

Elsevier Editorial System(tm) for Health &
Place

Manuscript Draft

Manuscript Number: JHAP-D-15-00664R2

Title: Unpacking the impact of older adults' home death on family care-givers' experiences of home.

Article Type: Full length article

Keywords: older adults; place of death; meaning of home; family carers; palliative care

Corresponding Author: Prof. Christine Milligan, PhD

Corresponding Author's Institution:

First Author: Christine Milligan, PhD

Order of Authors: Christine Milligan, PhD; Mary Turner, PhD; Susan Blake; Sarah Brearley, PhD; David Seamark, PhD; FRCGP DCH DFFP; Carol Thomas, PhD; Xu Wang, PhD; Sheila Payne, PhD

Manuscript Region of Origin: UK

Abstract: While the place of death is geographically uneven across England, given a choice, many older people nearing end of life would prefer to die at home (PHE, 2013). There is, however, a growing critique that policies designed to support home death fail to understand the needs and preferences of older people and the impact on family carers. Such policies also make assumption about within whose home the home death takes place. Hence, there are major gaps in our understanding of firstly, where and how care work undertaken by family members within domestic settings takes place; and secondly, how it can create tensions between home and care that fundamentally disrupt the physical and socio-emotional meaning of home for family carers, impacting on their sense of home post-death. This can have consequences for their own well-being. In this paper we draw on interview data from our 'Unpacking the Home' study to elicit an in-depth understanding of how facilitating a home death can create an ambiguity of place for family carers, where the issues faced by them in caring for a dying older person at home, and the home death itself, can fundamentally reshape the meaning and sense of home.

Division of Health Research
Faculty of Health and Medicine
Furness
Lancaster University,
Lancaster
LA1 4YT

12/01/16

JHAP-D-15- 00664R1

**Unpacking the impact of older adults' home death on family care-givers'
experiences of home.**

Dear Jamie

Please find attached our revised paper. As per the reviewer's comments we have undertaken the following minor amendments:

- 1) We have gone through the paper and revised all references to care-givers to carers. We found and replaced four in total;
- 2) We have revised the abstract to make it clearer that the focus of the paper is on 'whose home' and the experience of home post-death;
- 3) We have amended the two typos referred to by R1 and undertaken a final proof-read of the paper.

We have chosen not to alter the title of the paper as we feel it still adequately reflects the content of the paper.

We hope that you now find the paper suitable for publication in Health and place and look forward to hearing from you in the near future.

Yours Sincerely

Christine Milligan

Unpacking the impact of older adults' home death on family care-givers' experiences of home.

Paper submitted to the journal of

Health and Place

by

Christine Milligan, Mary Turner, Susan Blake, Sarah Brearley, David Seamark, Carol*

Thomas, Xu Wang, Sheila Payne.

*Corresponding Author: Professor Christine Milligan, Division of Health Research,
Lancaster University, LA1 4YT, email: c.milligan@lancaster.ac.uk

1
2 **Abstract**
3

4 Public Health England survey data indicates that while the place of death is geographically
5 uneven across England, given a choice, many older people nearing end of life would prefer to
6 die at home (2013). There is, however, a growing critique that policies designed to support
7 home death fail to understand the needs and preferences of older people and the impact on
8 family carers. Such policies also make assumption about within whose home the home death
9 takes place. Hence, there are major gaps in our understanding of firstly, where and how care
10 work undertaken by family members within domestic settings takes place; and secondly, how
11 it can create tensions between home and care that fundamentally disrupt the physical and
12 socio-emotional meaning of home for family carers, impacting on their sense of home post-
13 death. This can have consequences for their own well-being. In this paper we draw on
14 interview data from our ‘Unpacking the Home’ study to elicit an in-depth understanding of
15 how facilitating a home death can create an ambiguity of place for family carers, where the
16 issues faced by them in caring for a dying older person at home, and the home death itself,
17 can fundamentally reshape the meaning and sense of home.
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40

41 **Keywords:** older adults; place of death; meaning of home; family carers; palliative care
42
43

44 **Highlights:**
45

- 46 • the study identifies the paradox of ‘whose home’ in relation to the home death
- 47 • disruptions to the meaning of home following a home death can result in that ‘home’
48 becoming a ‘house’ for carers
- 49 • carers need better support post-death, especially those still living in the home where
50 death occurred
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

Background

1
2
3
4 Providing quality care at end of life, and understanding where best that care should take
5
6 place, has been high on national and international agendas for over a decade (WHO, 2004;
7
8 Venkatasalu et al, 2014; Morris et al, 2015). Within the research community this political
9
10 drive has resulted in a growing interest in what underpins and supports decisions around
11
12 place of death (see for example, Grundy et al, 2004; McNamara, 2007; Cardenas-Turanzas et
13
14 al., 2011; Lockett et al., 2013). Commentators suggest that this spatial turn has been part of
15
16 an international move designed firstly, to reduce hospital stays and increase community
17
18 support to facilitate the home death; and secondly to address the growing demand for patient
19
20 and family choice (Higginson et al, 2013). Evidence emerging from a number of systematic
21
22 reviews suggests that home-based palliative care not only results in greater carer and patient
23
24 satisfaction, but reduces the length of hospital stays, so increasing the likelihood of home
25
26 death (e.g. Finaly et al, 2002; Gomes and Higginson, 2006; Shepperd et al, 2011). However,
27
28 whilst a desire to increase patient and family choice may, in part, underpin this shifting
29
30 agenda, commentators also maintain that the drive to increase the numbers of home deaths
31
32 cannot be entirely divorced from concerns around cost containment (McNamara, 2007;
33
34 Seymour et al, 2007). Evidence about the benefits of home care at end of life is also
35
36 conflicting, although recent reviews suggest that the holistic well-being of the dying person
37
38 may be greater at home (Donovan et al, 2011; Higginson et al, 2013). While there is clearly
39
40 some debate around what underpins the changing emphasis on place of death, it is,
41
42 nevertheless, an agenda that has international traction. This is a debate that is not only of
43
44 relevance to palliative care stakeholders, but one that extends more broadly to public health
45
46 due to the rising numbers of home deaths and increasing health expenditure (Higginson et al,
47
48
49
50
51
52
53
54
55
56
57
58 2013).
59
60
61
62
63
64
65

1
2 Despite an international policy drive to encourage home over institutional deaths, researchers
3
4 have demonstrated the existence of significant social and spatial variations in the extent to
5
6 which it has succeeded in its aims (e.g. Cohen et al, 2008; Pinzón et al, 2011).
7
8 Geographically, the numbers of home deaths rose in North American countries during the
9
10 1990s and first decade of the 21st century, but this pattern was not mirrored in Europe where
11
12 numbers in many countries were seen to fall. In the UK however, there has been a slight
13
14 increase in home deaths since the introduction of the End of Life Care programme in 2004
15
16 and the subsequent End of Life Care strategy in 2008 (Jack et al, 2013). Indeed, one recent
17
18 Public Health England report noted that the proportion of home deaths in England has
19
20 increased from 26.5% in 2008 to 30.2% in 2013 for those aged between 65-74 years and from
21
22 12.4% to 14.8% for those aged over 85years (2013, p.12). Whilst recognising that spatial
23
24 variations exist within countries, Higginson et al (2013) also suggest that similar shifts in
25
26 national policies around end of life care in other European states could increase choice
27
28 around place of death, leading to a similar upturn in the numbers of home deaths. But policy
29
30 shifts are only part of the story, evidence points to a wide range of factors associated with the
31
32 likelihood of achieving a home death including affluence, culture, ethnicity, patient
33
34 preference, complexity and speed of disease progression, availability of home-based
35
36 palliative care and family support and age (Seymour et al, 2007; Jack et al, 2013; Higginson
37
38 et al., 2013). Older age is also a factor – UK data illustrate that while hospital is still the
39
40 mostly likely place of death for older people (61% of deaths of those aged 65+) this is
41
42 followed by older people’s own home (21% of deaths of those aged 65-84 years), at least
43
44 until late old age (85+) when deaths in nursing homes overtake the numbers of those
45
46 occurring at home (NCIN, 2010).
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

