

# **'I've no fear of dying alone': Exploring perspectives on living and dying alone**

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## **Abstract**

Dying alone is portrayed as undesirable in terms of policy, health and social care provision, the wishes of family and friends, and in popular culture. Despite this, people do often die alone, both in institutional and domestic settings. This paper reports findings from a study which explored ways of investigating individuals' perspectives on dying alone at home. It tested methods of recruitment and data collection, gathered preliminary data and explored the ethical issues involved. Interviews with 11 older people living alone and seven hospice at home nurses are reported here. For the older people, the idea of dying alone was less problematic than the idea of needing care and support from others, and the perceived loss of independence that this would entail. Participants reacted in differing ways to threats to their independence, but all utilised a form of relational reflexivity when considering the effect their actions might have on others. The nurses would prefer no one to die alone, but believed they had seen patients managing their own dying so that they could be alone at the moment of death. The paper suggests that dying alone may be a problem for survivors, rather than for the person who is dying.

**Key words:** choice; dying alone; hospice at home; independence; living alone; relational reflexivity.

## **Introduction**

Worldwide the number of single person households is increasing and, in northern Europe, almost half of households have only one person living in them (Jamieson and Simpson, 2013). In the United Kingdom (UK) figures published by the Office for National Statistics (ONS) indicate that 28% of households are occupied by a person living alone (ONS, 2015a), representing 7.6 million people (ONS, 2015b).

Living alone brings with it an assumption that the individual desires and values their independence and that they act as autonomous agents (Hague, 2011; Portacolone, 2013). However, this assumption may be overly simplistic, as agency and autonomy are not straightforward concepts. Agency encompasses a notion of acting on the world in order to generate some desired effect, but this cannot be done in isolation from other people and without acting in association with others, at least on some occasions (Burkitt, 2016). In addition, while autonomy is often understood as suggesting freedom of choice and self-determination, it is not generally the case that individuals make decisions in isolation; autonomy can be constrained and promoted by the actions of others (Collopy, 1988; Hague, 2011). Thus, while it may be assumed that an individual who lives alone is independent and acts autonomously, it is also the case that they do not act in isolation from others and their decisions and actions reference others, as well as being enabled and constrained by them; people live interdependently (Burkitt, 2016; Elias, 1978).

Although living alone has become more common, dying alone continues to be portrayed as undesirable, creating the perception that when someone does die alone, their death may be termed a failure of 'emotional accompaniment' (Seale, 1995, p. 378). English healthcare policy promotes the idea of choice for dying

adults, in the belief that the exercise of choice with regard to aspects of care will enable individuals to have a good death (Department of Health, 2008; Choice in End of Life Care Programme Board, 2015). Such choice is assumed to include dying while surrounded by family and friends (Department of Health, 2008), yet what counts as a good death is subject to an ongoing debate which is predominantly framed within a healthcare context (Hart et al., 1998). In healthcare research the impact of different aspects of care on views about the good death are reported as varying within and between groups such as people who are dying, their families and friends, and the professionals who are providing care for them. For example, quality of life in terms of maintaining hope or the feeling that life is worth living is of greater importance to family members than it is to the dying person or healthcare professionals (Meier et al., 2016).

Healthcare practitioners working in different social contexts, and particularly nurses who provide much of the professional care for dying people, are reported to believe that no one should die alone (Field, 1984; Fridh et al., 2009; Gunther and Thomas, 2006; Hadders et al., 2014; Izumi, 2006; James et al., 2010).

