and in degree but in many instances involved help with physical care as well as taking on practical household tasks and providing emotional support to patient and carers.

*My sons were here, I've got three sons, and two of them were here helping him, and we were able to wash him and he was able to get into the shower up until about the last week. (AYF 25) Wife of patient.*

*One daughter lives next door to me and the other one lives at X and they were fantastic. The daughter next door, she had three months off work as well. (BYF11) Wife of patient.*

*Yes, so we've got lots of um... lots of um you know, relatives. Um, although we have lost one or two. Um and quite a close family and if it wasn't for my brothers and my sons and their wives, you know, like things would have been a lot more difficult. But I, I had a lot of support and still do, you know, they look after me very well. (BYF09) Wife of patient.*

In a number of instances a continual flow of people in and out of the house took place which served to some degree to normalise the situation, replicating elements of life as it had previously been lived.

*...we just carried on around him and carried on... tried to carry on as normal... well we did carry on as normal, um but we did get rather a lot of visitors.. (BYF09) Wife of patient.*

*I mean we did get a lot of visitors, anybody... neighbours used to come round and sit for a couple of hours and um, you know, my relatives came and my friend who lives in Yorkshire he drove down here and they came a couple of times. And other friends from [nearby town] came over, so she had plenty of visitors, you know .....Because this house has always been like that, we've always... well still no bloody different to be honest with you, you know, it's an open house really. it's been always the same, you know, we've always had loads of people coming here. And this is the way we liked it, you know, we like people to come and have a cup of tea or couple of beers at night if you want to. (BYM 20) Husband of patient.*

None of the carers reported complete lack of involvement of with family members. In a small minority of cases these were more a source of stress than assistance. One wife who had moved to the area when she married her husband relatively recently prior to the onset of his illness, described contact with only one relative her stepson, who lived in the same house.

*He lived with both of us, now he lives with me obviously. But he works and he's a 42 year old bachelor so he doesn't... you know, he doesn't help much, but he does his best. He did his best*

*for his father but it upset him you see. And he couldn't really cope with it, his son, he couldn't cope with his illness. (AYF26) Wife of patient.*

No other family support was available, thus the input of the HCAs was crucial in enabling the home death that her husband desired. In this instance HCAs involvement with the family was atypically long, commencing at six weeks prior to the death of the patient.

*I just couldn't have coped without them, you know. Because I didn't involve anybody else; I didn't involve family and friends because I mean I'm a... I'm from X I'm not a Y girl, I'm from X .. so all my relatives and friends are over in X , which is an hour's drive away by car. (AYF26) Wife of patient.*

#### External support

The assistance of health care professionals and HCAs was described as of major importance in the ability of carers to continue to care at home. Even experienced carers expressed a view that this terminal situation required more than had been needed before.

*We couldn't have coped without the palliative care team, definitely not. No, we just couldn't have done it. You know, it does seem that cancer is tricky, there's much more... there's more intensity to the cancer treatment obviously because of the urgency of the disease. I mean something has to be done and you can't wait, it has to be done like within 10 minutes, you know. (BYM 20) Husband of patient.*

For some it was transformational, allowing a return to previous relationships that may have become obscured by the physical demands of caring.

*I curled up in the chair didn't I mum and I slept for about 2½ hours because it was just like somebody had taken a huge weight off me. It was lovely. And she said to me, she said the nicest thing to me, she said, what I want you to do now, she said, is to be a daughter not be a carer, and that was lovely. (BYF23) Wife and daughter of male patient.*

## **5. Reflections on experience of end of life caring at home**

### Burden of caring

Despite their willingness and commitment to caring until the point of death all carers expressed the physical and emotional strain involved.

*It's absolutely horrendous not only are you watching him, you have got to keep strong for him and it's very, very hard. Very hard. Er, emotionally, physically and mentally. To me I was exhausted in the end. (CYF13) Wife of patient.*

Physical demands such as lifting the patient even with help became increasingly difficult and keeping the patient clean frequently became more of a challenge. For older carers and for those who themselves suffered from health problems these demands were particularly wearing. In many instances however it was sleeplessness that caused the greatest problem. Several carers described extended sleepless nights that were spent awake, needing to attend the patient, or watchful, in case they were required.

*I'd been up with him nearly all night and I'd been doing that because my son-in-law had fitted up a baby alarm system so that - and it was right next to my pillow - so that if he... more or less if he just groans in the night I was down with him and helping him and, you know, making sure he was comfortable. (AYF27) Wife of patient.*

Complex emotions are necessarily associated with caring for a dying relative at home. While glad that their relative's wishes had been fulfilled, several carers expressed the view that they themselves would not choose home death knowing what was involved for the patient or carer.

*.....terrible thing but I made my kids promise that if, if go that way I want to go in a hospice I don't want nobody, yes I don't want nobody having to do. (CYF 15) Wife of patient.*

*I wouldn't stay at home, if it were me not now. Because I have a son and daughter and I wouldn't expect them to do what I did for my husband if you understand. I would go in the hospice. Because I don't think it would be fair on them for what I did for M. (CYF14) Wife of patient.*

Carer's response to their situation appeared to be mediated at least to some degree by the particular care trajectory of care. Where the care package had been arranged prior to discharge from hospital the level of physical and emotional strain was reduced from the outset.

*He was only home for a week when he died, and um we had 24 hour care. I was very grateful for them being here..... because I just felt that somebody was in control. (BYF09) ..everything just was on time, I never had to wait for anything, that's what I'm trying to say. Everything was there for him. All the equipment I needed was there. It all went, as far as I know, everything was good. (AYF26) Wife of patient.*

HCA involvement had occurred reactively and not as a part of a plan in many instances. In some cases the strain on carers had been evident to other family members or health care professionals even when carers themselves had not acknowledged that they were struggling to cope.

*Well I didn't want them for a while I kept saying no I can manage, I can manage. Until but then I wish I had had them in earlier. Because I did realise when it were all over what a strain I had put on me self, it wasn't a strain at the time when I were doing it. But when it were all over I realised I should have asked for help earlier. But I kept saying no I can manage I can manage.* (CYF14) Wife of patient.

#### 'Privilege' of caring

Even when it was felt that aspects of the patient's death had been harder to bear than they had anticipated, post bereavement, carers expressed satisfaction at having carried out the wishes of their relative. A number of participants went further, emphasising the positive aspects of the experience itself and expressing an element of joy in the role they had undertaken despite its many physical and emotional demands.

*It was a pleasure really. I knew he was dying and we both talked about it.* (CYF14) Wife of patient.

*It was a privilege, a great privilege. Um, it was tiring, hard going, just every day, but you know, I wouldn't have changed it for the world. Yes, I do feel very honoured to have been in that position to have done that.* (BYF22) Daughter of male patient.

*.....as far as I'm concerned he had an amazing end to his life because he was comfortable, he was loved, and nothing more could have been done for him, you know. It was... oh it was just wonderful, it really was.* (AYF 27) Wife of patient.

#### **Discussion**

We have described a range of trajectories that preceded the involvement of the health care assistants in supporting the informal carer's role within the home. Our sample has reflected a diversity of circumstances which may impact directly or indirectly upon carer experience and response to this final caring phase.

Care-giving by family members may have taken place over an extended period, sometimes as a result of multi-morbidity, allowing gradual adjustment and accommodation. In these circumstances, continuing to care at home during the last stages of the patient's life may occur as an almost inevitable progression of what has gone before. While this may be facilitative in terms of acceptance of the role, some carers may however still be unprepared for, or overwhelmed by the physical and/or emotional challenges, of caring for a dying patient.

Where patients have been diagnosed with advanced aggressive cancer, carers have relatively little time to accommodate and explicit decisions regarding place of end of life care become more evident. These decisions may be based on a simple response to the expressed wishes of their spouse or parent, or involve a more complex interaction between a sense of duty, love and a wish to reciprocate for care they themselves have received (Aoun 2004). In some instances, when the decision has been made in hospital, the rapid organisation of a care package within which HCAs formed an integral part, may have provided important assurance to the family that their caring would be supported by professional help.

Women outnumbered men in all three sites in which the study took place, reflecting both demographics and traditional role characteristics. While our study did not seek to explore the characteristics of male carers as such, it was notable that several of the male carers described an upbringing involving caring or past experience that enabled them to cope with the terminal care of their spouse. Limited attention has been given to male end of life carers, though one study has demonstrated a difference between male and female carers in the identification of their own experience of strain and patient need (Fromme 2005). Further exploration of informal male end of life carers may be valuable in the development of strategies to support and enable more men to take on this role.

Our study demonstrated an important role of various family members in addition to the spouse or son or daughter in enabling death to take place at home. Families provided both physical assistance and companionship in many instances on a daily basis. Whereas long term carers of the chronically sick report significant levels of increasing social isolation (Rhode & Shaw 1999, Boyd et al 2004) our data suggest that in this phase of cancer at least, where the patient is in rapid decline at home, isolation is mitigated by extensive family involvement.

Knowing what to expect from previous experience of cancer was mentioned as important in helping coping by a number of the carers interviewed. The value to carers of knowledge regarding progression of symptoms and their management has been repeatedly demonstrated (Bee et al 2008). The negative impact on carers of lack of information at various levels, has been identified in a range of settings (Broback et al 2003, Rutten et al 2005, Terry et al 2006). Some of the carers in our study had clearly not known what to expect. While this added to the immediate stress of caring, a further consequence in some instances was a decision by carers that they would not wish to be cared for at home at the end of their own lives. Findings thus further underline the importance of timely, sensitive information delivered by health care professionals with whom carers have good relationships, in the reduction carer distress and in supporting positive coping. This issue is explored further in Theme 2 (below).

