

Managing end of life medications at home – accounts of bereaved family carers: a qualitative interview study

Payne S, Turner M, Seamark D, Thomas C, Brearley SG, Wang X, Blake S, Milligan C.

International Observatory on End of Life Care, Division of Health Research, Lancaster University, Lancaster LA1 4YG, United Kingdom

Payne Sheila, *Professor of Palliative Care*

Turner Mary, *Research Fellow*

Thomas Carol, *Professor of Medical Sociology*

Brearley Sarah, *Lecturer in Palliative Care*

Milligan Christine, *Professor of Health and Social Geography*

Honiton Group Practice, Marl pits Lane, Honiton, Devon, EX14 2NY, United Kingdom

Seamark David, *General practitioner*

Susan Blake, *Research Associate*

Department of Psychology, Leeds Metropolitan University, Leeds, LS1 3HE, United Kingdom

Wang Xu, *Lecturer in Psychology*

Correspondence to:

S Payne s.a.payne@lancaster.ac.uk

Abstract

Objective To explore how bereaved family members recall managing end of life medications when delivering care to a patient dying at home in England.

Design Qualitative study.

Setting Domestic homes in two contrasting areas in England.

Participants 59 bereaved family carers who have delivered care to a patient who spent a minimum of two weeks at home prior to their death from cancer or other non-malignant condition. Cases were excluded if place of death was: hospice, nursing home or NHS hospital.

Results Participants identified a number of important concerns about managing end of life medication for the dying person at home. Although some support with medications is provided by general practitioners and nurses in the community, family carers take primary responsibility for drug administration and storage. They reported anxiety about giving correct and timely dosages, and concerns about keeping the patient comfortable without overdosing them or risking shortening their lives. In particular they reported that certain analgesic medications, especially opioids, were considered to have a symbolic significance and increasing analgesia and the use of a syringe driver were associated with deterioration and

approaching death. Key barriers to managing end of life medications at home included: complex regimes; unwanted responsibility in deciding when to use 'as needed' medication; disagreements with professional staff and anxiety about medication errors, especially if perceived to have implications for survival.

Conclusions Family carers require more information about end of life drugs and their effects, support and training in managing medication for a dying person. Significant concerns were identified, and these need to be addressed if current UK policy to increase the number of patients dying at home is to be safely realised.

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Key words: palliative care, end of life care, terminal care, medication adherence, general practitioners, community health nursing, caregivers, qualitative research

INTRODUCTION

In the context of limited health-care resources, and evidence of patient preferences for dying at home, the role of family carers (family, friends and significant others; hereafter called ‘family carers’) in delivering end of life care at home is increasingly important. Hospital care in the last year of life is known to account for a considerable proportion of health care expenditure in the United Kingdom¹ and the United States². Evidence from a review of cost and cost-effectiveness indicates that all types of palliative care, but especially home-based care, are frequently found to be less costly compared to other options³. There is strong evidence from a systematic review that home-based palliative care reduces symptom burden for patients while not increasing family carers’ grief during bereavement⁴. However, the presence of family carers able and willing to provide care in the home is a key determinant of outcomes for cancer patients⁵.

The End of Life Care Strategy⁶ for adults in England aims to improve the accessibility of high quality care for all people who are approaching the end of life. According to the Strategy, which describes family carers as ‘co-workers’ with the health and social care team, patients should be provided with more choice over where they receive end of life care. Evidence suggests that two-thirds of patients would prefer to die at home, with current trends suggesting a modest increase over the last decade in home deaths to 21% in 2010⁷. Policy initiatives have emphasised primary health care and have highlighted the important role of the general practitioner in co-ordinating and managing end of life care⁶. For example, there has been a widespread introduction of ‘anticipatory prescribing’ in community based palliative care across the UK, whereby GPs prepare prescriptions for patients identified to be nearing the end of life⁸. This ensures essential drugs are available within the home ‘out of

hours' to enable rapid symptom management and prevent unnecessary hospital admission. They are usually called 'just in case' medications, and comprise four core drugs including strong opioids and sedatives, although the drugs actually prescribed may vary across the country. Within the home context, community nurses are often involved in decisions about the actual initiation, dosage and delivery of these medications, which some nurses report as problematic⁹. Survey data from bereaved carers indicate that pain management is less good than in other care settings (insert reference to end of life survey).