Families are described as making strenuous efforts to maintain a vigil when one of their members is dying (Bradbury, 1999; Donnelly and Battley, 2010; Gould, 2012; Kastenbaum, 2000; McNamara, 2001; Porock et al., 2009). Popular culture also portrays dying alone as something which should not happen, with examples easily found, from fiction on television and in books, through to documentaries broadcast on radio and television, and idealised newspaper accounts of deaths.<sup>1</sup>

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<sup>1</sup> See for example 'The Time of the Doctor', broadcast 25 December 2013, BBC1 <http://www.imdb.com/title/tt2986512/> Stephen Booth, (2003) 'Blind to the bones', Harper Collins, page 159; Sue Grafton, (2014) 'Wasted', Pan Books, pages 270-271; 'My Last Summer', episode 4, broadcast 25 June 2014, Channel 4

In spite of the negative connotations attached to dying alone it has been suggested that some individuals exercise agency in relation to their own deaths, which results in them being alone as they are dying (Caswell & O'Connor, 2015; Howse, 1997; Kellehear, 2009; Seale, 2004), or in taking control over the timing of their death (Hardwig, 2009; Heinrich et al., 2011). For some people, the risk of living too long and dying too late is real; they feel that their life is complete and they wish for it to end. Such an individual is most likely to be an older person who has neither a terminal illness nor a serious psychiatric illness (van Wijngaarden et al., 2015). While many in this situation believe that suicide is wrong and do not take steps towards hastening the end of their life, the feeling of life's completion may also lead to pre-emptive suicide or assisted suicide (Hardwig, 2009; Heinrich et al., 2011; van Wijngaarden et al., 2015).

Despite its perceived undesirability, it is possible for a person to die alone in any setting, including hospitals and care homes (Gelo, 2004; Page and Komaromy, 2005). However, dying alone at home has a particular resonance, and represents '...a powerful symbol of social abandonment and failure' (Klinenberg, 2001, p. 503), for home is supposed to be a place of safety and family life (Collier et al., 2015). When the body of an individual who has died alone at home is undiscovered for an extended period of time there are likely to be negative inferences made, particularly in the media, focusing on supposed character flaws of the person who died and on perceived failings of the local community and wider society (Bradshaw et al., 1978; Howse, 1997; Seale, 2004).

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<http://www.channel4.com/programmes/my-last-summer/on-demand/54645-004> 'Lives in a Landscape', series 17, episode 2, broadcast 29 August 2014, BBC Radio 4  
<http://www.bbc.co.uk/programmes/b04fchlm> Lea, R. and Davies, C. (2015) 'Terry took Death's arm and followed through the doors', *The Guardian*, 13 March 2015, page 2

Research that prioritises the perspectives of people who live alone with regard to their choices about dying and their preferences for end of life care is limited (Aoun et al., 2013; Rolls et al., 2010). There is evidence to suggest that the idea of dying alone at home is a frightening possibility for some individuals (Gott et al., 2004), which leads to some people taking steps to guard against their body being undiscovered for a long time, should they die alone. For example, some research participants have described arranging for a neighbour to call regularly, or having milk delivered to the house in the belief that help would be summoned if they did not answer the door or take in the milk bottles (Lloyd-Williams et al., 2007).

This paper draws on findings from a small-scale study exploring perspectives on dying alone to suggest that people's views on dying alone are much more nuanced than might be thought from its portrayal in the literature. While people may die alone in any setting (Gelo, 2004; Page and Komaromy, 2005) the choice was made to interview people living alone as they are more likely to die alone at home than those who share accommodation and they are also more likely to have considered the possibility that they may die alone. Eleven older people living alone were interviewed about their perspectives on their future care needs as they came towards the end of their lives. Independence was important to them and death was not the biggest threat that they perceived. The idea of dying alone was not problematic for them and could even, in some circumstances, be preferable. Seven hospice at home nurses were also interviewed. They expressed the view that no one should die alone, but acknowledged that patients sometimes died in a way that suggested they would prefer to be alone. The paper begins by describing the study and then moves on

to discuss the findings in more detail, before drawing some tentative conclusions.

### **Study aims and objectives**

The aim of the study was to assess the feasibility of conducting a full scale research project exploring individuals' perspectives on dying alone and how this might best be approached. The study objectives were designed to fulfil this aim in four ways. First, the intention was to explore the most appropriate ways of gathering data about individuals' perspectives on the issue of dying alone at home. The second objective was to test possible recruitment strategies and the third was to gather some preliminary data. The final study objective was to explore the ethical issues involved in carrying out research in this sensitive field. The aim of this paper is to present the preliminary data, drawing on findings from interviews conducted with people living alone and with hospice at home nurses.

