

The Importance of Place of Death in Young Adults with Terminal Cancer

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ABSTRACT *This paper addresses issues relating to place of death in young adults with terminal cancer, through the perspectives of their parents. Evidence suggests that the majority of terminally ill cancer patients would prefer the option of a home death, but little is known about preferences among young adult cancer patients and their families. Through retrospective reflection by bereaved parents of young adults with cancer, this paper aims to understand the importance of place of death to this age group. The empirical data drawn on in this paper consist of accounts written by the parents of 13 young adults who died of cancer. A death at home is reported as a strongly held preference of the majority of young adults, and was supported by their parents. Eight of the 13 young adults were able to die at home, another wished to do so but died in a hospice. However, narratives describing death in places other than home signal that home may not always be the preferred or 'best' place to die. Life-stage factors do appear to play a role in determining both preference for, and the actual achievement of, a death at home, but if life stage issues are understood and respected a 'good' death can take place in other environments.*

Introduction

This paper examines place of death concerns and experiences as recalled in the narrative accounts written by parents whose young adult son or daughter, aged 18–25, died of cancer. It reports on parents' perceptions of their child's preference for place of death, and considers their accounts of deaths in particular settings. The aim is to discover if young adulthood carries with it particular meanings or preferences for both young adults and parents when decisions have to be faced about where to die.

It has been established by several authors (Brannen *et al.*, 1994; Lynam, 1995; Apter, 2001; Grinyer & Thomas, 2001; Grinyer, 2002a) that young adulthood is a distinctive life stage that carries with it characteristics that make a difference to illness experiences and behaviours. One dimension of this likely to have a bearing on place of death preference is that, when hospitalized, young adults dislike being

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placed on wards occupied mainly by young children or older adults: they just do not 'fit in' (Grinyer & Thomas, 2001; Grinyer, 2002a). While, in recognition of this fact, the Teenage Cancer Trust has funded a number of wards in the UK designed to be age appropriate, there are not enough for all those who might need them, and inappropriate admissions continue to be commonplace. Does this mean that death at home is certain to be preferred among young adults dying of cancer and their families, since hospices also tend to be either older adult or child oriented? This paper can go some way toward answering this question.

The UK health care policy climate is certainly supportive of increasing the opportunities for terminally ill cancer patients, of any age, to die at home. In acknowledging that only a minority of patients who want a home death can achieve this, the NHS Cancer Plan (Department of Health, 2000) promised additional investment to support death in a community settings. The impact of a series of funding initiatives has strengthened a belief amongst service providers and practitioners that a home death is the ideal (Thomas, Morris & Gatrell, 2003). These developments are much to be welcomed if this means that young adults dying of cancer can increase their chances of dying at home, should that be their preference.

Place of death: preferences and patterns

Clark & Seymour (1999: 22) suggest that part of the 'romantic appeal of the modern way of dying' is the emphasis on community and home, and the assumption that home is the best place in which to die. Research on place of death preference endorses this assumption. Higginson & Sen-Gupta's (2000) systematic review of the literature on such preferences identified 18 studies, half of which were undertaken in the UK. While having some reservations about the research designs employed in the studies, these authors concluded that over 50% of cancer patients would prefer to die at home, with the second choice being inpatient hospices. In an influential study, Townsend *et al.* (1990) found that of 59 patients who stated a preference, 58% preferred to die at home, 20% in a hospice, 12% in hospital and 2% somewhere else unspecified. Other studies show a similar level of preference for a home death, but as Higginson & Sen-Gupta (2000) note, the factors that shape preferences are poorly understood.

Despite the evidence that most cancer patients wish to die in their own home, the numbers who manage to do so are relatively small. While those with palliative care needs spend most of their last year at home there is frequently a final admission to hospital in the days preceding death (Clark & Seymour, 1999: 157). The UK and USA have seen long-term trends away from home towards institutionally located deaths. Between 1967 and 1987, the proportion of cancer deaths in hospitals in England increased from 45% to 50%, and from 5% to 18% in hospices and other institutions (Cartwright, 1991). In 2000, the proportion of cancer deaths in hospital in the UK stood at 55.5%, with 23% at home, 16.5% occurring in hospice, and 5% in other settings, principally nursing and residential homes (Ellershaw & Ward, 2003). Within the UK, large variations in the location

of deaths are found between and within regions (Higginson, 1999; Gatrell *et al.*, 2003).

Age is certainly a factor that predicts place of death, with young cancer patients more likely than their older counterparts to die either at home or in hospice (Gatrell *et al.*, 2003). In the absence of evidence to explain this it seems reasonable to speculate that reasons for home deaths in this age group may be related to factors such as the families' physical ability to manage a home death. Additionally, the perceived 'social worth' of a young person and the impact on a wide variety of friends and relatives may make it appear less appropriate for a young adult to die away from home in an environment more closely associated with the elderly.