Conceptualising home and the home death

Where we spend the most important moments of our lives is a relevant issue to all (Higginson et al, 2013). Geographers, gerontologists and sociologists have all attempted to theorise the nature and sense of home, placing emphasis on the home as a key site in which many of these important moments in our lives are played out. Through this lens, home is understood not just as a physical structure, but as a place that is imbued with multiple meanings linked to identity, safety and security, privacy, power and control, emotion, nurture and historical memory (e.g. Chapman and Hockey, 1999; Twigg, 2000; Milligan, 2000, 2009; Imrie, 2004; Blunt and Dowling, 2006; Langstrup, 2013; Collier et al, 2015). Our sense of home and the affective bonds that develop between people and their homes thus relates to both the intrinsic character of the home itself, and /or the meanings people attribute to it.

In considering the significance of home as the preferred place of death, Williams (2004) maintained that for many, the familiarity, physical arrangements and habituated routines within the home imbue it with a sense of comfort, security and ease; this can be important not just for the dying person, but also for family carers who are faced with the emotional upheaval of impending death and the sense of helplessness this can engender. We should not forget however, that people's experiences of home are both relational, co-produced by the key actors, actions and objects within it, and temporally situated, in that the complex socio-spatial relations of home can shift and alter over time. So, whilst claims for home as a place of ease, comfort and security etc. may well hold true for some people at some points in their lives, as Brickell (2012) points out, we also need to recognise that interpretations of home are often eulogised. Such understandings can ignore or overlook the ways in which the home can,

1 at different times, be a place of stress, loneliness, fear, neglect or confinement. Our sense of
2 whom and what we are is thus continually shaped and reshaped by how we feel *about* home
3
4 and how we feel *in* the home. This may relate to an individual's unique experiences of that
5
6 setting, or involve the mediation of others through intersubjective experiences of places. Our
7
8 emotional relationship to the home can thus alter the way the world *is* for us and feelings
9
10 associated with the home are an integral component of an individual's spatial experience. In
11
12 her work of family carers' experiences of older relative's care transitions from the family
13
14 home to care home settings for example, Milligan (2004) points out that whilst homecare
15
16 provision can create tensions around how family carers feel *in* and *about* the home, these are
17
18 not necessarily resolved once the transition to a care home setting takes place. Indeed, she
19
20 suggests that the transition from home to care home can be akin to the emotional experience
21
22 of bereavement, without the closure of death, but with a similar impact on the family carer's
23
24 sense of home. Brown's (2003) work on home hospice too, drew attention to the emotio-
25
26 spatial paradox of home arising from the home death.
27
28
29
30
31
32
33
34
35

36 To date, however, most of the literature on home death has focused either on geographical
37
38 and statistical variables related to the incidence of home death, or on specific disease
39
40 categories (e.g. cancers) as the main causal factor. Further, the focus has been on adults rather
41
42 than older people whose end of life experience is often underpinned by varying and multiple
43
44 health issues (Gott et al, 2008). With a few exceptions, this work has tended to focus on the
45
46 experience and desires of the person facing end of life themselves rather than those of family
47
48 carers. Whilst this is, of course, understandable, it is important to recognise that without the
49
50 support of the family carer, home death is unlikely to be an option. Yet research that
51
52 addresses family carers' experiences of the home death is relatively limited (Topf et al,
53
54
55
56
57
58
59
60
61
62
63
64
65

1 at end of life, highlighted not only the need for good qualitative studies that explore the
2 meaning of home across the caregiving process, but also the extent to which the experience of
3 care-giving can alter family carers' perceptions and attachment to home (Morris et al, 2015).
4
5 We would add that there is also a need for good quality studies that address the extent to
6
7 which these micro-geographies of death and dying alter the family carers' relationship with
8
9 the home not just during the dying phase, but post death. In this paper we seek to go some
10
11 way toward addressing these gaps by drawing on qualitative data from our 'Unpacking the
12
13 Home' study to focus firstly, on unpacking assumptions within policies around home death
14
15 regarding whose home that end of life care is being performed within and why; and secondly,
16
17 on how the home death of an older family member impacts on the meaning and sense of
18
19 home for the family carer post-death.
20
21
22
23
24
25
26
27
28

29 **Research Design**

30
31
32
33

34 Our paper draws on data from a two year cross-sectional qualitative study designed to gain an
35
36 in-depth understanding of the experiences of family carers who were caring for a dying older
37
38 person at home. In particular we were interested in the extent to which this impacted on
39
40 carers' experience of home both pre and post death. The study was conducted by a multi-
41
42 disciplinary team combining skills from primary care; nursing; health psychology; sociology
43
44 and health geography and undertaken in two locations in England, the North West
45
46 (Lancashire and Cumbria) and South West (East Devon). These regions were selected as both
47
48 have high proportions of older residents and whilst located at opposite ends of the country,
49
50 they have similar geographical characteristics. Both regions comprise a mix of rural and
51
52 remote areas as well as large areas of coastline. With the exception of the town of Blackpool
53
54 and city of Lancaster in the North West, most urban areas in both regions comprise relatively
55
56
57
58
59
60
61
62
63
64
65

1 small towns (population > 40,000 people) and villages (ONS, 2015). They do, however, have
2 different socio-economic profiles with higher levels of deprivation in the North West,
3 particularly in towns such as Blackpool and Morecambe, in comparison to the higher levels
4 of affluence in East Devon. There are also concomitant variations in health indices including
5 obesity and smoking rates (high in North West, low in South West) (Public Health England,
6 2015).

7
8
9
10
11
12
13
14
15
16
17 Study participants comprised bereaved family carers purposively recruited through GP
18 practices for two reasons: firstly, the practice checked the appropriateness of inviting a
19 potential participant based on their knowledge of the family and the circumstances
20 surrounding the death; and secondly, to ensure that confidentiality of patient information was
21 maintained. The practices identified potential participants meeting the criteria (see Table 1
22 below) through their patient databases. In practice, this meant searching for patients who had
23 died at home within the time frame of the study, and identifying the main carer; only those
24 whose main carer was also registered at the same practice were included. The initial
25 invitation therefore came from the GP, on behalf of the research team, with invitation packs
26 being sent by the practice to those expressing an interest in participating. Potential
27 participants were then asked to contact a member of the research team to discuss the study
28 and arrange an interview if appropriate. Initially we sought to recruit only those aged over 65
29 years; difficulties with recruitment led us to reduce the age criteria to those over 50 years in
30 order to widen the potential pool of participants (50 years and over being the age many third
31 sector organisations use to define ‘older people’). Interestingly, despite these initial
32 difficulties, the average age of our final sample was over 71 years.