Family carers play a crucial role in supporting those who wish to die at home. Of the 6.5 million people in the UK fulfilling an unpaid caring role for a family member, approximately half a million do so within the context of an end of life phase, and the majority of them will be female aged 50-64 years while in older groups slightly more men provide care¹⁰. It is widely recognised that they provide physical care, emotional and social support, financial resources, advocacy and anticipatory care, and assist patients' in negotiating and co-ordinating care during the final period of life^{11,12}. It is a challenging and demanding role, which few people aspire to, but which may be thrust upon them, in often difficult circumstances and following a 'crisis'. Undertaking this role may have physical, psychological, social and financial consequences for carers which outlast their period of care and may influence their bereavement. Despite focused policy initiatives^{13,14} to address these caring demands, a large study in England on transitions between places of care in end of life care, reported that in 2013 little has changed to improve family carers' experiences¹⁵. Until relatively recently, there has been little research about how family carers manage their role in caring for those who are approaching death^{16,17}.

It is family carers, rather than GPs or community nurses, who often have to manage the safe storage and delivery of end of life medications in the home on a day-to-day basis, and arrange for their disposal following the death. Evidence from a small study of 23 family carers of

patients in a home hospice programme in the USA, identified five conceptual factors that influenced medication management, however, major differences in healthcare systems limits its applicability in the UK (insert Lau et al references). A survey of 98 multidisciplinary US home-hospice staff indicated that 67% rated medication management as the most important role of family carers, but only 6% routinely offered education, support and counselling to facilitate this¹⁸. Little is known about the complex realities of managing end of life medications at home in the UK from the perspective of family carers. Therefore, we elicited in-depth interview accounts from bereaved family carers of their experiences of end of life medication¹⁹. The study is part of a larger project exploring the issues faced by family members caring for a dying older person at home, and the way the home is transformed in the process of providing end of life care. Details of the full study are published²⁰.

METHODS

Design

We utilised a cross-sectional qualitative research design.

Setting

The study was conducted in two areas: the North West (NW) (Lancashire and Cumbria) and South West (SW) (East Devon) of England. These regions were selected because they both have high proportions of older people in the population²¹. Census data and informal discussions with professionals and stakeholders indicated some differences between the two areas in terms of socioeconomic status, types of home ownership, ethnic and cultural diversity and health indices (such as smoking rates), which the research team believed would add diversity to the data collected.

Sampling

We used purposive sampling of bereaved family carers to select those with direct experience of providing care for an older person dying at home. The inclusion criteria included: family carers of older deceased people (aged 50 years +) from any cause of anticipated death; death occurring in the home of the carer or patient; a minimum of two weeks care in the private home prior to death; adult carer (≥ 18 years); and recruited at least 6 months but not more than 24 months following the death. The exclusion criteria included: carers who were cognitively impaired, unable or unwilling to give consent. Initially inclusion was limited to the first 13 months of bereavement but subsequently extended to 24 months to increase the sample.

Recruitment

Family carers were recruited through GP practices. Researchers (MT and SB) arranged meetings with GPs or other staff (e.g. research nurses or practice managers) in each participating practice, to discuss the study. Practice staff then searched practice databases to identify family carers who met all the study criteria, and information packs were posted to potential participants who responded directly to the research team if they wished to be involved.

Data collection

MT and SB conducted single face-to-face interviews of 15 – 102 minutes (mean = 47 minutes) in participants' homes from December 2011 to August 2012. Participants had been bereaved a median of 12 months (range 7-22 months). The interview guide was developed following a review of the literature and relevant policy, and sought to address the study aims. It was designed to elicit chronological narratives of care provision during the dying process, death and early period of bereavement using open ended questions and follow up prompts

(see Figure 1). The interview was pilot tested with three bereaved carers and modified to include further questions about medication management. In this paper, we report on perspectives from family carers on end of life medication at home.