Other factors identified as predicting place of death for cancer patients include: having informal carer support, the health status and emotional capacity of the main carer, the availability and use of specialist community based palliative care services, the need for specialist symptom control, tumour type, distance to services, gender, socio-economic status, attitude to dying, and the strength and visibility of the patient and carer preference for a particular place of death (Herd, 1990; Addington-Hall & McCartney, 1995; Karlsen & Addington-Hall, 1998; ② Grande *et al.*, 1999; Higginson *et al.*, 1999; Cantwell *et al.*, 2000; Amir *et al.*, ① 2002). The association between home death and informal caregiving is the most consistent theme in the literature (Brown & Colton, 2001), an association working in favour of home deaths for young adults.

It is in the context of these wider issues relating to preferences for place of death that this paper examines how death was managed and experienced by the parents of young adults with cancer and the extent to which life stage might be a contributory factor.

Methodology

The empirical data drawn on in this paper form part of a larger data set of narrative material generated by the parents of young adults with cancer. The written narratives were submitted in response to an appeal published by Helen, the mother of George who died after a 4-year battle with osteosarcoma at the age of 23. After George's death, Helen and her husband Geoff set up a charitable Trust to fund research on the effect on families when young adults have cancer. The authors were approached to work with the Trust, and after consideration of data collection methods with Geoff and Helen, launched the appeal for parental narratives. The appeal was distributed to parents via health professionals and cancer related organizations in the UK; it was also published in a number of cancer-related magazines and newsletters over a period of several months. Most responses were from the UK but two were sent from Germany and Australia. Indeed, the mother writing from Germany about the death of her son Alex went on to publish a book about her family's experiences (Grant, 2002), and we include an extract from this text in the findings below. The majority of the data were submitted in written form by post, although two contributions were made via e-mail. These narratives were sent directly to the authors.

This ‘narrative correspondence’ approach to data collection had been used successfully before by Thomas (1998, 1999a,b). It enables research participants to be in greater control of many aspects of information disclosure than other methods allow; the parents were able to decide whether or not to participate without pressure. If they did choose to contribute, they could produce their account in their own time without the expectation of having to engage with an interviewer at a prearranged time or place. Thus, they could pick up or put down their account according to their ability to address the issue at any given time. The characteristics of this method were thought to be particularly appropriate when asking the parents of young adults with cancer—some of whom were likely to have died—to participate in research.

Respondents were not asked to address any specific topic, but rather to ‘tell their stories’ in their own way, in their own words and at a time of their choosing. In total, accounts from 28 families whose adult sons and daughters were diagnosed with cancer were contributed. Of the young people whose stories were told by their parents, seven survived. The data drawn upon in this paper is a sub-set of the original data set and is based on accounts from the parents of 13 of the young adults who did not survive their cancers, and for whom the place of death is known. The majority of narratives were submitted by mothers and were written at variable lengths of time since the death of the contributor’s son or daughter, the range of this sub-set being written from 1 to 5 years after the death.

Undertaking research in such a painful and difficult area requires immense care and sensitivity and this was a constant cause for concern throughout the research process. Nadeau (1998) addresses the vulnerability of bereaved respondents as an ethical issue. She made the assumption that respondents were most likely to be vulnerable in the earliest months after their loss. Thus, she selected only those respondents who were 3 months or more past the death. However, the methodology used in our research means that the choice of whether or not to respond to the appeal, and when to do so, is left up to the participant to decide, thus minimizing the chance of the researcher being an unwelcome intruder on private grief at an inopportune time.

Once participants had responded, every attempt was made to be sensitive to their needs, thus they were consulted about and included in each stage of the research and publication process. Indeed, many of them attended the launch of the book (Grinyer, 2002a) to which their narrative data made such a substantial contribution and also took part in discussions and workshops surrounding this event. Though all spoke of the emotional demands of contributing to the research, most felt they had benefited from the process. Carverhill (2002) cites Gilbert’s work in bereavement research and suggests that the story telling approach to grief research helps to make meaning of our lives, and this appeared to be the case in this study.

This methodological approach clearly has considerable strength in terms of its ethical dimensions and is thus arguably the most appropriate way in which to approach bereaved parents. It also produces data of an extraordinary richness and depth allowing an insight into the experience that would be hard to achieve in

other ways. However, it must also be recognized that the method has limitations. It is based upon a small sub-sample of self-selected participants who spontaneously raised the subject of place of death while constructing narratives that asked them to reflect upon the cancer journey. The resulting data, while rich, are limited. But it was never the intention to generate a representative or generalizable sample; rather the aim was to reach an in-depth understanding of the lived experience of those who felt able to reflect upon it. Neither do we do know what significance place of death assumed amongst those parents in the primary sample who did not address the issue. We do not know if they were offered a choice or whether lack of provision limited the options. Nor do we know if some contributing parents felt unable to address the issue because they had feelings of guilt at not being able support a home death that would have been the preference of their son or daughter. Further research is clearly required to address these shortcomings and develop a fuller and statistically robust understanding.