Stadhujar et al (2010) in a recent review of studies of home based family care-giving at the end of life has described the many negative aspects of the informal carer role. In our study while the demands of caring are apparent and the physical decline of their family member was clearly painful to witness, many carers also expressed the positive aspects of their experience. Positive emotions have long been identified as important facilitators of coping in general contexts of care (Folkman 1997). The range of positive emotions expressed by end of life carers is described by Stadhujar et al (2010). Among these, studies have commented on family carers regarding end of life caring as an opportunity to express their love for the patient (Grbich, Parker & Maddox 2001, Aranda & Hayman-White 2001), a theme that was clearly apparent throughout our data.

Negative and positive emotions coexist within the caring experience to a greater or a lesser extent depending upon a range of individual and contextual factors. The importance of 'meaningfulness' to the response of carers to their role has been widely demonstrated (Stadhujar 2010). In our study, the difficulties of caring notwithstanding, the 'meaningfulness' of their endeavours to the bereaved caregivers was unquestionable. The death at home, to which they had committed themselves explicitly or implicitly, had been achieved.

The significant contribution of HCAs to this valued outcome, through the physical and emotional support given to both carers and patients, was acknowledged by our entire sample group. The specific nature of this contribution will be discussed in sections 2 and 3 below.

## Theme 2

### **The impact of Health care assistants on the experience of informal carers**

The findings included in this section reflect the informal carers experience of caring, their perception of the contribution made by the HCAs, their response to HCA involvement, and the views of the informal carers of the care packages and services they received.

#### **1. The experience of caring**

Carers expressed some ambivalence in their response to the experience of caring for the patient. Positive elements were acknowledged in that they were fulfilling patients' wishes in keeping them at home or seeing something through that they thought was right or had been a joint decision.

*It does get a bit desperate, it's not an easy thing to look after somebody. But that was a preference that we both had to um to going into sort of um... I suppose she could have gone into one of these sort of care places, I don't know what they call them, Macmillan type places where you go to die, but um I didn't want that anyway.* (BYM14) Husband of patient.



At the same time carers found it distressing to witness the decline in their relatives' health, particularly their increasing helplessness.

*He didn't know to pick up the spoon to eat. And that's when we had to feed him, and that was the worst bit. And um... we were both trying to feed him and then as I say he came back and sat in there and that's when he got up and he collapsed.* (BYF 16) Wife of patient.

*Um, it was hard... the thought was horrible that she was going to die. I used to cry.* (BYM24) Husband of patient.

*But it were just awful watching its awful watching somebody you love die slowly.* (CYF15) Wife of patient.

Wives in particular commented on a perceived loss of dignity.

*And of course I had to do all this changing, it was such a... he was such a particular man. And for me to have to do it and for the nurses to have to do it, it was dreadful, dreadful. I just felt so upset for him. But there we are.* (AYF26).Wife of patient.

The physical strain of caring was extreme. In many instances the exhaustion of caring in the last stages of life was greater than carers had anticipated. Carers described long days involving physical tasks as well as trying to maintain the spirits of the patient followed by nights that were either interrupted or spent only in light sleep in case they were required.

*And if she wanted to go to the loo it was back up the stairs again, so it was a... it was a struggle and as I say I'm sure when she couldn't get her arm around my neck one day I got hold of her and she was going down. And I got her on the seat but I think something went where I'd tore one of these things off inside, well you don't think, you don't worry about that. You just do it.* (BYM12) Husband of patient.

*I'd been up with him nearly all night and I'd been doing that because my son-in-law had fitted up a baby alarm system so that - and it was right next to my pillow - so that if he... more or less if he just groans in the night I was down with him and helping him and, you know, making sure he was comfortable.* (BYF16) Wife of patient.

*Because when you know somebody's like [wife] was, we knew that she was going down, every time they move you wake up. So you might go to bed and you might be in bed for 6-7 hours but you aint had 6-7 hours sleep because once... and then I used to... I'd be there for a couple of*

*hours and she'd move around or try and... want to go to the loo so I'd have to make sure she got to the loo alright and get back into bed. I'm awake then. (BYM20) Husband of patient.*

Even for those carers whose relatives had been ill for a considerable period and who were used to caring, this final stage of caring in cancer proved very demanding.

*You know, it does seem that cancer is tricky, there's much more... there's more intensity to the cancer treatment obviously because of the urgency of the disease. I mean something has to be done and you can't wait, it has to be done like within 10 minutes, you know (BYM20) Husband of patient.*

In contrast to the satisfaction expressed by carers in fulfilling patients' wishes by enabling death to take place at home, some had decided, as a consequence of their experience, that they would not wish to die at home themselves. The strain for relatives, they felt was too great.

*If you can have person at home I wouldn't stay at home, if it were me, not now. Because I have a son and daughter and I wouldn't expect them to do what I did for my husband if you understand. I would go in the hospice. Because I don't think it would be fair on them for what I did for M them last six months from October to May October to March and all April when he were you know had to shower him and do all this, I wouldn't expect me family to do that for me now. (CYF14) Wife of patient.*

*but I made my kids promise that if, if I go that way I want to go in a hospice I don't want nobody, yes I don't want nobody having to do. I mean I know in a hospice you have to watch them die but it's, there is no dignity in taking somebody to toilet for any of you it's just awful. (CYF15) Wife of patient.*

## **2. Health care assistants: involvement and contribution**

As has been discussed in Section1 above, some variation was seen in the ways that HCAs had been accessed by families. In some instances care packages had been arranged prior to discharge after a period of hospitalisation to enable the patient to die at home. In others the request for support had come from either the carer themselves or relatives or other HCPs.

The periods during which health care assistants had attended families ranged from a few days to up to a maximum of four weeks. The timing and amount of time that was spent in homes also varied considerably. HCAs from one service were predominantly present at night, whereas those from the two other services also attended during the day. Several patients received 24 hour care. Day-time visits ranged from half an hour to two hours and took place up to four times daily. In certain instances families had requested that HCAs visits be reduced from four times to twice daily as couples valued the opportunity to spend some time alone together. By contrast, one carer became

distressed at the suggestion by a district nurse that HCA night sits should be terminated as he was managing so well. In most instances a number of HCAs attended each family with a maximum of eight different HCA s attending over the course of a week. This variety of HCAs appeared generally to have been of little concern to the family carers and was only mentioned as an issue by a minority.

*Yes, it was nice when you did get the same one. I um... because you... even in that short time you build up a bit of a rapport with them and, you know... And also, I mean you know, you go off up to bed and you come down in the morning and, you know, you think, having a stranger here um, you know, when you get up looking like you've been dragged through a hedge backwards, and, you know. But I just thought, well that's nothing, you know.* (BYF09) Wife of patient.

The skill of the carers in rapidly blending in or adapting to the context of a particular household enabled in many instances, the establishment of warm and easy relationships despite the constraints of time.

*Well I only had same nurse [sic] twice. Otherwise they were different ones and every one were lovely. There wasn't one that I would have said I don't want her again. They were all compassionate.* (CYF14) Wife of patient.

*They were friendly and there wasn't one who didn't come in with a big smile. They were so natural to be with. They were absolutely fantastic. The loveliest people, absolutely lovely. Not one wasn't.* (AYF27) Wife of patient.

Without exception informal carers were appreciative of the presence of HCAs both for the help they provided and for their personal qualities.

*The care that we had from the 11<sup>th</sup> October until the 17<sup>th</sup> I will remember for the whole of my life.* (AYF26) Wife of patient.

*They were very understanding very caring and I couldn't fault them, the personalities they had were electric really. They were lovely really nice you know people.* (CYF11) Wife of patient.

*They were different ones and every one were lovely. There wasn't one that I would have said I don't want her again. They were all compassionate.* (CYF14) Wife of patient.

### 3. Health care assistants: challenges experienced by informal carers

Several female carers had resisted allowing others to help with the care of their partner regarding it as their responsibility and some had been wary at the prospect of the intrusion of strangers in the house over an extended period.

*Well I felt as though I didn't want other people in my house. And um I felt as though I didn't want somebody taking over from me .* (BYF17) Wife and Daughter in Law of male patient.

*.....at first it's daunting because you think oh you know 'I've got somebody in my house for nine hours and I'm up here er, I should be down there looking after him'.* (CYF17) Daughter of male patient.

These concerns had soon been allayed by the sensitivity of the HCAs and their ability to quickly perceive what needed to be done. Wives in each of the three localities commonly expressed the view that they could not have continued to care until the death without their input.

*... I just couldn't praise them enough for what they did. Much as I wanted to do everything myself, you know, with this complaint I've got I just couldn't... I can't... I just couldn't do everything, so I was extremely grateful for all the help I got, and they were all very good, excellent, you know. ....They were my saviours, there's no doubt about it, you know. Without their help I couldn't have managed.* (AYF26) Wife of patient.

*Without them he would have had to gone in hospital, and the thought of it would have killed him.* (BYF11) Wife of patient.

*If I hadn't had had people like them coming in it would have been twice as hard for me. I wouldn't have been able to do it all. I would have had to as I say put him into care or had him in respite a lot more than what I did you know just to get that break.* (CYF13) Wife of patient.

In a minority of instances informal carers were critical of individual HCAs. This occurred mainly when HCAs lacked apparent engagement with the family and an unwillingness to 'go the extra mile' which was so apparent in most cases. These HCAs contrasted sharply with the willingness to do whatever appeared necessary demonstrated by the majority. A limited number of instances occurred where HCAs were seen to be condescending or lacking concern for the patient's dignity. Criticisms were largely directed at agency staff employed by one of the services to fill gaps in staffing.