### **Methods**

Researching individuals' views on the possibility of dying alone at home involves engaging with issues that are both sensitive and ethically challenging (Wiles, 2013), and it also appeared possible that recruiting participants for such a study could be difficult both in terms of identifying potential participants and reaching out to them (Marpsata and Razafindratsimab, 2010). Conducting a pilot study prior to a full-scale study would allow the testing of different recruitment methods and also permit participants to express their views about the

acceptability of carrying out such interviews. Generating some preliminary data on the topic was also part of the rationale for conducting a pilot study, to discover whether this was an issue in the real world where people live their lives, or just a topic of academic debate (van Teijlingen and Hundley, 2001).

There were two separate strands to the study. In the first the sociological autopsy was used as a way of examining deaths of people who lived alone and whose bodies were found later. This methodology involves an ethnographic approach to the study of coroner records, thus utilising the records as both sources of information and objects of research (Fincham et al., 2011). This strand of the study has been reported elsewhere (Caswell & O'Connor, 2015). The second strand involved conducting semi-structured interviews with older people who lived alone. A focus group and a joint interview were also carried out with nurses working in a hospice at home service whose caseloads included people who lived alone.

During the process of developing the proposal the research was discussed with the Patient and Public Involvement (PPI) group which works with the research centre in which the researchers are based (INVOLVE, 2015). PPI members were active in helping the researchers shape the project, particularly in terms of what to ask, how to ask it and how to find participants. Two PPI members became part of the project's advisory group. Ethical approval was obtained from the University's Faculty Research Ethics Committee.

The study was presented to potential participants as being about 'Exploring views about independence and care towards the end of life for people who live alone'. Older people were recruited by advertising in a number of different places, including the local branches of Age UK and the University of the Third



Age (U3A) and also in a community newsletter that is delivered free of charge to homes in one postcode area. Recruiting in this way was intended to allow individuals to decide whether or not they were interested in being involved in such a study and, if they were, to make the first approach to the research team.

Nurses were recruited through a clinical service manager at the hospice for which they worked. Information about the study was distributed to those whose work was community based and they were invited to come along and meet the researcher. The participation of hospice at home nurses was sought because they provide care for people who are dying at home and are therefore likely to have experience of caring for people who live alone and opinions about the desirability of people dying alone at home.

Interviews were carried out by the authors of the paper and, with participants' permission, were audio recorded. Recordings were transcribed and the analysis was carried out using the constant comparative method, beginning with a process of initial coding before moving on to more focused coding (Charmaz, 2006). The analysis was carried out using Nvivo as a means of managing the data, and with the aim of grounding the findings in the data.

## **Findings**

### ***Acceptability of interviews***

At the end of the interviews with older people the researcher asked each participant for permission to contact them a few days' later to discuss their views on the interview process. The aim of this discussion was to find out how

the participant had experienced the interview and whether, on reflection, they felt that it was acceptable to carry out the research in this particular manner.

Six participants offered feedback on the interview process, either during a phone conversation or by email. They told us that they came forward for the study partly because they found this an interesting topic which was relevant to them and partly because they wanted to help. Participants felt that the research was worth doing and they were pleased to have taken part in it, despite the challenging nature of the topic. One participant wrote in her email:

I was surprised how I felt afterwards and was grateful I felt I could phone you and talk it through... I am pleased I took part in the interview not only because it was interesting but because it made me face up to reality. There is nothing wrong with being disturbed but also perhaps a little prepared.

Feedback was thus largely positive, although highlighted the need for awareness on the part of researchers of the potential effects of such a discussion for participants. Being available for follow-up discussions and finding ways to ensure appropriate support is available, if needed, are key reminders for future work.

### ***Participants***

Eleven older adults who lived alone, eight women and three men, took part in interviews and their characteristics are shown in Table 1 below. Seven nurses took part in the research, five in a focus group discussion, and two nurses were interviewed together on a separate occasion. Table 2 shows the professional roles of the nurses.