Analysis

Interviews were digitally recorded with participants' permission, then fully transcribed. All interview transcripts were 'cleaned' by MT and checked against the audio recordings for accuracy to eliminate errors, and to remove any identifiers to preserve anonymity. To ensure reliability, two transcripts were independently read, initial codes identified, then two more transcripts were again independently coded to check the initial framework and were agreed by all team members. Based on this, a final coding framework was refined and compared to subsequent selected transcripts within the team. This final coding framework was applied to all transcripts using the data analysis software NVivo, with any discrepancies discussed. The principles of a constant comparative approach to analysis were utilised, in that codes were derived from the data rather than developed a priori²². An iterative approach to coding of themes was taken until saturation of themes was achieved²³. These were presented at two deliberative workshops held in Lancaster and London of 33 people comprising members of our expert advisory group, practitioners and service users. Feedback from these events was incorporated into the final analysis presented here. Direct quotations have been selected to highlight typical responses, and are indicative of the diversity of views elicited. To establish rigor, we adhered to COREQ guidelines²⁴.

RESULTS

We interviewed 59 bereaved family carers (response rate 54%) who have delivered care to a patient who spent at least two weeks at home prior to their death from cancer or other non-malignant condition (see Table 1). In the SW, 52 invitations were sent out, and 38 people responded (73% response rate) but two subsequently declined to take part in an interview. The pattern of recruitment was markedly different in the NW, where 76 invitations were sent out, and 31 people responded (41% response rate). Of these, six subsequently declined, one did not meet the study's inclusion criteria and one agreed to participate but then withdrew.

The majority of carers (69%) were female, and the majority of deceased patients were male (59%), reflecting the fact that 73% were spouses. Three quarters of the people they cared for died from cancer. The median length of time that they had provided care at home was 11 months (range 2 weeks – 11 years).

Following an extensive analysis, we have selected two main themes to present in this paper.

Decision-making processes in managing end of life medication at home

Managing complex medications

All 59 participants interviewed reported that they were involved in some aspects of managing or assisting with end of life medications, especially once the patient became dependent and was in the final phase of dying. The degree to which they regarded this as burdensome was on a continuum from not at all, to greatly. The complexity of medication management was reported as problematic for those with chronic conditions where polypharmacy was highlighted .

'He'd been on quite a lot of tablets for some time, you know, blood pressure, heart tablets, warfarin and one or two other things' [A01 SW Female 78]

A number of strategies to facilitate medication management such as timely and accurate dosages were described:

‘I made a copy of all the tablets and the different times he was to have them and which ones [...] I made a chart on the computer and just printed it out each time, and that was very helpful.’ [A11 SW Female 60]

Taking responsibility

There appeared to be a shift in responsibility for medication management from self-care to the family member taking control as dependency increased. Some participants reported the responsibility as demanding because they feared the consequences of making a mistake or because they did not fully understand the medication regimes, especially in the context of their own distress, which made decision-making or assimilating new information difficult .

‘It’s a very big responsibility and in a way I felt helpless because I felt that some things needed increasing and the nurses weren’t there to do it, but at the same time I don’t think it would have been right for me to have total control over it because my head was all over the place at times. [B01 NW Female 77]

In addition, they highlighted that while the community nurses were, overall, helpful and supportive, they were not in the home all of the time, so variation to medication, especially for ‘as needed’ drugs, required them to make decisions unaided. One participant perceived that the occupational background of the patient (as an industrial pharmacist) had been an advantage. Her account offers an empowered and proactive role in which both the patient and carer were confident in managing medications. This experience was echoed in other examples where carers had previous qualifications in health professional disciplines.

‘Now he was an industrial pharmacist, so when the medication came along right at the beginning, he told me what was what and he queried the doctor, how it would be. He always used to check that I was giving the tablets in the right way, but eventually of course he was unable to do that. But he had trained me well.’ [B21 NW Female 80]

Disagreements with staff about medication

One consequence for carers with health professional expertise is that some of them challenged the prescribed medication regimes. .

He had [the syringe driver] in for three days, and then when he was settled and I knew he was going to die I asked them to take it out. And the doctor didn't think it was a good idea, but I said 'I don't want him dying with this thing in his arm, and I don't want him having drugs...' [...] I felt he needed to die a relatively natural death. [B19 NW Female 70]

In this case, the preferences of the patient, according to the carer, to have a 'natural death' seems to have been continued in the final days of life, with the participant requesting the removal of the syringe driver used to deliver end of life drugs. However, this was an atypical case; more often there was a desire for family carers to decrease the burden of their own decision-making, and a concern about explicitly challenging doctors' and nurses' care. One participant viewed the process of requesting increased medication for symptom control from nurses as offering the potential for being misconstrued to be hastening death. Overall, overt disagreements with staff were rarely reported in the interviews.