33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58 INSERT TABLE 1 ABOUT HERE
59
60
61
62
63
64
65

1
2 An in-depth interview was conducted with 59 bereaved family carers who met the criteria,
3
4 with the aim of eliciting their experiences of supporting the home death of an older family
5
6 member both before and after death. Thirty-six participants were located in Devon and
7
8 twenty-three in Lancashire and Cumbria. As Table 2 illustrates, the vast majority of
9
10 participants were women (N = 41 women versus N = 18 men). This gender difference is
11
12 reflective of the fact that, overall, women are more likely to undertake care than men (ONS,
13
14 2013). Family carers' backgrounds, as indicated by occupational status, varied widely –
15
16 including cleaners and housewives, company managers and clinicians (see Figure 3).
17
18
19
20
21
22
23

24 INSERT TABLE 2 ABOUT HERE
25
26
27
28

29 Only 5% of our total sample came from Black and Minority Ethnic communities: white non-
30
31 British (N=2); and Afro-Caribbean (N=1). The overwhelming majority of participants were
32
33 white British reflecting the ethnic make-up of these two locations (Census 2011, Office for
34
35 National Statistics).
36
37
38
39
40

41 While there was some difference in the length of time people had been caring for their older
42
43 family member, on average participants had been undertaking their caring role for 2.5 years.
44
45 Cause of death varied, the majority were reported as dying from differing forms of cancer
46
47 (N=36); others were variously reported as dying from heart disease/stroke (N=9);
48
49 neurological conditions such as dementia or Parkinson's disease (N= 7); 'old age' (N=4);
50
51 renal failure (N=2) and rheumatoid arthritis (N=1). The age range of carers participating in
52
53 this study was between 54-90 years with the median age being 71.3 years; the age of those
54
55
56
57
58
59
60
61
62
63
64
65

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

cared for at time death ranged from 59-98 years, with the average age at time of death being 79.8 years. Further details of carer and cared for characteristics are contained in Table 3.

INSERT TABLE 3 ABOUT HERE

The interviews were designed to elicit chronological accounts of family carers' experiences of the home death. In part, we sought to understand what forms of practical, social and emotional support made the home death possible and the deficits or gaps in that support. However, we also sought to identify how the socio-emotional space of the home is experienced and performed by family carers, both during the process of care-giving at end of life and in the early post-death period (up to six months post-death). Interviews were around an hour in length, were digitally recorded and transcribed in full. In all but three cases (all occurring within the home of an adult child), care-giving was undertaken within the home of the dying relative.

Two researchers (MT and SB) undertook the interviews (one researcher per location) using a common set of interview themes. A cross-sectional thematic analysis of the data was then undertaken. An iterative approach was used, with an initial framework of thematic categories applied to interview data drawing on the research objectives. The thematic categories and framework were developed and agreed by the whole team. A process of constant comparison was also undertaken to ensure that the early stages of analysis informed subsequent data collection and emergent issues were pursued throughout the research process.

1 Ethical approval for the study was awarded by the National Research Ethics Service (NRES)
2 Committee North West (Ref: 11/NW/0203) and the norms of good ethical practice in
3
4 research were applied throughout the conduct of the study.
5
6
7
8

9 One aspect of our study sought to unpack the impact of the home death on family carers both
10 pre and post death. Following analysis, it was evident that in terms of the pre-death
11 experiences, our data simply reinforced already well documented findings. That is, that
12 family carers can be exposed to a wide range of physical, social and emotional challenges
13 when undertaking home-based care that can impact on their sense of home and these
14 experiences can be exacerbated when the cared-for person is approaching end of life (see for
15 example, Carlander et al, 2011; Donovan et al, 2011). While this, of course, is a finding in
16 itself, there is limited value in reiterating these findings here. Instead, we turn our attention to
17 the more novel elements of our findings to focus on two core issues: firstly we draw on our
18 data to challenge assumptions about ‘home’ in relation to the home death. We discuss the
19 neglected area of whose home that care takes place in, and what this means in terms of claims
20 made about the meaning of home in supporting end of life care. Secondly we discuss how
21 home death impacts the spatio-emotional experience of home for family carers, and the
22 implications of these experiences for the meaning of home post-death.
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

48 *Findings*

49 50 51 52 53 54 55 **Whose Home?** 56 57 58 59 60 61 62 63 64 65

1 Work focusing on the importance and meaning of home for end of life care has tended to
2 overlook the issue of whose home that care takes place in, how that impacts on the meaning
3 and sense of home, and for whom. Within our study, sixteen family carers were non-
4 spousal/partner carers. Thirteen of these undertook care within their dying family member's
5 home; the remaining three undertook care within their own homes. Issues of distance, work,
6 family relationships, other familial obligations or the availability of wider networks of care
7 and support all played a deciding factor in negotiating within whose home end of life care
8 would be delivered. As one adult son noted:
9
10
11
12
13
14
15
16
17
18
19
20
21

22 *A31: there was no way that she could look after herself, so I said that I would stay*
23 *up there the week, or for how long, to look after her.... and I rang [J] after two days,*
24 *and said, 'Look, you know, this is ridiculous. ...' I couldn't take any more time off*
25 *work as such, 'We'll have to bring her [mother] home.'*
26
27
28
29
30
31
32
33

34 Balancing care and work responsibilities played an important role in some family carers'
35 decisions about where the home death could be supported. For some, this was also linked to a
36 pre-planning of care and support for a dying older relative when the practicalities of
37 undertaking care from a distance would become unmanageable. Our analysis revealed
38 examples of adult children encouraging an older parent to live independently but in a location
39 closer to their own home (often downsizing at the same time and moving to single level
40 accommodation such as a flat or bungalow), moving the older family member into an annexe
41 attached to their own home, or into their own home itself. As one adult daughter commented:
42
43
44
45
46
47
48
49
50
51
52
53
54
55

56 *B03: well my mum and dad moved in to live with us in millennium year, because my*
57 *dad had peripheral neuropathy, and erm he was going gradually downhill and*
58
59
60
61
62
63
64
65

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

obviously my mum was getting older and finding it harder to look after him... then we suggested that if they needed, they could move in with us, cos we've got a place through there, they have their own lounge, their own bedroom, their own bathroom really 'cos we had an en-suite, so they did that.

I: So you had plenty of room?

B03: erm yeah so they lived with us since then, and then my dad just got worse and worse obviously and eventually ended up in bed didn't he?

Husband: Yeah they lived in south [city], so every time you know there was a problem B03 was having to go down on the motorway, and that was inevitably going to get worse and worse and she was going to have to go more and more so that was really the reason wasn't it?

For others, particularly those who were themselves lone-dwellers, their own retirement, changed personal circumstances, or issues of practicality, such as the suitability of the home for facilitating care, sparked a decision to move closer to, or into, the parental home. One adult daughter noted:

B15:it's only because I have no husband, I have grown-up children, I have no commitments, I had no job... I'd retired... and no pets, nothing. So I said I would move in with him [father] ... I couldn't bring him here [own home]. Down there he had a walk-in shower. He had a bigger place than this even though it was just a flat. He had a lovely big room and I could put this camp-bed out in his sitting room.