The majority of accounts were articulate and expressed with skill and clarity. It would be tempting, therefore to make the assumption that the sample was limited to a particular stratum of society. This was however, not the case. The narratives were submitted in a variety of formats some word processed and grammatically correct, others were handwritten on lined paper and contained both grammatical and spelling errors. After some deliberation it was decided that such accounts should be 'tidied up' so that the authors should not feel that their published extracts were found wanting in comparison to the narrative accounts of others more at ease with the written form.

The motivation for participation is clearer in some instances than others—indeed some contributors were explicit about why they had responded. For example, some contributors had written contemporaneous journals or diaries throughout their son or daughter's illness, and to have a 'place' and a 'purpose' for these writings appeared to offer legitimacy and satisfaction to their authors. Others wrote specifically in response to the appeal and for these contributors the process, while acknowledged as painful, was in many cases commented on as having been therapeutic or cathartic. In the many follow up discussions with the participants it was clear that participation in the research—particularly in the knowledge that their material had been extensively quoted in a resulting book (Grinyer, 2002) had ③ represented 'closure' for them. Their stories existed in the wider world and would be read by, and perhaps serve to help, others to understand their experience and their pain.

The narrative data, consisting as it did of a range of styles and approaches to story telling, presented a challenge when it came to the process of analysis. The importance of rigour was recognized and a systematic data reduction, display and conclusion drawing method was used (Miles & Huberman, 1994). Miles and Huberman stress the importance of codification to facilitate the identification of themes and patterns, and warn against jumping to hasty or unfounded conclusions or the over weighting of particularly dramatic passages. Applying such a rigorous approach to data analysis should assist in managing text that is, as Miles and Huberman say, by its very nature poorly structured, dispersed and bulky.

Each of the extracts from the narratives is attributed to the contributing parent. All participants in this research project were, as a matter of course, offered anonymity which is standard practice and assumed by many codes of ethical practice (British Sociological Association, 2002; Grbich, 1999). However, before publication, participants' preferences were verified and surprisingly the majority of parents (75%) wished that they and their families be known by their real names. Thus, the resulting text is based on a mix of real names and pseudonyms according to the respondent's preference. This issue is discussed in detail in Grinyer (2002b)

The aim of the original research was to understand better the particular life stage effects on both the young adults and their family when cancer is diagnosed in young people between the age of 18–25. Information on place of death was not requested. It would have been inappropriate to suggest such a theme, as this would have carried an unfounded assumption that death was the inevitable outcome of cancer in this age group. Thus, the topic was not raised as an issue by all of the parents whose son or daughter had died—perhaps because we had asked parents to tell us about the cancer journey rather than its conclusion. Neither was place of death identified as necessarily being a 'life stage issue' by those parents who did raise the theme. In some cases, the parents mentioned the death of their son or daughter without specifying where this took place—an interesting omission in itself. Is this because 'place of death' was not central to the many distressing events that needed to be managed under such conditions? Might it be because it was too painful to address directly? Or was it simply not perceived as relevant to the issues under discussion? Helen, the Trust founder with Geoff, suggested that there are so many other, urgent, traumatic and pressing concerns to be faced during the illness that the actual place of death becomes a secondary issue. Of those 16 respondents who wrote about the death in their narratives; three did not specify where it occurred, two deaths took place in hospital, three in a hospice, and eight at home. Although the sub-sample of 13 parents who mentioned the place of death cannot claim to be statistically representative, it is interesting to note that a home death rate of two thirds in this group is considerably higher than would be expected from the UK place of cancer deaths statistics cited earlier. This may not however, indicate that home deaths are particularly desired, rather it may be that they are seen as some kind of ideal to which to aspire and are thus more likely to be commented upon. It may also be that where the material circumstances of the respondent's family were such that a home death could not be realized, the lack of resources to support a 'good death' at home would, as a result, not be addressed. However, the material resources of the respondents largely remain a matter of conjecture and it is with this lack of certainty of the wider context in which the narratives were written that we begin the analysis by presenting data on home deaths[1].