Table 1: Participant characteristics

Name	Status	Age	Time living alone (years)	Thought about dying alone?
Fiona Gough	Widowed	79	5	Yes
Andrea Taylor	Widowed	71	5	No
Rosalind Norton	Divorced	66	10	Yes
Emily Watkins	Divorced	70	15	Yes
Grace Hughes	Widowed	67	30	Yes
Jackie Spencer	Widowed	67	15	Yes
Freda Braithwaite	Divorced	72	12	No
Alison Slocock	Divorced	69	10	Yes
Archie Sutton	Widowed	79	7	Yes
Michael Carr	Divorced	64	31	Yes
David Keating	Widowed	83	1.5	Yes

Table 2: Nursing roles

Name	Role	Interview or focus group
Brenda	Deputy team leader	Focus group
Shona	Staff nurse	Focus group
James	Staff nurse	Focus group
Vera	Healthcare worker	Focus group
Karen	Healthcare worker	Focus group
Jenny	Staff nurse	Interview
Paula	Staff nurse	Interview

### **Older people living alone**

Participants had a number of characteristics in common. They all had family and all but one had adult children, although the level of contact with family members varied. Another common factor was that while all had retired from paid work, they were active outside their homes. They undertook voluntary work, took part in social activities either with friends, family or with organisations such as Age

UK, they provided support for family members or took part in sporting activities. Despite their activities outside the home, however, it was still the case that research participants spent most of their time alone at home. They all valued their independence, which they tended to equate with living alone. Rosalind, for example, said: 'my aunt once said it's very liberating, living on your own, and...I found it was.'

### ***Threats to independence***

Participants were aware that their independence could be threatened, and all had given some thought to this possibility. Death was not seen as the greatest threat, rather the loss of independence through illness or infirmity was perceived as something which could, in the future, cause the individual to be unable to maintain their independent living. Participant responses to this threat could be broadly categorised in two ways. The first group, comprised of seven participants, viewed this possibility as something that would be outside their control and they would handle this with differing degrees of pragmatism. The second group of four participants reacted to the idea of such threats by suggesting steps they might take to try and take control of the situation.

### ***Pragmatism***

David felt that, if he should need care: 'I would like to be looked after at home.' However, David went on to say: 'And some people have to go into a home... They need 24/7 care, don't they?...If it was very serious I'd have to go into a home. No question.'

David's perspective was influenced by his experience of caring for his wife when she was dying. He had looked after her at home, but in his view the health and social care services were inadequate, and left his wife and himself poorly supported. This left him with the opinion that it is impossible for someone to be cared for properly at home when they are dying, or needing full-time care.

When Andrea was taken ill with a suspected stroke she said that her family, 'just pulled together' to support her. She went on to say: 'I have got family support if I need it. However, should I have something like a stroke or cancer or, heaven forbid, dementia, they'd have to find a home for me. If I couldn't manage on my own.' In reflecting on this Andrea drew on her personal experience of caring for her widowed mother in the later years of her life. Andrea found this an exhausting and dispiriting experience and did not wish to make such demands of her own children.

Rosalind's opinion was that while moving into a care home may seem a dreadful thing she would, if it should happen, probably adapt quickly to the new environment and find there the social contact she needs. Rosalind said:

Human nature is incredible, isn't it? You get used to things very quickly. Even the most awful things you can get used to quite quickly, and, and you can make the best of it. I think it's completely up to you if, you know, you can make the best of a situation.

### *Wresting control*

Four participants responded differently to the idea of threats to their independence, talking instead about ways in which they could take control of the situation. One night Archie had been unable to sleep and had felt so ill he thought he might die. He did not summon help, but lay down on the sofa: 'that night, I was thinking then, I'm going to die sometime.' Since that experience the thought of his own death has ceased to worry Archie, but he is worried at the thought of needing full-time care. Archie said:

I don't want to go into a care home. Take a couple of tablets or something. That's the way, I think. You hear too many things, don't you, about care homes...I don't want my family to look after me, either.