1 Understanding 'whose home' is being referred to in the home death was further complicated
2 by evidence of adult children moving back into the parental home and purchasing it from
3 their ageing parent/s who then continued to dwell in the home with the adult child. As one
4 adult daughter revealed:
5
6
7
8
9

10
11 *B18:I lost my son at the age of 14, so I sold up my property and went to live with Mum and*
12 *Dad. Then I bought the bungalow off Mum and Dad to get back on the property ladder and*
13 *then I met my now husband, so the four of us ended up living together because we'd had quite a*
14 *lot of extensive work done to the bungalow. So we were all there anyway.*
15
16
17
18
19
20
21
22

23 For others, supporting a home death within their own home can be unplanned, and arise as
24 consequence of a breakdown in what had previously been a satisfactory care-giving
25 arrangement undertaken by other family members. As one adult daughter commented:
26
27
28
29
30
31

32
33 *A12: Well my mother had a long term heart problem, she lived at the top of a hill, she*
34 *lived in the same house where we were all brought up, sixty years. And we all panicked*
35 *because she was getting out of breath and so on. So my sister bought her a house in*
36 *[Town1] in [County1] which was where my sister lived, and she [mother] lived in that*
37 *house by herself but [sister] was quite close by and my niece was quite close by, and*
38 *they used to drop in and do her shopping and take her out and so on. So that was going*
39 *on for a while and then mum started falling, and basically my sister was working part-*
40 *time and had to keep going to take time off to take mum to the surgery and all the rest*
41 *of it, and it really got a bit nasty and there was a tremendous blow up which was most*
42 *unfortunate, and in a totally unplanned and unpleasant way she came down to us. And*
43 *she'd been staying with us for about 6 weeks, and we took her back and my sister was*
44 *in [County1] at a Christmas market, my brother-in-law was there and he said that it*
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

1 *was just, they just didn't, he didn't, want anything more to do with it - and my sister*
2 *wasn't there. So we said right, so we turned round and brought her back, and it was*
3 *very unpleasant and poor mum was terribly shaken up cos it wasn't like saying you*
4 *know this doesn't seem to be working, perhaps we ought to work something out you*
5 *know? It was just a slam in the face really. And so she came to live with us and that*
6 *was that ...*

16 Each of the above examples raise an interesting paradox around the home and the complexity
17 that underlies claims made for, and attempts to understand, those attributes of home deemed
18 to be supportive of the home death. In particular, they raise questions about for whom claims
19 around the meaning of home are being made. Related claims about the home as a site of
20 familiarity, habituated routines and physical arrangements that facilitate privacy, power,
21 control and historical memory that can be supportive for a home death are thus drawn into
22 question. Where end of life care is delivered within the family member's home, the degree of
23 closeness of familial bonds; the magnitude of familiarity with that setting; and the norms of
24 behaviour within it, all impact on the meaning of home for both the dying family member and
25 the family carer. The quote above from A12, for example, reveals how the dying family
26 member moved firstly from what had been the long-term familial home that would have been
27 imbued with those characteristics attributed to a sense of home, to an independent setting in a
28 different town where she could benefit from familial support. At a time when A12 clearly
29 required additional support, she was also faced with building a new sense of home, in a new
30 location, that was socio-spatially less familiar to her. Growing care needs and subsequent
31 breakdown of that family care-giving resulted in a further unplanned move to the home of a
32 second adult child in a yet another town. This, and the other examples given above, clearly
33 call into question the perception that a home death facilitates the ability of the older person to

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

‘die in their own bed’. Moving to different houses in different locations away from the familial home also raises questions about where power and control lies and the extent to which the dying relative is able to draw on the meaning of home – and relationships within - to help them truly feel ‘at home’.

Where end of life care takes place within a non-spousal care-giver’s home, pre-existing power relationships between the carer and cared-for can actively reshape everyday routines, norms and sense of home. For some, good relationships with the dying family member prior to supporting a home death act to override the difficult circumstances and considerable disruption that a home death brings to the meaning and routines of home. But this is not always the case. As one adult daughter caring for her mother noted:

A19:[husband] said I should have laid the law down when she [mother] came with us first because Mum was domineering. She looked after her parents from the age of 19 and they died when she was 62 or 3, when she was in her sixties, and they lived across the road and she waited on them hand, foot and finger. So it was expected, but she ruled the roost with everybody, even my Dad. I mean she ruled...

W: She thought then, when she moved in with [carer and husband], that she could take charge of them.*

A19: She told us what we were eating every day.

W: Would only have her meals at a certain time.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

A19: *Yeah. Her meal was nine o'clock – breakfast; elevenses; one o'clock – lunch; three o'clock - afternoon tea; five o'clock – dinner. Oh, yeah.*

*W is cousin to A19

Whether relationships are good or bad, even non-spousal family carers can find their own sense of home disrupted as they make physical and social transformations to their own home to accommodate the needs of the cared-for. This includes making way not just for the dying relative, but also for negotiating and adapting space for those possessions deemed necessary to make them 'feel at home'. As the same adult daughter went on to say:

A19: *... when Mum came she insisted on bringing all her furniture with her, we had a house-full as well, so we brought whatever she could with us. Some of it, when we got here, she realised she couldn't keep, but then it's clearing the room out...*

The alterations required to support a home death can also mean making way for the increased presence of professional care staff and the portable technologies and paraphernalia of care that, while disrupting the everyday rhythms and order of the home, are necessary to the provision of good care. In our study, such transformations included both permanent and temporary rearrangements of the home. For example, undertaking loft conversions and re-organising living and sleeping spaces to facilitate the dying relative's move to the carer's home; adapting rooms to create en-suite facilities or remodelling bathrooms to meet the needs of the dying relative. In addition, family carer's needed to make space in their homes for the aides and adaptations necessary to support the home death and the space required to work around them. One adult daughter commented:

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

B03: Well I had to empty upstairs as well didn't I? 'Cos it went through, well two hoists one over his seat and one over the bed and the one over the seat. We used the loft and I put some flooring down. We changed a lot when they [parents] moved in really. We sort of emptied that half of the house of our stuff and they brought their own furniture, and then when he needed a hospital bed we had to get rid of a bed.

The technologies and service arrangements required to provide home-based care can result in an institutionalisation of the home that impinges on both the family carer's and dying older relative's sense of home (Milligan, 2009). Carers in our study revealed how they were required to reorganise the home to make way for a wide range of portable technologies such as airbeds, wheelchairs, hoists, commodes, urine bags and bottles, swabs, catheters, syringe drivers and so forth. Yet whilst our evidence does indeed point to home death as creating an institutionalisation of the home, it was also clear that family carers – whether spousal or other close relative - sought to minimalise this, creating as much order and normalcy within the home as possible. As one adult daughter noted:

B02: Well erm I could kind of secrete them away, anything like that into that other room, which I just kind of used as a storeroom. But that wasn't so good because I tried to keep things very, very tidy, because there was pads, urine bottles, urine bags, gloves, swabs, everything all over the place you know, so I just tried to keep it all tidy as much as I could.

Perceptions of home post-death: from home to house?

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

Whilst much of the literature on family carers and the home focuses on experiences of home during the care-giving phase, we also sought to understand how the home death impacts on family carers' experiences of home post-death. The literature on care, home and older people highlights its importance as a site of historical memory and identity (e.g. Angus et al, 2005; Milligan, 2009; Brickell, 2012). Post-death, this can involve the purposeful retention of artefacts that hold meaning in the construction and maintenance of that memory, sometimes despite the benign intentions of other family members. As one spousal carer revealed:

A04: It will have to be changed and she [sister] wants to get a new suite of furniture for me erm but I'm not getting rid of his chair at the moment erm I'll do it in my own time, I think they mustn't force me. I will not get rid of his chair for anything. Mmm hmm and I've still got this feeling, this is why I don't want to be away in hospital for long, and I've got to get over it, I've just got a feeling ..'cos he did love it here and I think he might come back erm and I've got to be here if he comes back because I'm always here so I'm never away ... I know he won't come back but he might be back here in spirit mightn't he [starts crying]?