*He was a young man. I couldn't understand him. I asked him what his name was and I repeated it and he said, that's not right. And he said it again, and I still couldn't get it right and I said, can just call you... it sounded as if it ended in Bob, can I just call you Bob? He said, no, and he was that superior, and I was frightened of him. I think we only had him twice.*

*I didn't know what to call him and I didn't know what he was saying. I can't see the point of sending people like that. And he was working full time and doing a degree, and he said well... I thought how have you got the time, especially when you've got sit and be awake all night (BYF11) Wife of patient.*

*I said to her I said, "Oh you don't need to sit here, I said, you can go into the other room, that's where they normally sit". And she went, "Oh no it's alright, she said, I'm okay." She was reading a book. And I came in and um my daughter-in-law sort of looked at me as if to say, I've already told her that. Anyway, um she sat with him for a while and he started to sort of choke a bit. So my daughter-in-law... and he kept having to spit, and so my daughter-in-law got the kidney dish, you know, and she just stood up and she sort of looked and then it was like something clicked in her head and thought, "Oh I'd better go in and see if there's anything I can do". And she came in, and well by then my daughter-in-law was a bit niggled, you know. And she said, "It's alright, I can manage". And um anyways she then started to sort of appear to be, you know, doing something, (BYF09) Wife of patient.*

In one instance Agency staff were seen as lacking the skills to be helpful.

*Whereas I just classed them as the agency ones, the ones that weren't in uniforms, they virtually, as I said, if you'd got a broken hip and you couldn't get up to go to get a cup of tea, they would have been just ideal.*

*Int Right, but you didn't feel that they had the skills...?*

*Res I didn't feel happy with them. Not as people, but I didn't think they would have known much what to do, you know, because they hadn't got the experience on it, they were more... they were more like just sitters who would sit with someone and probably give them a cup of tea or something. That's how it just felt to me. (BYM12). Husband of patient.*

In general, it was a difference in attitude to the patients between Agency and regular staff that was apparent to family members.

*I think the difference was the ones that we had, they actually cared, you know, there was just those little touches, you know, things like brushing her hair and things like that. Whereas from the agency the bank ones, is for a lot of them I think it was just... well it's an easy... you know, I just have to sit here for 8 hours and read my book, I don't really need to... oh it sounds awful doesn't it, but it didn't feel as if they cared. (AYF18) Daughter of female patient.*

Patients were generally accepting of the presence of the HCAs particularly when they saw that this alleviated the strain on their partner or other relative. In situations where patients were able to communicate verbally, carers commented on the enjoyment they perceived patients had experienced from conversations or even brief exchanges with carers.

*I heard them talking about children and all these things and talking about when she was home helping and working It's one of the important things is company isn't it as well. And um of course she'd got female company which is different isn't it; I mean it is nice to have women chat. I'm okay but ] I'm a man, you know. (BYM14) Husband of patient.*

*I mean the first week when they started coming, Ee, he was still sitting at the table there wasn't he and chatting to them. Oh he liked... he got on with them well didn't he*

Res2 *And he got on really well with M*

Res1 *Oh yes, he was chatting her up. (BYF23) Wife and daughter of male patient.*

Some patients nevertheless preferred their spouse to undertake personal tasks,

*As far as right to the, the day she died, I mean I did all the sordid things. They didn't. I mean they'd take her... probably while she could have a wee, but anything else it was me that had to do it, I did everything, you know. (BYM14) Husband of patient.*

*I could have coped with the rest really because putting him on the bedpan, I used to do that a lot of the time because he didn't like them doing that. So luckily he would go in the afternoon so I would do it, change the sheets and do it all by the time they came again and half the time they didn't even know I had done it. But I wanted to do that. (BYF26) Wife of patient.*

In some instances of intergenerational caring these tasks were undertaken by the HCA as it was not considered by patient or carer to be acceptable for a child (albeit an adult) to undertake this aspect of care for a parent.

*Personal care because I couldn't do that and [husband] felt as if maybe my Dad might have felt a bit....even though they got on really well so they took over that side of doing the personal care and then really that was basically what they did. (BYF27) Daughter of male patient.*

#### **4. Multiple roles of the HCA**

The role of the HCA is loosely defined as one of providing support to carers at home. Our findings illustrate the wide ranging nature of the role they undertake. Physical care of the patient included assisting with feeding or mouth care, assisting with toileting washing and changing and changing bed linen.

*Well they just did everything. They washed him, they changed him, they shaved him. They were absolutely wonderful. (AYF27) Wife of patient.*

In addition HCAs would help with domestic tasks such as washing up, ironing or making tea for the informal carer.

*They emptied my washer and my tumble drier and folded it all up. I could have kissed them, I think I probably did. Because they said well we are here all night if he's asleep we can do whatever and they emptied my dishwasher and did strange things like that which I would never in a million years have asked anybody to do, but it was lovely that they did it. (CYM20) Wife of patient.*

The presence of HCAs provided a physical break for carers allowing them to go out or undertake other household tasks or importantly to sleep. The presence of the HCAs gave carers some degree of emotional breathing space in the form of respite from the continuous vigilance that their role demanded. One daughter caring for her father, expressed the view of many carers,

*...it was just like somebody had taken a huge weight off me. It was lovely. (BYF23) Wife and daughter of male patient.*

This daughter who with her mother had resisted help that had been offered until she became exhausted, remembered particularly being told by the Macmillan nurse that the presence of the HCAs would allow her to return to being a daughter rather than a carer.

In most instances HCAs provided implicit emotional support to patients and carers through aspects of their interaction. In some cases this was explicit and identified as the provision of emotional support by carers. This aspect of the work and the relationship between HCAs and families is described in depth under Section 2.

## **5. Balancing the relationship**

An extreme circumstance such as an imminent death may in itself serve to alleviate, to some extent, the degree of social discomfort that might be associated with the extended presence of outsiders in a household. As this carer expressed it, it was only in retrospect that privacy began to be valued once more.

*I mean there was a multitude of medical people coming in, you know, district nurse, um Macmillan nurses, XX, the doctor, um, you know, there was such a lot of other people in and out.....I mean I really thought I would have a problem afterwards, but... and then afterwards I suppose it was quite... in a way it was quite nice to get my house back to myself, you know, and not have all the traffic. (BYF09) Wife of patient.*

Carers nevertheless took an active part in normalising the situation by demonstrations of consideration and offers of hospitality to the HCAs. This was apparent particularly at night with

carers making sure HCAs were comfortable offering tea, or food and in some instances access to television. These actions perhaps served two functions for the carer, balancing the relationship through reciprocating the care given to the patient and concern shown to them and also reinforcing or reaffirming their sense of control over the domestic space.

In certain instances HCAs involved carers in some of the tasks they were undertaking for the patient. Where this occurred the opportunity to learn how to carry out certain tasks was welcomed by the carer. Several carers identified learning how to move the patient with the use of a slide sheet or how to carry out personal care without hurting the patient. Conversely instances occurred where the carer was able to instruct the HCA.

*And I watched them do it and me and my Dad sometimes if we was low, would do it on a slide sheet. Because if you do it on a sheet it can cause sores so you need the proper slide sheet.* (BYF26) Wife of patient.

*... oh it's terrible to have to do it for him but they showed me how to put these pants things on, you know, because they're quite difficult. It's like a nappy really, but they showed me how to put it on properly so that it, they showed me how to put those on properly. Um, I don't think... um, oh they told me, like when he had difficulty drinking they said, well have straw, you know, have a straw.* (AYF 26) Wife of patient.

*So... and occasionally there might be a new carer come along that wasn't used to somebody or not experienced somebody with a stoma bag so the experienced carer and I would sort of say, well this is what you do look, you know.* (BYM21) Husband of patient.

## **6. Experience of the care package and how services worked together**

### Information and Organisation

Carers were largely satisfied with the organisation of the care that they received. The few complaints were generally made in the circumstance where HCA input was organised when the patient was at home. Most frequently these concerned a lack of information on what was to happen.

*it would have been better sort of say, right you can have, right from the beginning, well we know that mum's on palliative care and you need support, is a bit like the NHS, we got two nights a week. It would have been better for A M to say, right you've got one night a week and this is the person that's coming in.* (AYF18 ) Daughter of female patient.



*Let's put it another way, if I had realised that I could have had that sort of care sooner I would have had it sooner because... I don't think that it was made clear to me that I could have Hospice at Home. (BYF09) Wife of patient.*

*You are not told anything you are not asked anything and hopefully from this things will get better because I think you need to know things, you might not need to know everything, but you are put in a system that you haven't got a clue how it works, and you just go along with the flow. (CYF09) Daughter of male patient.*

In a small number of instances too, carers had reached a point of desperation but had been unable to access immediate help.

*I was trying to get in touch with somebody and I rang the local district nurse and there was nobody there, and I rang another number that I'd got and I can't remember which one... I think it was the XX number, and there was nobody there.....there was a recorded message. Um, I rang BUPA and they said they could get somebody in on Monday for us, I said, well that's no good. I rang everybody I could think of.....I found just the weekend that everybody could come out on the Monday but nobody could come out on the Saturday just when we needed them really. However, when we did get people they were very, very helpful and um yes, so I've got no complaints as far as that's concerned. (AYF 25) Wife of patient.*

*It seemed I was battling all the time with somebody, especially the Macmillan nurses when they didn't answer the phone. I know probably they were short staffed, I can understand that. I know there's reasons for everything, but it wasn't good enough. (BYF10) Wife of patient.*

When care had been set up prior to discharge, almost seamless coordination was apparent (see section 1).