'I sometimes think [the nursing staff] need to listen to what the carer is saying; I think they did mostly but generally when I said she needs more sedation and they said 'well she's on such and such a dose', which apparently was quite a big dose but it still wasn't enough for her. And at one point I thought 'God, do they think I'm trying to bump her off?' which is another reason why I wouldn't have liked the responsibility of the drugs.' [B02 NW Female 57]

Managing end of life medications at home: concerns and rewards

Carers' anxiety about medications

There was also the view that managing end of life medications at home was anxiety provoking. There was recognition that these medications were necessary to provide symptom relief. Some of the most frequently cited concerns were related to getting the dosage wrong,

especially concerns about overdosing patients, or in failing to administer the drugs when the patient become too ill to use the oral route.

‘I was really anxious just to follow the instructions and I wrote everything down carefully that I had given her. I didn’t attempt to give her an overdose if that’s what you mean, I wouldn’t have known which one would have done it. ‘[B14 NW Male 72]

Perceptions about the effects of morphine

Underlying the anxieties about medication management was a specific concern and an apparent reluctance to use morphine or its equivalents (hereafter referred to as morphine).

The accounts from participants in some cases attributed the reluctance to patients but there also seemed to be some need for participants to explain and justify the use of morphine, in the context of persuasion from nursing staff rather than any weakness or lack of moral courage by patients .

‘When he was totally compos mentis he was doing it all himself, he used to say ‘these bloody tablets, you know they better do something’. But then when he became more sleepy then I was doing cos he was on liquid morphine then.’ [A08 SW Female 66]

One participant expressed a dilemma in whether to administer morphine, although elected to give it despite her discomfort .

‘[I gave him Oramorph] when he asked for it, I didn’t like to give him all... just when I thought he needed it, which was probably every day. At first I thought ‘Oh shall I use it or not?’ [B15 NW Female 63]

While all participants were open to the use of morphine for pain relief, there were many descriptions of the adverse effects of this drug, especially on the mental state of the patient.

Some perceived morphine to reduce the awareness of the patient, which was variously described as ‘a bit removed’, less ‘lucid’, ‘more and more distant’ or ‘very confused’ . A

participant attributed an increase in agitation and disinhibition to morphine usage which poignantly robbed the dying person of dignity and left lasting distressing memories .

‘I had my arms around him and he was talking to me normal whereas before he’d said some really horrible things, that’s the morphine.’ [A03 SW Female 76]

Another participant opined that the amount of medication resulted in making basic care provision even more difficult as the patient was unable to communicate his needs effectively .

‘And his speech started to go but we realised that he was so drugged we had awful trouble trying to find out whether he wanted something to drink, something to eat, to go to the loo, and I think he found it so frustrating cos he was an incredibly articulate person, so it was very hard.’ [A04 SW Female 67]

There were suggestions that the complexity of managing morphine and its side effects such as nausea, further complicated other types of medication and disease management.

Symbolic significance of syringe driver

There was a perception that a change in route of medication administration to the subcutaneous route via a syringe driver signalled a transition to a dying status. Two participants identified that the timing of starting a syringe driver was indicative of approaching end of life , although in not all cases was effective symptom management achieved .

‘On the Monday they came and put a syringe driver in, so you knew then that it wouldn’t be long.’ [A19 SW Female 69]

Rewards in managing end of life medications at home

Participants also reported that there were positive experiences in caring for a person dying at home. A critical first step in this process was feeling confident and competent to manage

medication delivery either by drawing upon prior healthcare training or general caregiving knowledge .

So it was okay... I think for the last few days I was giving her things like that [morphine].’
[B20 NW Male 82]

One participant highlighted her feelings of satisfaction in the final hours of life, when having insisted on the withdrawal of all medication, she recalled a few precious moments when she communicated with her lucid husband, creating valued last memories .

‘When all the medications ceased, he did become quite rational for about... oh... an hour. He was quite back to his old self and I sat with him and we talked (chuckles). And it was so lovely because he hadn’t known me. And just in that hour he did. And then he drifted off and he wasn’t really conscious anymore after that. [B13 NW Female 83]

DISCUSSION

This qualitative study examines, family carers’ accounts of the challenges of managing end of life care medications for a person dying at home. Our study adds to the existing literature which has predominantly presented evidence from the professional perspectives of GPs²⁵, community nurses¹⁰ or home-hospice providers¹⁹. Current policy recommendations stress the need to facilitate more people dying at home⁶. The family carers sampled indicated that they had a major role in providing care and ensuring symptom management by careful medication delivery. It is not surprising that it was perceived to be both a demanding responsibility and at times for some, anxiety provoking, given that they reported little information or education to facilitate their role. Our data indicate particular concerns about how end of life drugs, especially morphine, were perceived and experienced by family carers, and that the setting-up

of a syringe driver was seen to have a symbolic function as marking a transition into the final dying phase.