Yet our narratives revealed a mixed picture where, for some, it also provided an opportunity to remove 'artefacts of discord', to change décor or the usage of rooms. As one spousal carer noted:

A13: I've changed a lot

I: Have you?

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

A13: *Yes and I'm having my tea set that [husband] couldn't stand with flowers on that's been in that cupboard for years, I'm using that and the one that he liked, the Poole pottery one that he said we always used all our life, that went today. So that's a yes.*

11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

Importantly, our participants' narratives highlighted the ways in which home was constructed not just as a physical structure, but as a site of personal and socio-emotional relationships. The death of a spouse irrevocably changed the nature of those relationships. For some this was manifest in a shift from 'home' to 'house'. By this we mean that for the family carer, the home had become devoid of those personal and emotional relations that were an important component in the construction of the meaning and sense of home that they attached to that setting. This was particularly the case amongst spousal/partner carers. For some, this resulted in a desire to move and recreate a new home and a new life – one that was not laden with socio-emotional experiences and historical memory that had become shadowed by loss and loneliness. What underpins this shift from home to house is well illustrated through the narrative of one spousal carer who noted:

41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

B19: *..You know, it's nearly a year now and... it is still our home, but when I come home now it's a house and... I don't know, it hasn't been sold so I... well, we're thinking now that we'll have it rented, and I'm going to move. I think the worst thing is that I have to pack up all these things that we moved in here together and I think that's going to be the worst thing, but it doesn't feel... I don't want to stay here. I don't want to be here... and that's why I went to work. I need to get this place out of my system. We built this, our home, together: we did that for 30-odd years, and so I just have to... get my life going again.*

1
2 Moving to a new home of course is a major undertaking, one known to have the potential to
3
4 contribute adversely to mental well-being (e.g. Morse, 2000); not all either want, or feel able,
5
6 to undertake this task. Hence for others, efforts to recreate a *new* sense of home post-death
7
8 involved an alteration in their spatial practices and engagement with the physical space of the
9
10 home. For some, this involved the decision to avoid those spaces within the home most
11
12 associated with the home death. As one spousal carer commented:
13
14
15

16
17
18
19 *A06: I mean I never go upstairs now I live in this, I live in this room and the bedroom I*
20
21 *don't go in, I don't hardly go in the sitting room I just walk through it.*
22
23
24
25

26 For other spousal/partner carers, it involved rearranging the home as they sought to retain, but
27
28 'tuck away', those memories of home in ways that enabled them to move on with their lives.
29
30 This involved recreating a new sense of home that moved away from the home as a shared
31
32 site of dwelling and identity to one that allowed for the construction of new memories and a
33
34 new sense of identity. One spousal carer noted:
35
36
37
38
39
40

41 *A07: And as the months were going on, all these lovely pictures of him [husband] I*
42
43 *used to keep looking at, and it was making me more and more I didn't want to be here.*
44
45 *And this particular day I just thought I've got to move them, I can't bear it anymore, and*
46
47 *I moved all the pictures out the front. And then the sofa had never been here and that*
48
49 *chair had never been there and the sideboard had you know what I mean I tried to move*
50
51 *it so, and then I got rid of some of my - all this china it was our china anniversary - he*
52
53 *started to buy me that and it was everywhere and I thought 'no I can't'. And I put it all in*
54
55 *there [spare room] - quite happy with it now, but I bought new different things for myself*
56
57
58
59
60
61
62
63
64
65

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

and made it more mine if you know what I mean. Like he was in that bedroom and from the day he died I've never left that bedroom, but I've changed it now, I've put different wallpaper on the back, I've put my bed in there now.

The ways in which spousal/partner carers' sense of home changed post-death was reflected in many of narrative interviews, often characterised by decisions to no longer use specific rooms (particularly the marital bedroom or the room in which the home death occurred); re-organising furniture, renovating or redecorating rooms – to the extreme end of moving to a new home. In all, these narratives were underpinned by a need to remake a sense of home in ways that moved away from one characterised by shared identity and memories, to one that facilitated an ability to move forward with their lives and which reflected their new status as lone-dwellers.

Where non-spousal carers were undertaking care within their *own* homes, the issue was more of reclaiming that space which had been given over to the dying family member, but in ways that actively sought to imprint their own identity on that space. As one adult daughter noted:

A19:what is the dining-room now was our little bedroom because she [mother] had the biggest room, and we'd got a double bed in there and used to walk past the end of the bed. But it was fine. We decided then to re-do the bedroom and move in and paint that room a totally different colour, which my husband chose it...he chose the colour to be totally different.

Discussion

1
2 Much of the literature on home death focuses on why family carers opt to support a home
3 death and how home-based care can contribute to ‘the good death’, but there is little work
4 that seeks to understand how family carers’ experiences of the home death impacts on the
5 meaning and sense of home they attach to that setting (Morris et al, 2015). There is even less
6 work that takes a spatio-temporal approach, that is, one that seeks to understand how the
7 home death impacts on the meaning of home for family carers pre and post death. Actively
8 supporting a home death, we suggest, is just the first stage along the spatio-temporal
9 continuum for family carers, one that is characterised by a complex network of socio-
10 emotional factors. Whilst our findings around family members’ experiences of supporting a
11 home death largely reflect the findings of earlier studies, they also raised the far less
12 frequently discussed issues around *whose home* that care takes place in, how this impacts on
13 the meaning of home - not only for the dying older relative but also for family carers. Our
14 findings also raise issues about how the home death impacts on the meaning of home for
15 family carers post-death. These issues have led us to locate our paper, conceptually, within a
16 discourse of home and the socio-emotional meaning of home. Such conceptual insights are
17 important given the assumptions about home that are implicit within a growing policy
18 discourse that seeks to encourage home, over institutional, deaths.

19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46 We would suggest that where ‘home death’ means death within the home of a family carer
47 rather than that of the dying family member, the meaning of home and the notion of ‘dying in
48 one’s own bed’ is disrupted. Whilst a ‘home’ death in these circumstances may be preferable
49 to an institutional death, assumptions about the benefits of home should not be taken for
50 granted. Following Brickell (2012), we maintain that there is a tendency to ascribe home with
51 a set of characteristics that are often uncritically regarded as being supportive of a home

1 death. In doing so, both researchers and policy discourse fail to unpack the complex nature of
2 the meaning of home. There is a paradox here, in that for both the dying older person and the
3 family carer, the experience of home is altered, not just by whose home death occurs in, but
4 also by the actors, objects, actions and complex socio-spatial relations attached to that home.
5 Family relationships, the spatial setting within which these occur, and the meaning attached
6 to this setting all suggest that in reality, 'home death' encompasses a non-institutional death
7 that is experienced across a range of 'home' settings each with different levels of socio-
8 emotional meaning attached to them. This can range from a home death being supported
9 within the dying older person's own familial home, to relocation to an independent setting
10 close to family members from whom they can draw support, or to the family carers own
11 home.
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28