In most instances the whole health care team was highly regarded. While Macmillan nurses were in general very highly praised, a minority were criticized either because of a particular barrier to communication or because of a perceived lack of hands on involvement.

*The second Macmillan nurse, oh she was horrendous, she really was. She came and me and X didn't click with her at all, and um she came once and introduced herself. She made four more separate appointments, this was November 2010, that was the last time we saw her and she had four more appointments after that and she never came again ....she cancelled every time (BYF10) Wife of patient.*

More hands on involvement had also been expected by some carers.

*I mean everybody was really brilliant. The only thing...not a complaint but maybe me being wrong but when you see on the telly that they advertise that the Macmillan nurses are there for you, we felt there wasn't that. They may have come 3 times at the most. (BYF27)*

#### Relationships between HCAs and other health care professionals

These were generally reported to be good and roles well coordinated. Information appeared to be shared between all those involved such as district nurses and Macmillan nurses through both organisational procedures and personal relationships.

District nurses and HCAs communicated both efficiently through patient notes,

*the carers would always read what the district nurse had written in, and everything was signed off. It was all done properly, and everybody knew, you know, what was happening with the drug situation and everything. So yes. (BYF23) Wife and daughter of male patient.*

or through working together,

*I mean the nurses, the district nurse and the carers were fine together. You know, very often the district nurse would be here when the carers were here, but they'd all work together, you know. Um, one lot would wait for the other to finish what they were doing and then you know, but they'd come and, you know, do what they... they'd do what they could to help. (BYF17) Wife and daughter in law of male patient.*

Often there was a shared willingness to make an extra effort, in the interest of the patient.

*I mean they seemed to work very well, you know. Because sometimes the nurse (sic) from XX would come in and she'd say, oh are the nurses coming in the next half hour, I'll wait for them, you see, so she'd wait if she wanted to speak to them about something. ... and I'd say, well as far as I know they'll be here, you know, in the next 20 minutes. So she'd hold on. And they'd meet up and have a chat, (AYF26) Wife of patient.*

In a minority of instances however, when multiple agencies were involved of the provision of care, the family carer found themselves passing important information between staff.

*The district nurse wouldn't have seen any of the hospice staff anyway. She worked with the NHS carers that came in, basically to talk about the um... and we'd pass messages on. Like the carer would say, it's weeping quite badly we need to get the district nurse back in again to have a look at it again, and so she'd come back in.*

Int *But she would tell you that to pass on rather than calling the district nurse?*

Res     Yes, yes, we were sort of the go-betweens and they wouldn't call in the district nurse, it would be us that would actually... and occasionally the district nurse would get here at sort of 1 o'clock to see them, just to sort of go through with them the physical care. (AYF18) Daughter of female patient.

#### Suggested improvements

A small number of suggestions were made as how services could be improved. One suggestion related to age and sex of HCAs. One wife felt a younger woman performing personal care for her (50 year old) husband was very demoralising for him. This respondent suggested matching between carer and patient. Other suggestions related to information both about the service and regarding sources of help and the kinds of help available from each source. One carer suggested the provision of a laminated sheet with contact numbers for all the services that might be needed. Another would have liked more flexibility regarding the timing of the HCA shifts as well as longer hours of care.

*I don't know I mean I allus had them when I wanted them, I know they were a bit limited as to when I could have them, I couldn't sort of say, right can I have them tomorrow, if they were none available I couldn't and er so I had to wait while they got sort of slot for me. Er, but er, when they did have slot for me I had to sort work me outings round that. But er it would have been nice like er ,if I could say can I have one tomorrow, but er, I mean not always available are they but er, yes they were brilliant, and I don't know whether you could have them any longer. Think it was just two hours which really if you are going shopping it's not a long time you can have an hour in a supermarket can't you I think it would have been nice one more hour, I'm not being ungrateful but it would have been nice just a little bit longer then you weren't rushing back sort of thing. (CYF11) Wife of patient.*

Even when suggestions were made participants were at pains to point out the value of the assistance they received.

*the only negative thing I could say it would have been nice to have same person but then yes, but I mean it's a minor point really, minor point. (CYM10) Nephew of female patient.*

One wife expressed the appreciation of the HCA role and its importance felt by many,

*And it must be hard. I mean you look it from their side, it must be hard for them to come into people's houses that they don't know, you know. They're coming into people's houses, they're coming into a situation they don't know... they maybe don't know much about, you know. They don't know how long the person's going to be here for. They don't know how it's affecting*

*the family, how anybody's coping. I mean when they initially came out to us um I think their initial reaction was, how tired we all were. You know, we'd had so many nights without sleep that we were just so shattered, and we were just so glad to have somebody come in and say, well you just go to sleep, you just sit down, have a cup of tea and take it easy, and it was just so nice to have somebody to just say that to us, wasn't it?* (BYF23) Wife and daughter of male patient.

## **Discussion.**

The interviews with bereaved carers, three to nine months post-bereavement, who had received care from one of three services employing HCAs as home care workers, provides a useful insight into the benefits and burdens of caring for a dying cancer patient at home with the assistance of HCAs. As the majority of carers had cared for their family member before the HCAs were involved, this enabled a comparison of these issues before and after receiving the service. Those with no previous experience were the ones where the patient had been discharged from hospital having had no preadmission illness.

The data illustrates the intense difficulties involved with caring for someone who is dying at home. Carers invariably indicated that they had not realized the extent of the burden of caring before they had got to the terminal stage. The work was physically as well as emotionally demanding and took place in the context of facing up to the death of a loved-one. Hudson et al (2011a) have reported high levels of anxiety and depression in carers at the time of referral of patients to palliative care services. None of the participants in this study claimed to have been depressed, but their descriptions of their emotions indicate depression may well have been present.

Many carers, however, had been reluctant to access a home care service from HCAs, with the uncertainty about having a stranger in their house. Carers have been identified as being ambivalent about receiving home care services (Harding and Higginson, 2001), which could be for many reasons for including concern that receiving care could be interpreted as a failure to perform their allotted task (Wilkinson, 2010). Funk et al (2009), point out that further research is needed to understand the nature of this ambivalence. Our results suggest that accepting a HCA to provide "sits" within the home can be seen as an invasion of the patient and carers' private space which has potential and uncertain costs for the carer.

Despite initial reluctance, all participants expressed a positive assessment of the care that HCAs had provided in the strongest possible terms, admitting that they could not have continued caring without the help they received. This positive assessment is likely to have been influenced by the skill the HCAs showed in being unobtrusive, flexible in working together with informal carers in providing care as well as in providing emotional support (see Section 3). Carers also often tried to normalize life within the home (Stajduhar and Davies, 2005) by accepting the HCA as being "like a family member" and reciprocating for the HCA's work in offering hospitality. When the attributes

necessary for this negotiation of roles was lacking in HCAs, the carers expressed dissatisfaction with individual care assistants. This seemed to invariably implicate staff from agencies, rather than employed HCAs from the services hosting the study. HCAs themselves have also described their concern over the care provided by staff from agencies (Munday, 2007).

The carers accounts of the tasks the HCAs undertook corroborated remarkably well with HCAs own accounts: nursing tasks - mouth care, toileting, changing bed linen and domestic chores - ironing, washing up, making drinks. Carers occasionally expressed surprise at the wide range of tasks were undertaken and in some services at least, domestic chores would be seen as out-with the duties of HCAs (Munday, 2007).) Offering respite so that the carer could take a break or have a night's sleep was a major benefit of having HCA sitters within the house; carers being able to benefit from this needed to have confidence in the HCA providing the service.

One area in which HCAs needed to display flexibility was in delivering personal care to patients. A number of wives were keen to retain that function for their husbands, whilst children were happy for HCAs to perform that role for their parents. The data suggests that despite personal care being an issue for carers, they did not express concerns about the HCAs' role.

Concerns which carers expressed about the services they received suggested that lack of availability of care at certain times and lack of flexibility as to when services could be provided. For the carers this was problematic as was lack of information about services. Carers sometimes indicated it had been difficult to find out what services were available. These issues have been highlighted in other studies focusing on carers needs for home care (Funk et al 2009). However in our study these concerns were very much balanced by high levels of satisfaction with the work of the HCAs. Lack of continuity has also been cited as being problematic (Devlin and McIlfatrick, 2009), however we found that this was not frequently cited as a problem in our sample. One explanation for this is that it seems HCAs displaying good communication skills, friendliness and flexibility mitigated for the lack of continuity. Lack of information about changes in times at which care was being offered, however did lead to dissatisfaction for the carers. It seems therefore that most of the concerns carers expressed were related to systematic issue regarding how services are configured, rather than being within the control of HCAs.

HCAs in the key informant interviews and in previous research have expressed concern over the lack of value placed on their skills and the work they undertake by other health care staff, particularly district nurses. Good palliative care is predicated on effective team working and the bereaved carers in this study with only a few exceptions reported that this aspect of care had been good. It is unclear whether this was because in the instances they experienced this was the case, or because HCAs managed their frustrations by being discrete and not relaying them to the carers.

The work of caring and the indignity of the dying process affected some carers' views about their own management if they found themselves in need of end of life care. Some had decided that they would not want to pass that burden onto their family members and had determined not to request a home death. The duty, love and altruism which they displayed for their dying loved ones seemed to have a reverse effect in considering what they would want for family carers called to look after them. This may be a normal feature of the nurturing altruistic role family members show each other, however, it is a challenge to researchers and service providers to investigate if there are types of support which might be provided to mitigate for these feelings (Hudson et al, 2011b)

## Theme 3

### Emotional support

It was apparent from our research that the bereaved carers largely recognised and valued the emotional support which was provided by the health care assistants (HCAs). Emotional support was demonstrated in the following ways: the relationship which the HCAs developed with the patients; the relationship which the HCAs developed with the carers; the sensitivity which the HCAs displayed in being able to fit into individual homes and situations; the ability to give the carers a break, whilst not excluding or alienating them from the care of the patient. In this results section, each of the above aspects of emotional support will be considered in turn.