Strengths and weaknesses of the study

The diversity of the findings are increased by purposively sampling across two areas of England. Further discussion of the analysis with key stakeholders, practitioners and service users (patients and carers) confirmed them as resonant with their clinical or practical experiences. We did not use respondent validation because of ethical concerns to minimise distress in our bereaved participants. In comparison to previous research which has focused only on cancer patients cared for at home²⁶, those with other chronic conditions were included. A potential limitation of our research design was the use of cross-sectional, retrospective accounts where the experience of bereavement may have influenced the self-reports provided, especially for those later in the bereavement trajectory. Future research should use serial interviews conducted throughout the caregiving trajectory. Caution is also required in interpreting the findings as we collected no data from GPs, community nurses or patients. As befitting a qualitative study, our intention has been to illuminate the experiences of family carers and provide clinically useful insights, rather than to make claims of population level generalizability.

Strengths and weakness in relation to other studies, discussing important differences in results

The participants identified several barriers to managing end of life medications at home, largely due to their inexperience compounded by an apparent lack of knowledge or access to information. This is consistent with previous research done in the context of US hospice-home care which highlighted the lack of specific medication management strategies such as education, support or counselling offered to family carers by the multidisciplinary team¹⁹ (add other references). This is a paradox, in that health professionals, especially nurses, require extensive training and are regulated by procedures to ensure medication safety but there was little evidence from this study that similar attention is directed towards supporting family carers. These difficulties are not unique to end of life medication management. There is evidence that external cognitive support and education promote adherence to medication in older people²⁷. This lends support to the strategies initiated by family carers in our sample. A key finding was the degree of anxiety reported by family carers and the perception of responsibility and its burdensomeness in managing these medications. In some cases, they appear to have to make critical decisions about delivering ‘as needed’ drugs or in altering dosages to achieve symptom relief, without, at times, support from primary care professionals. Most carers’ accounts indicated that community nurses offered support either during home visits or over the telephone, but remarkably little reference was made to the involvement of GPs beyond the prescription of the drugs. Our findings accord with those from a recent ethnographic study of decision-making by community nurses about the use of anticipatory end of life medication in two areas of England which demonstrates that initiation of the use of these types of drugs are largely at the discretion of nurses²⁸. Furthermore, our data indicated that family carers used the initiation of a syringe driver to deliver medication as a cue to the transition to dying. They also reported considerable concerns about the use of morphine, and what has been described elsewhere as opioidphobia²⁹. As has been observed in research on palliative sedation, there seemed to be a strong need for participants to explain

that they were not seeking to hasten death³⁰. Our study indicated that there were advantages for those with healthcare experience in that they reported a more proactive and equal relationship with the primary care team, and unsurprisingly had better access to information resources.

Meaning of the study: possible explanations and implications for clinicians and policymakers

In the context of the End of Life Care Strategy⁶, the findings from this study indicate that the family carers sampled did not believe themselves to have adequate support to safely deliver end of life medications to patients dying at home. It raises questions about the way family carers are engaged as ‘co-workers’ as described in the Strategy. Without adequate preparation, sufficient information/education and support in dealing with end of life medication, the implementation of current home-based end of life care policies seem destined to result in additional distress and burdensomeness for family carers. A correlational study from Sweden indicates that feelings of preparedness for the role of caring was significantly associated with higher levels of hope, reward and with lower level of anxiety³¹. There may be opportunities to increase the role of community pharmacists to provide advice and training in the safe management, storage and disposal of medications. Our study indicates that more effective communication is required from the primary care team about end of life medications. Our evidence suggests that community nurses were most often mentioned as involved in medication delivery, and that generally they were found to be supportive^{10,28}. The responsiveness and availability of home-based nurses and physicians is known to predict caregiver satisfaction³², however, for the majority of time, family carers have to manage alone. It is noteworthy that specific drugs, opioids, appeared to raise particular concerns for

family members and this possibly relates to residual aspects of the Shipman case, where a British GP was found guilty of serial murders of older patients using diamorphine. We believe that open communication between GPs, community nurses and family carers regarding their roles and responsibilities during the use of end of life medications will help to prevent the anxieties reported. The subgroup of family carers with healthcare knowledge appeared to establish more equitable relationships.