29 Where home death occurs within the dying family member's familial home, the supportive
30 characteristics attributed to home (safety, security, familiarity, historical meaning etc.) are
31 most at play for the dying family member. To some extent, this also holds true for
32 spousal/partner carers, though for them, the meaning of home is more likely to be disrupted
33 by the work of supporting a home death. Though often clearly advised by healthcare
34 professionals about what is involved and what support will be available, family carers are
35 often unprepared for the disruption and challenges caring at end of life will make to their own
36 sense and experience of home. Alterations to the physical structure of the home, the
37 requirement to make way for the technologies and paraphernalia of care, interruptions to the
38 daily rhythms of life to meet the regimes of care professionals or those of the dying family
39 member, and the impact on family carers' own socio-emotional engagement with the micro-
40 geographies of home, all act to challenge the sense and meaning of home for the family carer
41 in ways that can be contradictory and not necessarily positive. Whilst further work is needed
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

1 on the impact of a home death on both the family carer and dying relative where home refers
2 to that of the family member, our study has begun to unpack how issues of safety, familiarity,
3 power, control and disruption can play out very differently in these settings.
4
5
6
7

8
9 It also seems evident from our study that the home death can have a significant impact on the
10 meaning and sense of home for family carers' in the post-death period. For some, the home
11 death brings a sense of comfort and closeness to the relative that has died, but many also
12 describe a socio-emotional disengagement that alters their sense of home. For some this is
13 manifest through a restructuring of their daily routines to facilitate an avoidance of those
14 rooms associated with the home death, for others it is about altering, redecorating, or
15 consciously 'putting away' aspects of the former shared home that are emotionally
16 overpowering and which thus hinder their ability to move forward. The extreme end of this
17 avoidance tactic (mainly among spousal/partner carers) can result in a decision to move to a
18 new location where they can begin to construct a new sense of home – one that facilitates
19 their ability to move on with their lives post-death.
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38

39 In many ways we are at the early stages of conceptualising how these experiences act to
40 shape and reshape the meaning and sense of home for dying older adults; and for family
41 carer's ability to successfully recreate new lives and a new sense of home in the post-death
42 period. Nevertheless, our work expands conceptually on Brickell's (2012) critique of home as
43 some universally positive phenomena, to highlight not only the complexity of the meaning of
44 home and for whom in understanding the home death, but also the ways in which the
45 meaning of home shifts and changes over time. Our work also adds to that body of literature
46 that has begun to critique the notion that the home death is somehow better and should be
47 promoted whenever possible. Indeed, while the home death is clearly the preferred option for
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

1 many older people at end of life, and many family carers do their utmost to support this –
2 there is contradictory evidence about the extent to which this helps or hinders the grieving
3 process (e.g. Higginson et al 2013; Luckett et al., 2013). Whilst further work is needed, it
4 would appear from these data that the picture is complex so whilst on the one hand family
5 carers gaining a sense of satisfaction in ‘having done the right thing’, on the other, their sense
6 of home, belonging and identity can be disrupted by the home death.
7
8
9
10
11
12
13
14
15
16

17 Our analysis thus illustrates how the home is a deeply nuanced and complex site of
18 (sometimes shifting) social relations; a site of paradox, ambiguity and contradiction, where
19 attributes are conditional, contextual and not necessarily positive. Any understanding of the
20 impact of home death on family carers’ experiences of the home both before and after the
21 death needs to be alert to these complexities and the ways in which shifts in these socio-
22 spatial relations can alter the meaning and sense of home for those individuals concerned.
23 Disruptions to the meanings, objects and routines that are integral to the concept of home can
24 have profound consequences for the emotional and material landscapes of care that can
25 impact of family carers’ own well-being.
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40

41 Whilst community services are available (to varying degrees) to support home-based end of
42 life care, policies and practices designed to encourage opportunities for a home death are
43 reliant on family carers’ willingness and ability to support the everyday care needs of their
44 dying family member. A deeper understanding of the disruption of home arising from care
45 and caring practices at end of life - and how family carers might be supported to minimise the
46 impacts of this disruption both before and after death - is crucial if we are to find ways to
47 help to maintain their well-being and in doing so encourage choice around place of death.
48 Interestingly, whilst we sought to draw comparisons across two socio-economically different
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

1 regions, the lack of any emergent differences in people's experiences was striking. What was
2 perhaps more striking was that even where good support packages were available to family
3 carers during the dying phase, post death these services stopped completely, leaving carers
4 unsupported to deal with the aftermath. Hence, if policy makers wish to increase the numbers
5 of home deaths, more attention needs to be paid to supporting family carers during
6 bereavement, especially where the carer continues to live in the home within which the
7 person has died.
8
9
10
11
12
13
14
15
16
17
18

19 **Limitations**

20
21 One limitation of this study is that only those who responded to the invitation to take
22 participate were included; those who had a particularly negative or difficult experiences of
23 caring may have been more likely to decline the invitation. Recruitment through GPs may also
24 have resulted in some people, who may have wished to have participate, being excluded by
25 the gatekeeping process. Finally, only three of the 59 participants were BAME communities,
26 the vast majority were White British; hence we are unable to say whether the findings are
27 generalisable to other ethnic groups. A further study looking specifically at the impact of
28 home death on BAME carers would add further insights to this issue.
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43

44 **Acknowledgements**

45 This research project was funded by Marie Curie Cancer Care.
46
47
48
49
50

51 **References**

52
53
54
55
56
57
58
59
60
61
62
63
64
65

1 Angus, J., Kontos, P., Dyck, I., McKeever, P. and Poland, B. 2005. The personal significance
2 of home: Habitus and the experience of receiving long-term care. *Sociology of Health and*
3
4 *Illness*, 27, 161-187.

5
6
7
8
9 Blunt, A. and Dowling, R. 2006. *Home*. Abingdon: Routledge.

10
11
12
13
14 Brickell, K. 2012. Mapping' and 'doing' critical geographies of home. *Progress in Human*
15
16 *Geography*. 36(2) 225–244.

17
18
19
20
21 Cardenas-Turanzas, M., Torres-Vigil, I., Tovalin-Ahumada, H. and Nates, J.L. 2011. Hospital
22
23 versus Home Death: Results from the Mexican Health and Aging Study. *Journal of Pain and*
24
25 *Symptom Management*, 41:5, 880-892.

26
27
28
29
30 Carlander, I., Ternstedt, B.M., Sahlberg-Blom, E., Hellström, I., and Sandberg, J. 2011. Being
31
32 Me and Being Us in a Family Living Close to Death at Home. *Qualitative Health Research*
33
34 21(5) 683 –695.

35
36
37
38
39 Chapman T and Hockey J (eds) (1999) *Ideal Homes? Social Change and Domestic Life*.
40
41 London: Routledge.

42
43
44
45
46 Cohen J, Bilsen J, Addington-Hall J, et al. 2008, Population-based study of dying in hospital
47
48 in six European Countries. *Palliative Medicine*. 22, 702-710.