Home deaths

Before presenting extracts from the narrative data that addresses home deaths, it is important to emphasize the fact that the accounts—all written by mothers—reflect

the mothers' own retrospective interpretations. Additionally, it must be acknowledged that the fathers' accounts may have been different. As Riches & Dawson (2000: 48) say, the differing roles of mothers and fathers can lead to contradictory responses to loss and 'sometimes to conflicting ways of trying to make sense of it'. Thus we do not claim that the empirical material represents the views of their sons and daughters who have died, but rather is mediated by time and through a parental–maternal–lens after the event. Nevertheless, some parents do claim to be recounting their adult child's strong preference to die at home, a preference that their parents wholeheartedly supported. It is in this context that the quotes from parents must be situated. We are not privy to the wishes of the young people, only the interpretation of those wishes after the event.

The need to be surrounded by friends and family was an important theme in the narratives about deaths in home settings, for example in Iris' account of her son Matthew's death at the age of 21:

Mat finally gave up his fight on Saturday, 31 May 1997 at ten past one in the afternoon. The most wonderful memory I have of this day is that I had left him holding his brother's hand. Someone had made me a drink. The house was full of people. His friends had called round one by one wanting to say goodbye. No one ever expected this day to arrive. He had always beaten this disease—they all expected him to sit up and shout, "fooled you!" But he didn't. I was out of his room just drinking this drink, when my niece ran in and said "Mat wants you". He had been semi-conscious until then. I ran to his room, stroked his hair and asked, "What is it sweetheart, what do you want?" And he looked at me and smiled and his eyes rolled back and he was dead. It was over. It was as though he had to say one last goodbye to me.

(Iris)

That the house was full of people, drinks were being made and offered, and that Iris is able to use the word 'wonderful' all appear to be related to the fact that Mat died at home—though this is implicit in the quote rather than explicitly articulated. We assume that it was Mat's preference to die at home, but clearly it was of great significance to his mother.

A home death was clearly also of some importance to Michael, whose mother lists his four wishes as follows:

Michael was talking to . . . the social worker and he said he'd got four wishes:

1. *To be at home.*
2. *He wanted his mum and brother to be there.*
3. *To die in his sleep like his granddad did.*
4. *And to be buried with his granddad.*

He got all four wishes, they all came true for him.

(Elizabeth)

Here we see that dying at home was the first on Michael's list of wishes and that this was accompanied by a wish to be surrounded by his family—perceived to be more likely in a home setting. In addition, Michael expressed the wish to die in his sleep, again perhaps the perception is that with less interventions than might be the

case in a medical setting this too is a more likely possibility in a home death. Here we appear to know more about Michael's preference than his mother's and though the mothers speak on behalf of their lost children Gabrielle also documents her son Steve's earnest wish not only not to die in hospital but at to die at home:

You are moved to Ward 10 for the weekend. An awful experience, men dying of cancer, you hate it. "Please don't let me die in hospital mum" you beg me. . . As you felt your strength slipping away you made it clear again to your doctors that you wanted to die at home. You asked them to help you with extra sedation when it was all too much for you. You didn't want oxygen, tube feeding or more drugs. You didn't want to be resuscitated. You were afraid of ending up like the men you had seen in [the hospital], on oxygen, drips and heart monitors, dying publicly. You said that you had seen the fear and sometimes panic in their eyes. You didn't want to experience that fear. You had made all this quite clear. In the last two days you became too tired for lots of visitors, only three special friends, Warren, Steve and Chi. You will wanted to be clean, to smell nice. You asked me to wash your hair, to shave you. In control to the end.
(Gabrielle)

It is clear from this quote that Steve's experience of hospital had not been positive and that his wish to die at home may have been at least in part related to his fears of what a hospital death would entail. However, despite his experiences of hospice care being positive and contrasting starkly with his views of the hospital Steve's wish to die at home was still strong. Nevertheless, his mother, Gabrielle, speaks very positively about the sensitive and supportive care Steve experienced in his local hospice:

You go into [the] Hospice . . . to have your calcium levels corrected and to be rehydrated. You also need to get your drugs balanced. Stephanie Cooper has great faith in [the] palliative care doctor. She is lovely we all like her. She is very direct, very thorough and visits you a lot over the first few days to help get things under control. You don't find the hospice too bad. It is a big converted house. Your own room and bathroom, 1 – 1 nursing. A lovely garden, friends, relatives and dogs visit daily. They are very kind and really understand. They spend a lot of time talking and listening to you, letting you cry, letting you laugh. They help you come to terms with your need for total dependence. They help you to admit that you are dying.
(Gabrielle)

Yet, a home death is still the aspiration in spite of the obvious care and sensitivity demonstrated by the hospice staff. Lynn also documents the importance attached to being at home and in common with other mothers specifies the value of being surrounded by family and friends:

The District Nurses and Doc visited every day to refill and increase his morphine as the pain was still not easing and meanwhile Simon was still insisting on getting up and coming downstairs. It must have taken so much of his strength but he was always aware of others, not wanting to alarm us too much. He wanted to see as much of his family and friends as possible to say

goodbye . . . When he died, it was perfectly natural to have his body cremated and be able to bring him back home to his bedroom—I now know this is what he really wanted.