#### 1. The relationship which the HCAs developed with the patients

Many of the carers praised the HCAs for their caring attitude in performing all of their tasks for the patients, and there was a sense that the emotional support undertaken by the HCAs underpinned other, more physical aspects of their role, and this is illustrated in the following example given by one carer:

*One morning I came down and...he wet himself....And [the HCA had] stripped him but she had covered here all across his private parts, she had covered him with a towel. And she were washing him face first. Now different face cloths for different parts and I thought, "well, I weren't here, there were just her and him, and she could have thought "well don't bother", but she cared because it were, he were, he were sort of semi-conscious at this stage, and I thought well even at this stage she still cares and showing him dignity, and er, and then when I came in like she said "well you can do that if you like", and I said "alright then I will". And I thought that were lovely that, to me. To show people dignity like that, which they were. As I said they are special people, they really are. (CYF17) Wife of patient .*

The importance of the HCAs' emotional support to the physical tasks of caring, and the carers' valuing of this was also revealed when several carers favourably compared the HCAs from the three services involved in the study, with other paid care workers - particularly agency staff. The example quoted below illustrates this, and contrasts sharply with the quotation above, from carer

CYF17. The following example is a quotation from one carer whose husband received support from a local social services care agency:

*it were just these carers that come in, get them out of bed and wash them and then get them into bed er, they and they were okay, there were a lot of different ones and like I say he didn't really respond to most of them, cos I think they were a bit like er, came in, "right come on", you know "let's get you washed and let's do this", and because they have a lot of people to see to you know and I'm sure they are really busy and I'm sure they with right intentions but he didn't really respond to 'em and if I probably if I'd thought about it I would have stopped them coming cos I didn't, cos he didn't really like them. (CYF15) Wife of patient.*

Carers also valued the HCAs for treating the patients as individual people, and for having 'normal', everyday conversations with them:

*Oh yes he was quite happy because they would sit and chat to him made him a cup of tea and be with him. You know they didn't sort of leave him in bed and sit and watch telly they sat in with him. You know which was nice...Oh they would talk about he was a piano player, so they would take about and she would ask him where he played things like that you know just things that would interest him. You know but just general conversation in a lot of ways but they were good at it... I could tell by my husband's expressions that he had enjoyed the company and the conversation you know. (CYF12) Wife of patient.*

One carer also acknowledged that the patient may have confided in the HCA when perhaps she didn't feel able to talk to her own family:

*Perhaps she was worried, I don't know, about things that she didn't want to talk to me about. People do talk to somebody that's slightly on the outside that you can trust.(BYF22) Daughter of female patient.*

The above example also neatly summarises the 'insider-outsider' status of the HCA, which emerged as a strong theme in our research. On the one hand the HCA was a trusted, capable person who spent many hours, and often many nights in a patient's home. On the other hand, they were not a family member, but a paid care worker, and this ambiguity in their role enabled them to 'fit in' to individual homes and family settings, whilst retaining a sufficient professional distance which allowed them to receive confidences such as those described in the quotation above.

## **2. The relationship which the HCAs developed with the carers**

The carers who we spoke to across all three services were conscious of, and grateful for, the sense that the HCAs were there to care for them, and not just for the patient:

*You know I felt er, they were there for me not only for [the patient], for me, you know and I thought I were getting the care as well. That's what I felt like and that they were like making me feel you know important and like they were there for my care as well, and that were a big thing. Yes I thought they were brilliant.* (CYF11) Wife of patient.

Some carers explicitly mentioned this support in terms of emotions, with one carer stating that,

*But they look after emotionally, they look after you as well, emotionally they looked after me. Which I thought were good, and me son and daughter, when they were here. [INT: And were you expecting that to begin with?] No I thought it would be very clinical, I thought they would come in and say "right, off to bed, leave it us" you know John Blunt, but they weren't, they weren't. It were like having another member of the family here. That's what they are like.* (CYF14) Wife of patient.

In the same way that the carers welcomed the HCAs conducting 'normal', everyday, non-medical conversations with the patients, they also commented upon and valued the same sorts of conversations that the HCAs would have with themselves.

*And er, they used to say, "are you alright then [name of carer]?" and er, we had a cup of tea and chat and then if it were time to go to bed I'd get ready and go to bed, or we would just sit and chat. About chit chat like ladies do but we never sort of talked about [the patient's] illnesses. They never made me feel low, they allus talked about their family and their children, and I talked about my children and it were quite nice and comforting that we were like talking about something other than aches and pains, and pills and medication and you know cancer and things like that. It was nice. Nice conversation.* (CYF11) Wife of patient.

*They'd chat about, you know, things, the family and whatever. Because you don't just want to talk about sort of medical things, do you know what I mean?* (BYF11) Wife of patient

While many carers discussed the advantages of having in the home HCAs who were trained, experienced and competent, the HCAs were careful to work *with* the carers, and not give an impression that, because they were paid and had received training, 'they knew best'.

*'Cause they were doing what we wanted, not what they want. Not one of them did it said, "no it's got to be done like this". It were what, it were what we wanted, and that's what it should be like at end of life.* (CYF14) Wife of patient.

### **3. The sensitivity which the HCAs displayed in being able to fit into individual homes and situations**



While many of the carers acknowledged that it was challenging to have a number of strangers (i.e. HCAs, health professionals, other paid care workers) in their homes at a very difficult time in their lives, the general feeling was that the initial strangeness wore off once they got to know the health staff, and also that the inconvenience was a price worth paying to allow the patient to be able to die in their own home.

*It's just something that you have got to accept gradually if you want to keep your husband at home and he wants to stay at home, you have got to accept whatever is put in place for you which is hard at first, because it's like an intrusion on everything, but I couldn't have done, I couldn't have done it, without their help no way, I couldn't, definitely, they were all they were all good, apart from the care company that were lacking in experience. (CYF13) Wife of patient.*

*No, no. I mean sometimes you think, "oh what's it's going to be like having strangers in the house", you know er, but I never had that feeling at all. Never got that feeling that you know "what type of people going to be alone with me in the house?" I never had that feeling at all. Er, which I thought might have done, but I didn't. No. I felt as though they were having friends in the house sort of thing. That's the feeling I got from them. Yes. (CYF11) Wife of patient.*

One carer mentioned that, while initially she had found the coming and going of various health and social care staff to be intrusive, it was worse after the patient had died, and the visits stopped.

*once I got used to these people it was easy, they became my friends so I wasn't upset by it, it's more upsetting when it stops because your friends stop and I suppose that's something that a lot of people even while they are doing that job they don't think about that, because they are onto the next job immediately and that's what they are there for so we can't complain about that can we? (CYF07) Wife of patient.*

The HCAs were valued for their ability to put the carer at ease, and one carer stated:

*You get the impression that you have known them for years, when you have only known them for two days....and I was quite at ease with them. (BYM20) Husband of patient*

The HCAs' ability to 'fit in' to the carers' homes and put the carers at ease was reciprocated by the many carers who emphasised how they attempted to make the HCAs 'feel at home'.

*but you know we were trying to make them as comfortable as possible cos you know under circumstances we thought you know they are doing a hard job staying up all night and you know letting us get in a few hours. (CYM08) Son caring for male patient.*

*I would just say to her help yourself to tea biscuits and stuff and have you got stuff to read and she usually come with a book or a word search thing and sit there.* (CYF15) Wife of patient.

To return to the 'ambiguous' nature of the HCA's role, which allowed them to be close enough to the patient and their family to be trusted, whilst distant enough to be privy to confidences which could not be disclosed to the family carers, the ambiguity of the HCA's role was also noticeable in their ability to move from the 'public, medical' sphere into the 'private, domestic, non-medicalised' home setting. This was commented on by one carer who described the HCAs as like,

*a liaison service between us and the medical people.* (CYF07) Wife of male patient.

The HCAs successfully cared for the patients and the family carers in an environment which contained much 'medical paraphernalia', such as medicines, catheters, syringe drivers, without seeming to alienate the carers from their own home, or transforming the domestic home into a fundamentally clinical environment. A couple of the carers commented on how the care the patient received in their own home was vastly preferable to the care they had received in hospital.

*they are all fabulous ladies who obviously have got the ability to say "I can't do with hospital nursing anymore, I've got more compassion than that". 'Cause there is a huge difference, and the team that I had here er, all of them had tons and tons of compassion. Which helped us. It wasn't just another job. You know up in the hospital it was just another job, they were ticking boxes.* (CYF07). Wife of male patient.

#### **4. Giving carers a break**

One of the key themes which emerged from the interviews was the way in which the presence of the HCAs gave the carers a break from caring. Some carers emphasised the physical strains of caring, and some the emotional strains, but more often than not, the physical and emotional stresses were interlinked and could not be separated. For many carers, the main relief from receiving the services of an HCA came from knowing that they were no longer alone in the home, and moreover, the HCA had the experience, knowledge, and competence to know what to do.

*To have somebody trained to know what to do, it took all that pressure off you. You know it was a relief.* (CYF09) Daughter caring for male patient.

*They just take it all off your shoulders. It's just knowing someone is there who is used to dealing with it. And they can deal with it for you. It's just peace of mind really. You have enough going on in your head when you know you are losing your husband without having to think next, I didn't want to think one step ahead like they did.* (CYF14) Wife of male patient.