49
50
51
52
53 Collier, A., Phillips, J.L., Iedema, R. 2015. The meaning of home at the end of life: A video-
54
55 reflexive ethnography study. *Palliative Medicine*. 29(8) 695 –702

1
2 Donovan, R., Williams, A., Stadjuhar, K., Brazil, K. and Marshall, D. 2011. The influence of
3 culture on home-based family caregiving at end-of-life: A case study of Dutch reformed
4 family care-givers in Ontario, Canada. *Social Science and Medicine*, 72, 338-346.
5
6
7

8
9
10
11
12 Finally IG, Higginson IJ, Goodwin DM, et al. 2002. Palliative care in hospital, hospice, at
13 home: results from a systematic review. *Ann Oncol*, 13(Suppl. 4): 257–264.
14
15
16

17
18
19 Gomes, B., Higginson, I. 2006. Factors influencing death at home in terminally ill patients
20 with cancer: systematic review. *BMJ* 332: 515.
21
22
23

24
25
26 Gott M, Seymour JE, Bellamy G, Clark D, Ahmedzi S. Older People's Views About Home as
27 a Place of Care at the End of Life. *Palliative Medicine* 2004; 18: 460–67.
28
29
30

31
32
33 Grundy, E., Mayer, D., Young, H. and Sloggett, A. 2004. Living arrangements and place of
34 death of older people with cancer in England and Wales: a record linkage study. *British*
35 *Journal of Cancer*, 91, 907 – 912.
36
37
38
39

40
41
42
43 Higginson, I.J., Sarmiento, V.P., Calanzani, N., Benalia, H. and Gomes, B. 2013. Dying at
44 home – is it better: A narrative appraisal of the state of the science *Palliative Medicine*,
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

66
67
68
69
70
71
72
73
74
75
76
77
78
79
80
81
82
83
84
85
86
87
88
89
90
91
92
93
94
95
96
97
98
99
100

1 Jack, B.A., Baldry, C.R., Groves, K.E., Whelan, A., Sephton J. and Gaunt, K. 2013.
2 Supporting home care for the dying: an evaluation of healthcare professionals' perspectives
3 of an individually tailored hospice at home service. *Journal of Clinical Nursing*, 22, 2778–
4 2786.
5
6
7
8
9

10
11
12 Langstrup, H. 2013. Chronic care infrastructures and the home. *Sociology of Health & Illness*
13 35:7, 1008–1022.
14
15
16
17

18
19 Lockett, T., Davidson, P.M., Lam, L., Phillips, J., Currow, D.C. and Agar, M. 2013. Do
20 Community Specialist Palliative Care Services That Provide Home Nursing Increase Rates of
21 Home Death for People With Life-Limiting Illnesses? A Systematic Review and Meta-
22 Analysis of Comparative Studies. *Journal of Pain and Symptom Management*, 45:2, 279-297.
23
24
25
26
27
28
29

30
31 Macnamara, B. and Rosenwax, L. 2007. Factors affecting place of death in Western
32 Australia. *Health & Place*, 13, 356–367.
33
34
35
36
37

38
39 Milligan, C. 2009. *There's no place like home: place and care in an ageing society*, Ashgate:
40 Farnham.
41
42
43
44

45
46 Milligan C. 2000. Bearing the burden: Towards a restructured geography of caring. *Area* 32:
47 49–58.
48
49
50
51

52
53 Morris, S., King, C., Turner, M. and Payne, S. 2015. Family carers providing support to a
54 person dying in the home setting: a narrative literature review. *Palliative Medicine*, 29:6, 487-
55 495.
56
57
58
59
60
61
62

1
2 Morse, D.L. 2000. Relocation Stress Syndrome is Real. The American Journal of Nursing,
3
4 100:8, pp. 24AAAA - 24DDDD.
5
6

7
8
9 NCIN. 2010. Variations in Place of Death in England: Inequalities or appropriate
10 consequences of age, gender and cause of death? Report available at: [www.endoflifecare-](http://www.endoflifecare-intelligence.org.uk)
11 [intelligence.org.uk](http://www.endoflifecare-intelligence.org.uk) [accessed: 10/09/15].
12
13
14
15

16
17
18
19 Office of National Statistics. 2013. Full story: The gender gap in unpaid care provision: is
20 there an impact on health and economic position? Available at:
21 http://www.ons.gov.uk/ons/dcp171776_310295.pdf [accessed: 10/09/15].
22
23
24
25

26
27
28
29 ONS. 2015. Population and Migration. How Densely Populated is Your Area?
30 http://www.neighbourhood.statistics.gov.uk/HTMLDocs/dvc134_c/index.html [accessed
31 30/11/15].
32
33
34
35

36
37
38
39 Pinzón LC E, Weber M, Claus M. 2011. Factors influencing place of death in Germany. J
40 Pain Symptom Manage 2011; 41: 893–903.
41
42
43
44

45
46 Public Health England. 2013. What We Know Now 2013: New Information Collated by the
47 National End of Life Care Intelligence Network. Available at: [http://www.endoflifecare-](http://www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now_2013)
48 [intelligence.org.uk/resources/publications/what_we_know_now_2013](http://www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now_2013) [accessed 29/09/15].
49
50
51

52
53 Public Health England. 2015. Protecting and Improving the Nation’s Health. Available at:
54 <http://www.apho.org.uk/resource/item.aspx?RID=50417> [accessed: 30/11/15].
55
56
57
58
59
60
61
62

1 Seymour, J., Payne, S., Chapman, A., Holloway, M. 2007. Hospice or home? Expectations of
2 end-of-life care among white and Chinese older people in the UK. *Sociology of Health &*
3
4 *Illness*, 29:6, 872–890.

5
6
7
8
9
10 Shepperd S, Wee B & Straus SE .2011. Hospital at home: home-based end of life care.
11
12 Cochrane Database of Systematic Reviews, Issue 7, Art. No. CD009231. Doi:
13
14 10.1002/14651858.CD009231.

15
16
17
18
19 Topf, L., Robinson, C.A., Bottorff, J. 2013. J When a Desired Home Death Does Not Occur:
20
21 The Consequences of Broken Promises. *Journal of Palliative Medicine*, 16:8, 875-880.

22
23
24
25
26 Twigg, J. 2000. *Bathing - the body and community care*, Routledge: London.

27
28
29
30
31 Venkatasalu, K.R., Seymour, J.E., Arthur, A. 2014. Dying at home: A qualitative study of the
32
33 perspectives of older South Asians dying at home in the United Kingdom. *Palliative*
34
35 *Medicine*, 28:3, 264-272.

36
37
38
39
40
41 World Health Organisation. 2004. *Palliative care: symptom management and end-of-life care*
42
43 *guidelines*. Available at: <http://www.who.int/hiv/pub/imai/genericpalliativecare082004.pdf>
44
45 [accessed: 10/09/15].

46
47
48
49
50
51 Williams, A. M. 2004. Shaping the practice of home care: Critical case studies of the
52
53 significance of the meaning of home. *International Journal of Palliative Nursing*, 10 (7), 333-
54
55 342.

Table 1: Inclusion and Exclusion Criteria**Inclusion criteria:**

- Family carers of older deceased people (aged 50 years +) from any cause of anticipated death;
- Death occurring in the home of the patient or carer;
- Two weeks minimum period of family care prior to death;
- Any age of adult carer (excluding children);
- Participants recruited at least 6 months, but not more than 24 months, following the death.

Exclusion criteria

- Sudden deaths e.g. stroke, myocardial infarction ;
- Death in hospital or other institution;
- Less than a two-week period of family care at home prior to death;
- Carers below age of 18;
- Participants in early bereavement (less than 6 months) or more than 24 months.