Our house was like a shrine with family and friends visiting to say their goodbyes to Simon, accepting little gifts as a memoir and hearing Simon's thoughts on his life and approaching death.
(Lynn)

This quote seems to suggest that not only was it of significance that home was the place of death, it was also important that Simon was brought home to rest in his bedroom after death. Lynn uses the word 'shrine' in relation to the space where friends and family could visit during the last stages of illness. Thus it may be that not only does the place of death matter at the time to the family and the dying, but it is also of immense significance after the death for those who may indeed regard the physical space where their loved one died as a kind of shrine. Other parents have talked of spaces in their home where the young person died that becomes their 'corner', lit with candles and adorned with flowers, the focus for memories on significant dates such as anniversaries. Should the young person have died outside the home, such spaces may be more difficult to create. After the death it becomes highly significant to the family (parents) that there is a place in the home that will always be remembered as the place where the fight for life was lost.

Jill's mother, Joyce, does not reflect on her own feelings about Jill having died at home, but rather on Jill's own wish to be at home and her own continuing pain since her daughter's death some years ago:

I gave up my full-time job, when Jill was diagnosed with cancer . . . I took indefinite leave, to nurse her at home. I found her pain level and kept her pain free with morphine. She was still alert, not frightened and happy to be at home. She became weaker and bedfast. I had to keep her propped up with lots of pillows because she was still haemorrhaging. Her breathing became laboured, it was difficult for her to swallow at the end.

One night after I had made her comfortable, she put her arm on my shoulder and whispered, "thank you for everything". I left her room and said to my husband "I am ready to let her go, she cannot carry on like this". She passed away in the early hours of that morning.
(Joyce)

In her book about her son's struggle with cancer, Grant (2002) emphasises the extreme importance of a home death (in Germany) for her and for her son, Alex (22), and its significance for his family. Yet as we see from the extract below, such an undertaking was discouraged by medical professionals. Once again, the theme that a home death allows the dying young adult to be surrounded by family and friends is paramount:

Alex said he wanted to come home to die with his family all around him, and we did just that, so there was time for the other members of the family to be with him and say goodbye . . . "Don't do it," said a doctor-friend when I told her I

wanted to bring my terminally ill son home. I'd no idea how exhausting and emotionally draining this caring business is, she warned. Honestly, I'd be much better off leaving him in hospital till the end, and anyway, I should think of myself and the rest of the family . . . So I thought of myself, of my son and the rest of the family. And I brought him home. There wasn't much more to consider. That he wouldn't have to die in hospital was a promise we made him when he was first diagnosed with cancer . . .

Once we were free of the hospital, the tension and pressure began to fall away . . . Because I could not make him well again I felt helpless. But being able to support him in his wish to die in the familiarity of his own home with his family around him was a great consolation . . . Our daily routine relaxed. He didn't want the dressing on his thin arm changed today? Fine. Let's do it tomorrow. Or not at all. It didn't matter any more . . . Instead we had lots of time to exchange memories, to be close together, undisturbed by the noise and inevitable hectic of a hospital ward . . .

Both of us—mother and father—camped on the living-room floor that final night. His brother and sister waited upstairs. So when the end came, we could hardly have asked for a more beautiful one. We were all with him and could let him go peacefully, gently and with great dignity.

Am I glad that I did it.

(Sue, in Grant 2002:1–4)

Here we are offered considerable insight into the process of death and what it entailed for it to take place at home. In the full version of this text, Alex's mother makes it clear that there were many practical problems to be overcome, yet it seems that the fact that she is able to use terms such as 'gently', and 'dignity' in relation to such a tragic event enabled her at least to feel that her son's death had been managed in the most positive way possible, and that this brought some measure of comfort as well as fulfilling Alex's wishes. In Sue Grant's experience, the family needed specialized equipment at home to manage the death, and a home care nurse from the hospital also supported them [2].

Hospice and hospital deaths

We now move on to consider deaths that took place away from home. While accounts of these are limited in number, they do offer some insight into the experience. A second mother named Helen, wrote in her account of her son's death in a hospice in London. Simon's death in this setting was associated with the fact that he was thousands of miles away from his family who lived in Australia. Simon had chosen to spend his final weeks of life travelling abroad with friends from university, thus a home death was not a possibility. He had issued his parents with specific instructions not to accompany him, thus risking the possibility that not only would he not die at home, neither would his family be with him at his life's end. Shortly before he died, his parents had begun to journey to Britain, but on a stopover in Singapore heard that he had died. The following account is of his parents' arrival at the hospice to see him after his death and his mother's feeling about his place of death:

He was very pale, composed-looking. They'd dressed him in his favourite black T-shirt and jeans. It was hard to get used to the dyed hair he'd had done just before he left. It was his last chance for a bit of teenage rebellion—black dye with purple highlights. (It sounds worse than it looked). The nurses said the purple came off on their hands . . . Perhaps I'm too attached to the hospice. But they continue to help me to grieve, and I feel I still need them. The chance to write this story came through the social worker at the hospice. The memory of Simon seems to live on there . . . The staff and Tyson and Peter did what I would have liked to do—they accompanied Simon through his dying. Simon was wise in going to London. These people weren't his parents, they loved him and cared for him as if they were.
(Helen)

This quote raises a number of issues. Despite Simon's death away from not only his home, but his home country, his mother recognized that the quality of the care he was given resembled that which she wished she could have given (whether or not this would have been in the family home we do not know). She comments on the sensitivity with which the staff had dressed Simon, respecting youth culture and the importance he attached to it. She also likens the care he was given with the love and care she would have offered had he died with her present. It is also significant that, since Simon died, his mother—despite living on the other side of the world—has continued her contact with the hospice where he died, and on her visits to London spends much time there. Thus, it seems that the need for contact with the place of death is of continuing importance to the bereaved—in this case rather than being a corner of the living room, it is a hospice room many thousands of miles away, yet its significance is comparable.

Susan's mother, Jean, also writes of her daughter's death in a hospice, in this instance accompanied by her family. Yet Jean does not reflect upon place of death in any specific way. Rather it is mentioned as a matter of fact in the wider account of the illness and its effects on the family.

10.30 a.m. we were called to [the hospice] . . . Dad put his hand on her (crying) and said "daddy's here". We, Mark, Lesley. Ian, his mum at the other side. . . they injected her at 4.30 p.m. they changed her nightie and sprayed her favourite perfume round (Lulu).

5.55 p.m. Susan opened her eyes and say "Bye" and died.
(Jean)

Moira focuses on the assistance given to her and her family to enable them to allow Alasdair to stay at home for as long as possible. Although Alasdair wanted to die at home, this, in the event, proved to be impossible, as he never left the hospice after his 'temporary' admission for pain control. Nevertheless, Moira feels that it was enough for him to know that she was willing to take him home:

We will always be grateful to the army of nurses who made it possible to keep Alasdair at home until he was taken to [the] Hospice . . . for pain control. It was only to be for a few days, but it proved impossible to get it controlled. Dr.

Sugden said a lot of it was mental agony. I had tried to get Alasdair to talk about how he felt, tried to get him to tell me what he was thinking, tried to drop gently hints about the way things were going, but he wouldn't "bite". I encouraged him to talk to the wonderful hospice staff, but he wouldn't or couldn't?

He went in on Wednesday 2nd June and never got out. On the Tuesday (8th) we were sent for because he had deteriorated. They put him on a syringe driver with morphine. He waited till his dad went away to fetch his wee brother before he finally asked "am I going to die?" Thank God! I got a chance to speak to him about it. His main concern was for his Gran, and his friends, how were we going to tell them? (They, of course knew, but I didn't let on). He wanted to die at home. I knew he wouldn't make it in the ambulance, but the hospice agreed to let him go home with their carer in situ. However, all Alasdair needed to know was that I was willing to take him home to die. He was to go home on Wednesday 9th but slept most of the day peacefully—he had totally relaxed. My husband and I spent his last day, 10th June, just talking to him. He knew we were there. We got the odd smile as we told him about escapades from his childhood. He died peacefully at 11.01 that night.
(Moir)

This account raises a number of important issues about admission to hospice or hospital for pain control or symptom management. While, according to his mother, Alasdair's wish was to die at home, the reason that this was not achieved was the attempt to control pain through admission to a hospice. However, if the family are prepared and willing for a home death, and that is the express wish of the patient, admission to hospice or hospital—even with the intention of it being temporary—can only serve to exacerbate the patient's condition. Thus, in many such instances the patient is, after admission, subsequently deemed not well enough to leave the hospice or hospital to be allowed to die at home. Yet 'what is well enough?' It seems to be a contradiction in terms that a person is too ill to be allowed to die in their preferred setting. What is the worst that could happen? Indeed, as we saw in Sue Grant's (2002) reflections on her son Alex's death at home, if they decided not to change the dressing on his arm—'it didn't matter any more'. It was clearly the quality of the last days that was of paramount importance, even if being at home shortened the time left.