Unanswered questions and future research

Further in-depth research is needed on the roles and responsibilities of family carers regarding the use of end of life medications, especially anticipatory prescriptions. We are aware that our method of constant comparative analysis does not permit detailed accounts of changes over time to be traced, therefore a narrative analysis paper is forthcoming. Research on the views of dying patients on medication usage and how this is negotiated with their family members is warranted. Likewise, research examining the effects of family carers' education, age and information needs is required before appropriate interventions can be designed³³.

In conclusion, our study reveals how participants perceive end of life care medications as a core; but largely unrecognized and undervalued function of caring for a dying patient at home. Family carers require more information about end of life drugs, their effects, and support in managing these medications. When formulating suggestions for end of life care policy at home, we suggest keeping in mind the central role of family carers. Significant

concerns were identified, and these need to be addressed if current UK policy to increase the number of patients dying at home is to be safely realised.

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Competing Interest

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare that (1) SP, MT, DS, CM, CT, SB, XW, SB have support from Marie Curie Cancer Care for the submitted work; (2) SP, MT, DS, CM, CT, SB, XW, SB no relationships with Marie Curie Cancer Care that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (4) SP, MT, DS, CM, CT, SB, XW, SB have no non-financial interests that may be relevant to the submitted work.

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What is already known on this subject

We know from previous work that family carers deliver the majority of physical, psychological, social and anticipatory care to a patient dying at home.

We know from research with GPs, community nurses and hospice-home care that delivering end of life care medications at home, especially using 'as needed' anticipatory prescriptions, is beneficial in improving symptom management and preventing hospital admissions but is practically challenging.

What this study adds

This study uses comprehensive in-depth interviews to explore the accounts of bereaved family carers on decision-making and delivery of end of life medications to a patient dying at home.

Our study suggests that, in two areas of England, bereaved family carers report insufficient information, education and support, and anxieties about the use of end of life medications.

This indicates the need for better communication if current UK policy to increase the number of patients dying at home is to be safely realised.

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All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare that (1) SP, MT, DS, CM, CT, SB, XW, SB have support from Marie Curie Cancer Care for the submitted work; (2) SP, MT, DS, CM, CT, SB, XW, SB no relationships with Marie Curie Cancer Care that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (4) SP, MT, DS, CM, CT, SB, XW, SB have no non-financial interests that may be relevant to the submitted work.

Table 1 Characteristics of participants in interviews.

	N = 59	%	range	median
Location in England				
North West	23	39		
South West	36	61		
Gender of carer				
Male	18	31		
Female	41	69		
Age of carer				
All	59		44 – 90	72
< 50	1	2		
50 – 59	7	12		
60 – 69	19	32		
70 – 79	15	25		
80 – 81	16	27		
> 90	1	2		
Ethnicity of carer				
White British	56	95		
White other	2	3		
Black Caribbean	1	2		
Relationship to deceased				
Spouse	43	73		
Daughter/son	15	25		
Sibling	1	2		
Gender of deceased				
Male	35	59		
Female	24	41		
Age of deceased				
All			59 – 98	82
50 – 59	3	5		
60 – 69	8	14		
70 – 79	15	25		
80 – 89	23	39		
> 90	10	17		
Time cared for in the home			2wks – 11 yrs	11 months
Cause of death				
Cancer	37	63		
COPD	1	2		
Heart disease	6	10		
Dementia	3	5		

PD	3	5		
Old age	5	8		
Renal failure	1	2		
Other	3	5		
Occupation of carer				
Modern professional	17	29		
Clerical / intermediate	15	25		
Senior managers	3	5		
Technical / craft	2	3		
Semi-routine manual	7	12		
Routine manual	3	5		
Middle/junior managers	5	9		
Traditional professional	2	3		
No paid employment	5	9		
Occupation of deceased				
Modern professional	13	20		
Clerical / intermediate	7	12		
Senior managers	1	2		
Technical / craft	8	14		
Semi-routine manual	5	9		
Routine manual	6	10		
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