*The safety net of somebody being here...yes it were a massive comfort blanket knowing that there was somebody there if something happens and you think you can't cope. (CYF15) Wife of male patient.*

Having an HCA in the home meant that the carer could 'switch off' a bit, get some sleep, have a shower, or leave the home for a while to go shopping or go to the gym. The moment the HCA arrived, the carer could relax a little, knowing that they did not have to be quite so vigilant.

*You knew when it was coming ten o'clock, well ten to ten, they would be walking in the door, they would be putting the kettle on if it wasn't already on, you know, and you knew once they had arrived, "okay, you don't have to, I don't have to be totally in control any more, I can, okay", and that ability to hand off that pressure was particularly positive. (CYM20) Son caring for male patient.*

Carers also valued the HCAs for their ability to quickly appraise the situation, and their willingness to do whatever was needed.

*I can't really explain it...it's just the way they came in and nothing was too much trouble...if I was there they would go and make me a drink. They emptied my washer and my tumble drier and folded it all up. I could have kissed them, I think I probably did. Because they said, "well we are here all night, if he's asleep we can do whatever and they emptied my dishwasher and did strange things like that which I would never in a million years have asked anybody to do, but it was lovely that they did it. (CYM20) Son caring for male patient.*

*I can't fault 'em. I can't think of anything whether anybody else can I don't know but for me they were great. And I'm eternally grateful to 'em. I just can't think of anything that anything more they could have done you know. They sort of took over everything that I would have been doing, like if he had messed the bed they said you know we'll do it, you, you know it doesn't matter we will do it. You go and rest, you carry on what you are doing. No they, they were great I just can't think of anything off hand...[INT: what was the main benefit of having them here?] To relieve my pressure. And to see that he were well cared for. You know with compassion and dignity. And that's what they did. (CYF13) Wife of male patient.*

*They were very nice and on a morning they used to have me a cup of tea. Er, waiting on the working top. Which were nice you know they would say I've made you a cup of tea before I go. And I used to think, "oh wasn't that nice?" You know little thing like that, they make me this cup of tea. And er, they were brilliant. (CYF11) Wife of male patient.*

While the HCAs were valued for getting on with whatever needed doing, they were also highly skilful in knowing when to step away and not be too intrusive - an attribute that was particularly important immediately after the patient had died.

*They would give you space, they would give you time, and they weren't in your face. "If anybody wants to go and sit in there on their own with him just let us know and we will come out" you know. And they would come and sit in here with you and they'd sit and talk to mum or make mum a cup of tea. They were most respectful of everybody's wishes. The night he died... she was so...just kind and er, "when you are ready I will inform everybody, just tell me when and er, who are you going to have for undertaker?" and she just cleared off and we went and said to her, "yes we are ready now. Let everybody know" and er, I realised then I couldn't we couldn't have coped without her because well you panic don't you, you don't know oh what shall I do? What shall I do, er, and she, they were lovely. Really are nice girls. (CYF17) Wife of male patient.*

*The very last night when D. started deteriorating er, well very rapidly there were two came and er, and they left there were all family members around all family members round bed and we knew it were just a matter of time and er, even though there were Marie Curie nurses in another room in background they just left us to it, and er when D. did pass away they took over and they were marvellous, they knew exactly what to do and er ,like I say I know it's their job but they didn't just do their job they were fantastic in every aspect and er, will allus be, will allus be grateful. (CYM19) Husband of female patient.*

While many carers spoke of the relief they felt once the HCAs arrived, as it meant that they could relax a little, they also welcomed attempts by the HCAs to involve them in the patient's care. This was another example of how the HCAs demonstrated great skill and sensitivity by looking after the carers, whilst being careful not to exclude or alienate them from caring for the patient.

*And they would leave a report, every time they come they write down don't they? I thought that were involving me as well. Telling me the report. And I think that's a good thing. Didn't feel shut out from it..... I mean I just felt so involved with them. (CYF14) Wife of male patient.*

*[the HCA would say] you know "I'm going to do such and such for your mum now, is that okay?", so the opportunity was always there for us to go in to be with her and you know if my sister had wanted to go in and sit in all night with her that would have been fine. (CYF18) Daughter of female patient*

## Discussion

We have identified a number of ways in which health care assistants demonstrated emotional support: through their relationships with the patients and carers, their ability to sensitively enter and work within private, domestic homes at a time of great difficulty and stress, and their skill in giving carers a break from caring, whilst not excluding them.

Previous research has noted the ambiguity of the health care assistant's status (Munday, 2007), and the lack of an in-depth understanding of their role in palliative care. The findings from this study suggest that, rather than this necessarily being a problem, this ambiguity helped the HCAs to negotiate relational, spatial and temporal 'boundaries' in their work, and provided them with the agency to skilfully provide emotional support in complex situations.

The emotional awareness and sensitivity of HCAs was crucial in allowing them to negotiate 'relational boundaries'. As paid care workers, HCAs were distinct from carers, yet their unqualified status distinguished them from nurses and other health professionals. Many carers welcomed this 'in-between' status occupied by HCAs, with some carers regarding the HCAs as helpful liaisons who were able to facilitate communication between themselves and health professionals.

In this study, which concerned home care respite services, the HCAs were also able to sensitively negotiate spatial boundaries. Regular, often daily visits by nurses, doctors, and other health and social care staff, together with equipment such as hospital beds, drips and syringe drivers, contrast with the more usual concept of the domestic home as being a private, non-clinical environment. As has been found in previous research (Ingleton et al 2011), the HCAs in this study were able to 'fit in' to homes and were welcomed by carers, who in some cases came to regard the HCAs as members of the family. The unobtrusive and trusted presence of the HCA not only meant that the carers did not have to worry about a stranger in the house, but also allowed the carers to retain a sense of control and autonomy in their own home that may have been threatened by the constant visits of health professionals. It is important to note that while carers spoke of the apparent ease with which the HCAs made themselves at home and 'fitted in', HCAs were very much aware of their need to successfully negotiate their access to, and presence in the home. Therefore, while the HCAs' presence in the home may have been regarded as 'natural' by the carers, this was something that the HCAs were conscious of and had to work to achieve.

It is important to note that many of the HCAs in one of the services in this study often made overnight visits. These HCAs successfully negotiated the 'temporal boundary' of the daytime, which was often characterised by visits from health professionals, and the night time, during which the only people usually present in the home would be the patient and family members, i.e. the 'normal' residents. The HCAs were able to normalise their night time visits, often by arriving slightly early so that they could chat with the carers before they went to bed, and by not rushing off in the mornings so that they could discuss with the carers what had occurred in the night. The

HCAAs tempered the ‘strangeness’ of their night time presence by engaging in activities such as watching television, reading or knitting. The ability of the HCAAs to make themselves at home reflected well on the carers’ maintenance of a ‘normal’ environment at a non-typical time, and is also another example of how the HCAAs were able to fit in to wherever they needed to be.

The HCAAs we spoke to identified emotional support as a key aspect of their work, and it was clear that this was recognised and appreciated by the carers. Emotional support was not distinct from the physical support which HCAAs provided, such as lifting, turning and feeding. Rather, emotional support underpinned and informed all aspects of the HCAAs’ role, and indeed *allowed* them to perform other tasks. Some carers reported being unhappy with the attitude shown by health professionals and social care agency staff, and on occasion requested that certain personnel did not return to the home. The carers’ unhappiness was not necessarily because of any technical incompetence on the part of staff, but more because of the manner in which they performed their work. Therefore, when carers often spoke of HCAAs as being ‘compassionate’, ‘lovely’ or ‘friendly’, these characteristics weren’t merely seen as being ‘bonus’ personal qualities. Instead, the display of such emotions was crucial in allowing the HCA to be in the home and successfully conduct all aspects of their work.

The flexibility and ambiguity of their role allowed HCAAs a great deal of agency in supporting the patients and carers. Our study shows that HCAAs successfully negotiated a number of boundaries - relational, spatial and temporal - and demonstrated considerable skill in providing the patients and carers with emotional support.

## Final Discussion

This study has enabled us to explore the experiences of bereaved carers three to nine months after the death of a family member for whom they had cared with the assistance of HCAAs. Participants had had experience of one of three separate services in the English West Midlands and Yorkshire. We believe this is the first and largest study to explore bereaved carers experiences of HCA working in the home at the end of life that has taken an in-depth qualitative approach.

A number of studies have reported the roles which HCAAs in end of life home care undertake (Herber and Johnston, 2012). Our key informant interviews with HCAAs in the three services enabled us to ascertain that their reports of their role, its rewards and its challenges were in line with the findings in these studies. HCAAs described how they delivered practical health and domestic care to patients and provided respite for their carers. They described how they would be a calming presence within the home, they would monitor the patient and would be aware of who to call in the event of deterioration. They were experienced in managing the patient’s death and supporting

relatives at this time, including giving explanations of changes during the dying process. They also described the emotional support they offered to patients and their carers, through general reassurance, work to calm the distressed patient and providing a listening ear for patients or their carers who wanted to discuss difficult or distressing issues. They described the pride that they took in delivering good care and expressed their concern over staff from nursing or social care agencies who may not have had the same skills or display the same care and dedication as they did. It was remarkable how similar the HCAs accounts of their work was, given the different geographical areas in which they worked and the different configurations of the services.

The bereaved carers' accounts corroborated with those of the HCAs in a remarkable fashion in terms of the work HCAs undertook. They expressed high levels of satisfaction with the care they had received and described the HCAs as professional, caring, flexible and fitting in well into their home, an issue that many carers had been concerned about before they received care from the HCAs. Many carers agreed that HCAs had offered them emotional support, and even when they had difficulty in naming it as such, their narrative frequently indicated that they had received this type of care. Bereaved carers also described a lack of satisfaction when HCAs did not display these attributes or were distant and non-communicative - identifying agency and social care staff principally for this criticism.