Having looked at admittedly very limited examples of death in a hospice, we now turn to the two deaths that took place in hospital. Again the accounts covering such deaths are extremely limited in number, however they do appear to contribute in a small way to the debate on a home death necessarily being the 'best' death and are offered as a contrast to the assumption that a home death is the ideal to which to aspire. In the two instances cited here we see that one death in hospital was valued by the mother for being suffused with 'love and joy', the other was a necessity for the parents, who for personal reasons felt unable to support a home death. What is also notable about these cases is that we are given no information by the parents on whether this was their adult child's preferred location, nor on whether other place of death options were available; but both parents appear satisfied with this place of death outcome. Carol tells us of her daughter Sara's death in hospital as follows:

We stayed with Sarah night and day. The previous week we had gone home at night since we lived close to the hospital. One evening we went to leave as usual, but I stayed outside Sarah's door and watched as the brightness' in her face dimmed and a curtain of despair came down: a tear slid down her cheek, and then I knew I had to stay beside her until the end . . . We enveloped her in love during those last weeks. I know she was worried about me, how I would be, how I would cope—even in the midst of her own approaching death, she was concerned about me. We filled her room with flowers and love; we brought in our dog and her cat, Magic, from home. There was laughter, there were tears. I have a faith of sorts, but I also believe in some of the Buddhist ways. Death is part of life and I wanted her to die with love and joy in that small, sunny room. (Carol)

Carol uses the words 'love' and 'joy' in relationship to Sara's death, and remembers fondly the 'sunny' hospital room. There is no comment that indicates regret that the death did not take place at home. The fact that the family pets were brought to the hospital suggests that staff in this particular institution were keen to accommodate the wishes of Sara and her family, and could allow her to be surrounded with the loved and familiar as much as possible. It is interesting to contrast the positive account of this hospital death—surrounded by friends, family and pets—with the assumptions made by other parents that home would be the only environment in which such a death could occur.

The other young adult who died in hospital was Chris, the son of two doctors. Chris' mother, Anne, reflects on the difficulty of managing both visits to the hospital—a significant distance from the family home—and on the limited provision of personal care through lack of satisfactory staffing levels:

Most of his treatment was . . . in London, a good three-hour journey from our home. We travelled to and from the hospital several times a week often together, too often alone. One parent with Chris, the other at home trying to keep life normal for our 11 year old. For me personally as his mother, the pain of watching your child suffer physically, mentally and emotionally is torture. His death was a relief to us all after watching him suffer so much. For so long the image of his last days fighting for breath will always be with me.

One of the problems for onlookers is the feeling of helplessness. I was able to buy him comfort, foods he fancied, etc, but the most difficult thing was his fundamental care. When I was with him I could perhaps persuade him to eat but I couldn't help him to shower without the loss of any small dignity he had left. The nursing staff were wonderfully supportive, hi-tech skilled people, but there was no time for what used to be basic nursing care, really looking after the personal needs of a patient. I helped as best I could when I was with him, but he hated it, and I knew it. (Anne)

There is no indication here that, despite the pain of watching her son die, Anne wished that this could have taken place in her home—or indeed in a hospice. It may even be that given the resistance both Anne and Chris appear to have had to her giving him personal care, a home death would have been even more problematic for them. It might be tempting to jump to the conclusion that parents

who are medically qualified are in a better position to offer the care and support required by a home death. However, despite Anne and her husband both being medically trained and qualified, it did not follow that a home death would have been preferable to either Chris or his parents, even though his parents were clearly stressed by travelling to the hospital. Thus it seems that the factors that contribute place of death preference and outcome are complex and unpredictable.

Discussion

What can be learnt about the significance of place of death from these parental accounts of young adults dying of cancer? A death at home is reported as the clear and strongly held preference of the majority of the young adults. Two-thirds of the 13 young adults whose stories are told here were able to die at home, and one wished to do so but died in a hospice. For those that died at home, the parents present this outcome as being of critical importance to both themselves and their dying son or daughter. Some families went to considerable lengths to achieve a home death. Home deaths were believed to maximize the opportunity for the young adult to be surrounded by family and friends, and to be in a calm and familiar setting. Farewells could be expressed and comforts attended to. For some parents, the room in which the death occurred could become a private and almost sacred memorial site, one that they could adorn with flowers and mementos as they saw fit. They present this as assisting in the grieving process.

In combination, these observations suggest that young adults with terminal cancer are more likely than other age groups both to wish for and to achieve a supported death in a home setting. First, the parents' accounts suggest strongly that a young adult can usually take it for granted that the parental home will always 'be there for me'—dying at home with the support of 'mum and dad' seems normal and natural to all concerned. Second, as noted earlier, young adults' rather alienating experience of spending time on hospital wards with either children or much older adults is likely to contribute to a desire to die at home. Third, parents are usually highly motivated to enable the death to occur at home if that is their adult child's preference; they will go to considerable lengths to meet their son or daughter's last wishes. Fourth, the parents, being relatively young themselves, are likely to have the physical and emotional capacity to care at home, and are motivated to put pressure on the health care services to provide the support required to make this possible.