Table 2: Carer Relationship to deceased

Relationship	No.
Wife	28
Husband	13
Partner	2 (male)
Daughter	13
Son	2
Sibling	1 (brother)

Table 3: Family Carer and Cared-for Characteristics

Carer Characteristics					Cared for (deceased) characteristics								
Code	Gender	Age	R/ship to deceased	Occupation	Gender	Occupation	MSD*	A@D	Place of death	HO*	No. LiH	MLiH	TCF@H
A01	Female	78	Wife	Secretary	Male	Electrician	12	83	Own home	O/O	2	22	12 mths
B01	Female	77	Wife	Nurse	Male	Baptist Minister	16	77	Own home	O/O	2	13	3 mths
A02	Male	72	Husband	Roofing contractor	Female	Weaver	8	70	Own home	S/R	2	15	11 mths
A03	Female	76	Wife	Care assistant	Male	Bricklayer	16	77	Own home	O/O	2	10	3 mths
B02	Female	57	Daughter	Nurse/OT	Female	Civil Servant	15	77	Own home	O/O	2	20	3 mths
B03	Female	64	Daughter	Secretary	Male	Housing Manager	11	90	Daughter's home	O/O	4	11	11 yrs
B04	Male	75	Husband	Catering Manager	Female	Nurse	14	71	Own home	O/O	2	23	2 wks
B05	Male	54	Son	Civil Servant	Female	Ward Clerk	11	84	Own home	O/O	3	15	18 mths
B06	Male	73	Brother	Farmer	Female	Family business	19	67	Own Home	S/R	3	5	12 mths
A04	Female	67	Wife	Housewife	Male	Contracts manager	13	67	Own home	P/R	2	13	2 yrs
A05	Male	88	Husband	Civil Servant	Female	Pension insurance	9	85	Own home	O/O	2	28	few wks
A06	Female	76	Wife	Farmer	Male	Farmer	14	74	Own home	O/O	2	30-35	4 yrs
A07	Female	60	Wife	Housewife	Male	NVQ Assessor	19	65	Own home	O/O	2	1	6 mths
A08	Female	66	Wife	Retail sales	Male	Financial advisor	18	72	Own home	O/O	2	6	4 mths
A09	Male	77	Husband	Catering Manager	Female	Teacher	18	73	Own home	O/O	2	42	7 mths
A10	Female	64	Wife	Sales assistant	Male	Hospital porter	10	67	Own home	O/O	2	2	2 yrs
B07	Female	82	Wife	Farm Manager	Male	Farmer	7	89	Own home	O/O	2	26	9 yrs
A11	Female	60	Daughter	Teacher	Male	Bank Manager	18	84	Own home	O/O	1	5	3 mths
A12	Female	69	Daughter	Secretary	Female	Clerical worker	19	91	Own home	O/O	3	1.6	1 yr
A13	Female	80	Wife	Teacher	Male	Architect	8	83	Own home	O/O	2	21	6 wks
A14	Male	80	Husband	C of E Minister	Female	Housewife	11	87	Own home	O/O	2	5.6	2-3 mths
A15	Female	67	Daughter	Special needs worker (retired)	Female	Housewife	13	98	Own home	O/O	2	60	6 yrs
A16	Male	77	Partner	HGV driver (retired)	Female	Technician	9	71	Own home	O/O	2	3	3 yrs
B08	Female	64	Daughter	Dispatch Manager	Female	Housewife	19	92	Own home	O/O	1	4	3 yrs
A17	Female	67	Wife	Farmer	Male	Farmer	20	70	Own home	O/O	2	26	9 yrs
A18	Male	87	Wife	Company Director	Female	Almoner	12	86	Own home	O/O	2	27	2 yrs

B09	Female	57	Daughter	Nurse	Male	Telephone engineer	14	88	Own home	O/O	2	60	9 wks
A19	Female	69	Daughter	Housewife	Female	Housewife	9	96	Daughter's home	O/O	3	17	10 yrs
B10	Female	72	Wife	Telephonist	Male	Local Government Officer	7	80	Own home	O/O	2	1.1	13 mths
B11	Female	63	Wife	Cleaner	Male	Factory worker	7	65	Own home	O/O	2	36	10 mths
A20	Female	68	Daughter	Secretary	Male	Company director	13	98	Own home	O/O	2	4	4 yrs
A21	Male	71	Husband	Teacher and school inspector	Female	School Matron	9	67	Own home	O/O	2	7	6 mths
A22	Male	85	Husband	Gardener (Retired)	Female	Domestic help	13	80	Own home	O/O	2	56	2 yrs
B12	Female	63	Partner	Medical Practitioner	Male	Medical Practitioner	19	87	Own home	O/O	1	33	12 mths
A23	Male	82	Husband	Civilian operator for police (retired)	Female	Farmer	11	94	Own home	O/O	2	15	2 yrs
A24	Male	54	Husband	Agricultural contractor	Female	Haulier	10	59	Own home	O/O	3	1	9 yrs
B13	Female	83	Wife	Classroom assistant	Male	Engineer	8	88	Own home	O/O	2	60	10 yrs
B14	Male	72	Husband	Teacher	Female	Artist	13	70	Own home	O/O	2	30	5 wks
A25	Female	58	Daughter	Housewife	Female	Office clerk	22	87	Own home	O/O	1	6	4 wks
A26	Female	83	Wife	Housewife	Male	Chartered Accountant	11	86	Own home	O/O	2	24	2 mths
B15	Female	63	Daughter	Care assistant	Male	Boatman	11	86	Own home	S/R	1	10	4 mths
B16	Female	59	Wife	Care assistant	Male	Electrician	18	59	Own home	O/O	2	27	12 wks
A27	Female	67	Wife	Lecturer	Male	Car engineer	22	67	Own home	O/O	2	5	9 mths
A28	Male	82	Husband	Education Officer	Female	Clerical worker	22	76	Own home	O/O	2	28	10 yrs
B17	Female	82	Wife	Nurse	Male	Electrician	13	88	Own home	O/O	2	59	18 mths
B18	Female	54	Daughter	carer	Male	Retail manager	18	88	Own home	Family owned	2	15	18 mths
A29	Male	90	Husband	County Education Advisor	Female	Teacher	10	91	Own home	O/O	2	40	3 yrs
A30	Female	88	Wife	Administrative assistant	Male	Architect	21	87	Own home	O/O	2	15	1 yr
B19	Female	70	Wife	Nurse	Male	Church minister	12	86	Own home	Church owned	2	8	6 mths
A31	Male	60	Son	Car valeter	Female	Housewife	10	84	Son's home	O/O	3	0.75	9 mths
A32	Female	63	Wife	Bank official	Male	Bank Manager	11	64	Own home	O/O	2	30	5 mths
B20	Male	82	Husband	Chemical factory manager	Female	Housewife	17	79	Own home	O/O	2	42	6 wks
A33	Female	82	Wife	Secretary	Male	Naval engineer/chiropracist	12	81	Own home	O/O	2	19	3 wks
B21	Female	80	Wife	Social Worker	Male	Industrial pharmacist	9	77	Own home	P/R from family	2	2 1/2	9 yrs

A34	Female	61	Daughter	Teacher	Male	Joiner	12	82	Own home	O/O	1	34	5 mths
B22	Female	76	Wife	Nurse	Male	Teacher	21	93	Own home	O/O	3	5	8 mths
A35	Female	72	Wife	Auxilliary nurse	Male	Carpenter and joiner	11	73	Own home	O/O	2	38	5 mths
A36	Female	87	Wife	Draughtswoman	Male	Sound recording engineer	10	91	Own home	O/O	3	5	11 yrs
B23	Female	57	Wife	Police officer	Male	Police officer	22	59	Own home	O/O	2	4	5 mths

HO (home ownership): O/O= Owner occupied; P/R = private rented; S/R = social rented

*MSD=months since death

A@D= age at death

No.LiH = number living in home

MLiH = months lived in home

TCF@H = time cared for at home