James, (1992) in her seminal paper on caring in hospices, described how care-work in hospices was a combination of 'organization, physical care and emotional labour' (p488). Physical care was given in the context of emotional labour; it was frequently during acts of physical care when patients would discuss sensitive issues with clinical staff, the physical contact, privacy and intimacy seeming to enable these things to be raised. Frequently this care-work was undertaken by nursing auxiliaries (equivalent grade to HCAs). There are resonances between James' findings and ours. HCAs performed their caring role most effectively and to the greatest satisfaction of bereaved carers when they performed all their work in an attitude of caring and emotional support. When this attitude was lacking, care was substandard according to bereaved carers.

James' critique of care-work within the hospice explored how despite the hospice attempting to produce the ambience of "home from home", the organizational structure of the hospice and the necessary division of labour in a formal institution meant that it largely failed in this respect. In our study, we found evidence both from the key informant interviews with HCAs and also the interviews with bereaved carers that HCAs showed flexibility and were prepared to take on tasks, such as some domestic duties, which were not in their job description. This suggests that for the HCAs working in the homes of people who were dying, whilst they might have a core care-work role to perform, their flexibility and their ability to see "what needs to be done" meant they also took on the role more usual for a family carer, where division of labour is relatively lacking.

As discussed in section 3, the HCAs ability to project and maintain a caring attitude was seen by bereaved carers as being entirely natural. The HCAs' interviews however indicated how they needed to constantly reflect on their approach and to adjust it according to the relatives' preferences within the home. This 'naturalness' was therefore the result of considerable work and skill on the part of the HCA. This could therefore be constructed as emotional labour (Hochschild, 1983). Exploration of emotional labour in HCAs will be the subject of future theoretical work by the project team.

HCAs in their interviews expressed the belief that they enabled dying patients to stay at home rather be admitted to hospital. From bereaved carers' narratives it is clear that they identified the important role HCAs had played in enabling them to continue caring. Since it has been identified that carer fatigue, anxiety and inability to carry on caring is a reason for hospital admission at the end of life (Rhodes and Shaw, 1999), it is quite possible that HCAs do have a positive effect in enabling patients to remain at home. However this study was not designed to address this question. A previous RCT of hospital at home failed to demonstrate that the service under investigation reduced emergency admissions of patients at the end of life (Grande et al., 1999) although bereaved carers in the intervention group showed higher levels of satisfaction with the care received (Grande et al., 2000). Reflecting on the failure of the RCT to demonstrate effectiveness in reducing hospital admissions, the authors suggested that such a service would need to be evaluated using a complex intervention model (Grande and Todd, 2000). Such a study would require substantial resources. As recently suggested, further research into the effectiveness of various models of home care are needed (Hudson et al., 2011). However, this study along with other studies of the work of HCAs caring for dying patients in their homes (Heber and Johnson, 2012) suggest that HCAs who have received appropriate training and support are likely to form part of the solution to effective home care.

This study has demonstrated the skill which HCAs display in delivering end of life care at home to patients and their carers. Whilst we have not attempted to map the interviews to the competencies HCAs need to have for this type of care, our results have illustrated the importance of training and support for HCAs and also the need for their important contribution to be appropriately valued by managers and other health care professionals. The dissatisfaction expressed and the lack of skill in caring of some agency staff also illustrates the importance of ensuring that staff are properly trained, supported and supervised. Working within a person's home is a privileged and a responsibility; failing to recognise this by both the individual worker and the services providing such care represent a lamentable professional failure.

### **Strengths and Limitations**

This study was an in-depth exploration into the experiences of bereaved carers having the services of HCAs caring for dying relatives within their homes across three diverse services; as far as we are aware, the first such study in the UK. Support for the carers of patients dying in the community is



an important area for research and policy development, therefore this study can make a significant contribution to the evidence base of home based care.

We were able to compare bereaved carers experiences with HCAs own accounts of the role they perform, both from the literature and our own key informant interviews. Using these insights we were able to construct the interview schedule for bereaved carers so that we were asking the appropriate questions regarding HCAs. Comparing bereaved carer experiences and HCA experiences has enabled us to triangulate our results to give us confidence that we have gained a clear picture regarding the role of HCAs in this context.

Undertaking the study in three distinct services enabled us to also compare the results across the three areas. The results were indeed very similar for all services suggesting that our insights are likely to be transferrable to other geographical areas offering similar types of service.

Many studies have sampled bereaved carers as proxies for patients at the end of life, to give insights into the services received. These studies can be problematic as the bereaved carer's experience does not necessarily reflect that of the patient. In this study, however, we viewed bereaved carers as in receipt of the service from HCAs themselves, so we did not consider them proxy reporters although they we did ask them about the patient's experiences also.

Recall after an event changes over time, particularly following bereavement. We interviewed bereaved carers between three and nine months after the death of the patient, which was a compromise between interviewing immediately after the death, or during the time that the caring was still taking place. We considered both of these times to be unfeasible for ethical and practical reasons. However we believe that the interviews occurring reasonably soon after such a memorable event would have meant that recall of their own feelings would have been good relatively good at that time. Also it can be argued that an important aim of end of life care is to make sure the experience of the death is as positive as possible as it 'lives on in the memories of those who are bereaved.' A delay following the receipt of the service being investigated can therefore be seen as both a strength and a weakness, depending on the perspective taken.

Two major limitations of the study are that we were only able to interview four bereaved carers at the hospice site, as there were no other respondents to our request to be interviewed despite 40 invitations being posted to bereaved carers. This was well below the 12 - 15 that we aimed for each service. Whilst we were confident that the interviews had reached saturation for the other two services as no new themes were emerging, we cannot be confident of this for site one. We tried to open up the study in another service which was similar in configuration, but despite having the agreement to do so and having undertaken key informant interviews with staff, the managers of the service did not have the time to invite bereaved carers to take place due to service constraints.

The other major limitation is that whilst we intended to draw a purposive sample, in the end all bereaved carers who responded were interviewed at all sites as we did not have sufficient responses to select them purposively. It would be more accurate to say that we had a convenience sample of carers who were happy to respond to the request for an interview. This needs to be borne in mind when interpreting the results because it may be that only bereaved carers who had a positive experience of the service agreed to be interviewed.

We did find that we had a good spread of bereaved carers who participated and the demographics of the final sample remarkably similar to our original sampling frame. We had a good spread of participants in terms of gender, age and relationship to the patient. We only had the bereaved carer of one patient who had died as an inpatient. It would have strengthened the study to have more participants from this distinct group as their experiences may have been different to those who had died at home.

### **Dissemination**

We have submitted an abstract to the EACP Congress and await a response (see appendix). We now plan to draft and submit three articles to peer reviewed journals following the content of each of the three sections in the results. There may be other publications which will emerge over time. We will return to each of the services with a copy of the final report and discuss the findings with them so that they are able to benefit from the insights and possibly use them for further service development.

### **Reference List**

AOUN, S, M., KRISTJANSON, L, J., CURROW, D, C. & HUDSON, P, L. 2005. Caregiving for the terminally ill: at what cost? *Palliat Med*, 19, 551-555.

ARANDA, S., HAYMAN - WHITE, K. 2001. Home caregivers of the person with advanced cancer . *Cancer Nurs*, 24, 300-307

BAINES, M. 2010. The origins and development of palliative care at home. *Progress in Palliative Care*, 18, 4-8.

BEE, P., BARNE, P., LUKER, K, A. 2008. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *J Clin Nurs*, 18, 1379-93.

BOYD, K.J., MURRAY, S, A., KENDALL, M. et al. 2004. Living with advanced heart failure: a prospective, community based study of patients and their carers. *Eur J Heart Fail*, 6, 585-591.

BROBACK, G. & BERTERO, C. 2003. How next of kin experience palliative care of relatives at home. *Eur J Cancer Care*, 12, 339-346.

CLARK, D., FERGUSON, C. & NELSON, C. 2000. Macmillan Carer Schemes in England: results of a multicentre evaluation. *Palliative Medicine*, 14, 129 - 139.

DAVIES, S. & SEYMOUR, J. 2002. Historical and policy contexts. In: *Palliative Care for Older People in Care Homes*. Open University Press: Buckingham.

DEVLIN, M. & MCILFATRICK, S. 2009. The role of the home-care worker in palliative and end-of-life care in the community setting: a literature review. *International Journal of Palliative Nursing*, 15, 526-532.

End of Life Care Strategy. 2008. Promoting high quality care for adults at the end of life. Department of Health, 1-171.

FOLKMAN, S. 1997. Positive psychological states and coping with severe stress. *Social Science and medicine*, 45, 1207-1221.

FROMME, E, K., DRACH, L, L., TOLLE, S, W. et al. 2005. Men as caregivers at the end of life. *J Palliat Med*, 8, 1167-1175.

FUNK, L., STAJDUHAR, K., TOYE, C., AOUN, S., GRANDE, G. & 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, 594-607

GRANDE, G. & TODD, C. 2000. Why are trials in palliative care so difficult? *Palliative Medicine*, 14, 69 - 74.

GRANDE, G., TODD, C., BARCLAY, S. & FARQUHAR, M. 2000. A randomized controlled trial of a hospital at home service for the terminally ill. *Palliative Medicine*, 14, 375 - 385.

GRANDE, G. E., TODD, C. J., BARCLAY, S. I. G. & FARQUHAR, M. C. 1999. Does hospital at home for palliative care facilitate death at home? Randomised controlled trial. *BMJ*, 319, 1472-1475.