These factors mean that young adult patients score highly on the key predictors of home deaths as reported in the literature: having informal carer support, having a carer who has the capacity to care, and the presence of a strong and visible patient and carer preference for a home death (Addington-Hall & McCartney, 1995; Grande *et al.*, 1999; Higginson *et al.*, 1999). Thus, life-stage factors do appear to play a role in determining both preference for, and the actual achievement of, a death at home.

However, in four of the five accounts of parents whose son or daughter died in hospital or hospice, there is no apparent expression of regret that the death did not

take place at home. For parents in this group, the place of death appears to be of less significance than other features determining the quality of their adult child's care and death. Indeed, in one instance, positive terms were used to describe features of a death in hospital. In this case, it is evident that staff in the hospital concerned went to considerable lengths to acknowledge and make allowances for the life-stage of the young adult, not least in attempting to make the environment as 'homely' as possible. Reproducing 'normality' was aspired to in this setting, with a policy of open access to and inclusion of friends and family, even pets, and through respect for sartorial preferences. Such relatively small details assumed enormous significance for the parents at a time of great distress. In the other case involving a hospital death, it seems that end of life care at home would have exacerbated worries over the problems of providing intimate personal care for, and sustaining the dignity of, the young adult concerned. This reminds us that it cannot be assumed that the nature of the relationship between parent and adult child is such that the latter can comfortably slip back into childhood dependency in the parental home in the face of a life-threatening illness. It is also the case that the physical location of the death remains important to parents. However, where this is not situated within the family home, it can nevertheless be a place that continues to hold significance and become a focus for visits and memories, even if it is on the other side of the world. These narratives describing death in places other than home signal that home may not always be the preferred or 'best' place to die.

Conclusion

This paper has suggested that place of death is of significance to many young adults with cancer and their parents, and that deaths at home may be both preferred and achieved at this life-stage (18–25 years). It has presented data indicating that the desire for a home death is frequently perceived as strong by the parents of these young people, and is thus supported by them when this is socially and materially feasible. There appear to be life-stage factors in operation that make a home death more probable in this age group than among cancer patients in general. The parents of the young people are likely to be of an age and life stage themselves where their social and physical resources are greater than those of elderly people caring for a husband or wife with cancer. But it must be appreciated that a home death is not always the preferred or 'best' option. For some young adults and their parents, a hospice or hospital may be perfectly acceptable, or preferred, as a place in which to die. This indicates that palliative care professionals should be sensitive and alert to the dynamics in play in the familiar relationships involved so that they can respond appropriately, and support place of death options that best fit preference and need.

The parental accounts indicate strongly that a death handled with sensitivity, in whatever setting, supporting both the patient's and the family's preference and maintaining respect for the dying person's individuality, can be of great comfort. In the case of young adults, that individuality may prove challenging and demanding, but perhaps at this life stage, when other identities are fragile, it is of

even greater importance that connections to the young person's desires are sustained through the dying process.

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Notes

- [1] A supplementary source of data arises from an interview that AG conducted with Mary Baines in 2002 on the theme of place of death. Dr Baines, is one of the pioneers of the hospice movement in England in the late 1960s. The conversational style interview took place in association with her visit to Lancaster University.
- [2] The importance of such support is crucial and arose as a theme in the in-depth interview with Dr Mary Baines. She confirmed that in her extensive experience, most cancer patients, at whatever age, prefer to die at home but that only 50% have their wishes fulfilled. According to Baines, this is, in part, because many women over the age of 65 live alone; thus, there is no one to care for them. Even those who do not live alone may live with an elderly spouse who cannot manage the death at home. However, when addressing the possibility of death at home for young adults, not only did Baines believe this to be of even greater importance—in a bid to retain as much normality as possible and to allow for maximum interaction with friends—she also said that it was frequently an increased possibility in this age group as young adults were likely to have parents of an age and ability to provide the necessary support in the home setting. As one of the founders of the hospice movement, Baines' emphasis on the desirability of home death might at first sight appear to be contradictory, yet the concept of hospice is, for Baines, one that extends beyond a physical building and should, according to her philosophy of hospice care, be extended into the community. Thus, her belief is that the hospice movement should have much to offer young adults through specialist palliative care provided in the home. Indeed, she went so far as to say that specialist hospices for young adults should not be a priority, rather that any resources should be channeled into care at home.

In Baines' experience, a good home death frequently helped with the grieving process. However, she recognised that not all families would be able to manage a home death, and if that were the case they should never be made to feel that they had failed. She also observed that the stereotypical expectation that higher socio-economic status was related in a positive way to the ability to manage a home death was not necessarily the case. It was not the conditions or facilities available in the home that were of prime importance; rather, support within a community and the presence of an extended family. This, in her experience, was frequently associated with lower, rather than higher socio-economic status.

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