GRBICH C, F., PARKER, D. & MADDOCKS, I. 2001. The emotions and coping strategies of caregivers of family members with terminal cancer. *J Palliat Care*, 17, 30-36.

HARDING, R. & HIGGINSON, I, J. 2003. What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine*, 17(1), 63-74.

HARDING, R. & HIGGINSON, I. 2001. Working with ambivalence: informal caregivers of patients at the end of life. *Support Care Cancer*, 9, 642-645.

HERBER, O. R. & JOHNSTON, B. M. 2012. The role of healthcare support workers in providing palliative and end-of-life care in the community: a systematic literature review. *Health Soc Care Community*.

HOCHSCHILD, A. 1983. *The managed heart: Commercialization of human feeling*. Berkeley: University of California Press.

HUDSON, P, L. & PAYNE, S. 2011. Family caregivers and palliative care: current status and agenda for the future. *J Palliat Med*, 14, 864-9

HUDSON, P.L., THOMAS, K., TRAUER, T., REMEDUIS, C. & CLARKER, D. 2011a. Psychological and social profile of family caregivers on commencement of palliative care. *J Pain Symptom Manage*, 41, 522-34.

HUDSON, P. L., ZORDAN, R & TRAUER, T. 2011b. Research priorities associated with family caregivers in palliative care: international perspective. *J Palliat Med*, 14, 397-401.

INGLETON, C., CHATWIN, J., SEYMOUR, J. & PAYNE, S. 2011. The role of health care assistants in supporting district nurses and family carers to deliver palliative care at home: findings from an evaluation project. *Journal of clinical nursing*, 20, 2043-2052.

INGLETON, C., PAYNE, S., NOLAN, M. et al. 2003. Respite in palliative care: a review and discussion of the literature. *Palliative Medicine* 17: 567-575.

JAMES, N. 1992. Care = organisation + physical labour + emotional labour. *Sociology of Health and Illness*, 14, 488 - 509.

MCKENNA, H, P., HASSON, F. & KEENEY, S. 2004. Patient safety and quality of care: the role of the health care assistant. *Journal of Nursing Management*, 12, 452-459.

MCLAUGHLIN, D., SULLIVAN, K. & HASSON, F. 2007. Hospice at home service: the carer's perspective. *Support Cancer Care* 15: 163-170.

MUNDAY, D. 2007. *Exploring complexity in community palliative care: a practitioner based approach to research and development* PhD Thesis, University of Warwick.

NHS 2012. Monthly NHS Hospital and Community Health Service (HCHS) Workforce Statistics in England - July 2012, Provisional Statistics. London: National Health Service.

NHS CAREERS. 2012. *Entry Requirements* [Online]. Available: <http://www.nhscareers.nhs.uk/explore-by-career/wider-healthcare-team/entry-requirements/> [Accessed 21/01/2013].

PAYNE, S., SEYMOUR, J., INGLETON, C., SARGEANT, A. & KIDD, H. 2008. Independent evaluation of the Marie Curie Cancer Care "Delivering Choice Programme. International Observatory for End of Life Care, University of Lancashire.

RHODES, P. & SHAW, S. 1999. Informal care and terminal illness. *Health Soc Care Community*, 7, 39-50.

RUTTEN, L., ARORA, N., BAKOS, A., AZIZ, N., ROWLAND, J. 2005. Information needs and sources of information among cancer patients: a systematic review of the research. *Patient Education and Counselling*, 57, 250-261.

SFC 2012. Developing end of life care practice. London: Skills for Care, Skills for Health, End of Life Care.

SKILBECK, J., PAYNE, S., INGLETON, M., NOLAN, M., CAREY, I. & HANSON, A. 2005. An exploration of family carers experience of respite services in one specialist palliative care unit. *Palliative Medicine*, 19, 610-618.

STAJDUHAR, K. I. & DAVIES, B. 2005. Variations in and factors influencing family members' decision for palliative home care. *Palliative Medicine*, 19, 21 - 32.

STAJDUHAR, K. I., FUNK, L., GRANDE, G, E. et al. 2010. Home-based Family Caregiving at the End of Life: A comprehensive review of published quantitative research (1998-2008). *Palliat Med*, (in press).

TERRY, W., OLSON, L. G., WILSS, L. & BOULTON-LEWIS, G. 2006. Experience of dying: Concerns of dying patients and of carers. *Intern Med J*, 36, 338-346.

THORNLEY, C. 2005. Still waiting? Non-registered nurses in the NHS - an update. London: UNISON

WILKINSON, A. M. The carer experience in end-of-life cancer caregiving: a discussion of the literature. Cancer Forum, 2010. The Cancer Council Australia, 91-94.

WILMSHURST, M. 1943. *Handbook for Queen's Nurses*, London, Faber and Faber

## **Appendix**

1. Bereaved Carer Interview Schedule
2. Sample Characteristics
3. Sample Group by Setting



## Appendix 1

Dimbleby - Receiving End of Life Care at Home Study	
Bereaved Carer Interview Schedule	
<p>1) Thank the participant for agreeing to take part.</p> <p>2) Introduce the study.</p> <p><i>We want to understand some of the issues faced by people who have cared at home for someone who was coming towards the end of their life and who have had carers from (specific service) helping to care for their family member. This is so that we can understand the issues better and improve the services which are delivered.</i></p> <p>3) Check that the information sheet has been read and understood and answer any questions arising.</p> <p>4) Go through the consent form, making sure that the participant knows that quotes may be used in publications but will be anonymised.</p> <p>5) Assure the participant that they can stop the interview at any time if they need a break or are finding it too difficult.</p> <p>6) Ask permission to switch on recorder and start the interview.</p>	
Question	Prompt
It would be useful to have a little background about N and you? Would you be able to describe N and your relationship to him/her and something about their illness?	How old (person they cared for), relationship, living arrangement (together/ apart), disease, length of time cared for at home, date of death, place of death.
Can you tell me what it was like for you caring for N at home?	What type of care did they need? (help with activities of daily living).
Did you get any help from friends and family?	Could include neighbours.
Did N receive any help from professionals at home?	District nurses, Macmillan nurses, other nursing help. GP? Social carers. Could include carers arranged by the family themselves.
When did N start getting care from (specific service)?	Try to be clear when this was (in relation to date of death) and that carer understands who we mean.

<p>What role did the carers* from (specific service) play?</p> <p>*use specific term used by the service: HCA, family support worker, etc.</p>	<p>Practical tasks - list</p> <p>Did having carers enable them to have a break from caring?</p> <p>[Be prepared to describe the HCAs if carers are unclear about which staff you mean e.g. uniforms worn]</p>
<p>Were there any things that you and the carers did together?</p>	<p>For example, did you turn/wash N together?</p> <p>Did the carers show you how to do any of the tasks needed?</p> <p>Were there any tasks that you would have liked to do that the carers did instead? Why was that?</p>
<p><i>(Ask these 2 q's separately ie you and N)</i></p> <p>How did N find having (specific service) involved in his/her care?</p> <p>How did you find having (specific service) involved in N's care?</p>	<p>How many carers (about) were involved?</p> <p>What sort of relationship was built up? (Try to distinguish between different carers)</p>
<p>What kind of conversations did you have with the carers from (specific service)?</p>	<p>What did you talk about?</p> <p>Did they talk to you about how you were feeling, or did you feel able to talk to them in this way?</p> <p>(If yes, did you find those conversations helpful?)</p> <p>Do you think N or other family members received emotional support from the HCAs?</p>
<p>Were there any particularly positive things about having carers from (specific service)?</p>	
<p>Were there any problems/challenges with having carers from (specific service)?</p>	<p>Was it sometimes difficult for you having carers in the home? (Why?)</p> <p>Were there occasions when the carers seemed to lack the skills to care for N?</p>

	Sometimes people mention that having many different carers involved is difficult. Did you find that to be the case?
Did carers from (specific service) work with other professionals involved in N's care? If so, how.	District nurses, Macmillan nurses, social care  Did they work well together? Were there any problems?
Are there any ways in which you think the (specific service) could be changed or improved?	Allow them to be quite broad in saying what could be improved. May not relate specifically/exclusively to the service of interest
Is there something else you would like to add?	Is there anything important about your experience of caring for N and of (specific service) that we haven't covered?
<p>Thank the participant for having taken part in the interview.</p> <p>Turn off the recorder.</p> <p>Ask if they have any questions following the interview. Check that they know whom to contact if they have any questions.</p> <p>If they are distressed, ask permission to contact the service lead on their behalf who will contact them and discuss appropriate support services.</p>	

## Appendix 2 Sample characteristics

	Wife caring For husband	Husband caring for wife	Daughter caring for mother	Daughter caring for father	Son caring for mother/father	Other	Total
Caring > 1 year	9	4	2	0	0	0	15
Caring <1 year	7	2	2	4	2	1	18
Cancer only	12	2	2	2	2	1	21
Multiple Morbidity	4	4	2	2	0	0	12
Help from relatives	12	6	4	4	1	2	29
Not living with patient	0	0	3	1	0	1	5
Patient >75	5	0	0	2	0	0	7
Carer >75	3	0	0	0	0	0	3
Carer l.t. health issues	5	0	0	0	0	0	5

## Appendix 3 Sample group by setting

Setting	Wife caring For husband	Husband caring for wife	Daughter caring for mother	Daughter caring for father	Son caring for mother/father	Other	Total
1	5	5	3	2	0	0	15
2	7	1	1	2	2	1	14
3	4	0	0	0	0	0	4
Total	16	6	4	4	2	1	33

1. NHS care service
2. Supportive care at home
3. Hospice at home