Grace, Emily and Michael had also considered how they might respond to threats to their independence. Grace thought she might join Dignitas, the Swiss organisation which supports people with a terminal illness or an unendurable disability to end their lives.<sup>2</sup> Grace had a friend who had suffered with severe arthritis and he had become a member of Dignitas with the intention of going to Switzerland to die. In the end he had died at home but, Grace said, 'the last two years of his life were awful'. Through witnessing her friend's life as he was dying Grace had come to realise that:

There's a quality of life, not a quantity, you know...I don't want to hang on...so if it was something like that (that my friend

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<sup>2</sup> Information about Dignitas may be found on their website here: [http://www.dignitas.ch/index.php?option=com\\_content&view=article&id=20&lang=en](http://www.dignitas.ch/index.php?option=com_content&view=article&id=20&lang=en)

had), if I ended with something like that, I'd be looking to doing something, you know, ending my life that way.

Michael also expressed the view that assisted suicide may be a good thing for some people in some situations, although he was cautious in his approach. Assisted suicide is illegal in the United Kingdom and Michael did not directly suggest that he would seek such support for himself. He did, however, suggest that such support might be a good thing, saying:

I'm a big believer in, you know, if you've decided, you know, you've had enough of life, then you know, some kind of help wouldn't be a bad thing. I'm a big believer in that...I think (assisted suicide) should be far more in the open and recognised and accepted.

Michael was unsure how he might handle the situation should he find himself in need of constant care, but believed that 'people should be given power over their own destiny kind of thing, shouldn't they?'<sup>3</sup>

Emily had the most closely thought-out plan. She had a neurological condition and had almost died a few years previously, about which she said, 'I sometimes wonder if that might not have been the best thing (if I had died)'. She particularly enjoyed the peace and quiet of living alone and dreaded the idea of being trapped in a care home where 'you're not seen as individuals'. Emily said:

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<sup>3</sup> Information about the legal position with regard to assisted suicide in the UK can be found on the NHS website here:

<http://www.nhs.uk/conditions/Euthanasiaandassistedsuicide/Pages/Introduction.aspx>

One set of arguments put forward by a pro-assisted suicide organisation can be found here: <http://www.dignityindying.org.uk/assisted-dying/lord-falconers-assisted-dying-bill/>

One set of arguments against assisted suicide can be found here:

<http://www.carenotkilling.org.uk/about/>

I would rather die than go into a care home. And I have a plan. And it's always as well to have a plan. You don't have to stick to it but I know what I would do...I've got some sleeping pills and I've got some (pills), this name I've forgotten...Plan B would be just not to eat but it would be a long death...it's one of those things that when it comes to it, you don't know if you will. But it's quite nice to have your insurance policy.

Emily's plan was well thought out and the idea of moving into a care home was anathema to her. However, she also had two adult children and she was worried about the effect on them if she should kill herself but, as Emily said, 'you can't control how people are going to feel'.

### ***Dying alone at home***

All except two participants had thought prior to the interview about the possibility that they might die alone at home. Andrea said she had 'never thought about it' and moved the conversation on to talk about the phone and panic button beside her bed. She was comfortable talking about the possibility that she might become incapacitated in some way and thus need care and support, but not about the possibility of dying alone at home. Freda thought that most people would want to 'just go to bed and just don't wake up', but did not relate this idea specifically to herself.

The other nine participants, however, had thought about this issue and had views on its desirability for themselves. Broadly speaking, a sudden death at home was considered to be a good thing, as there would be minimal suffering



and the participant would know nothing about it afterwards, because they would be dead. Fiona did not mind the idea of dying alone at home, saying, 'Well, if I died in bed, I wouldn't mind...I've no fear of dying alone.' While some people might think such a death a bad one because there was no time to say goodbye Fiona did not agree with that view. Her husband had died after a long illness and they had both known that he was dying but they had never spoken about it: 'we never said cheerio to each other, because I was too emotional' (Fiona).

The belief that it would be a good thing to die suddenly at home was shared amongst this group of participants, even although that meant being alone. Archie said, 'I just go to sleep in the chair, and that's it, I wake up and I'm dead, that's it.' He went on to say that there is no point worrying about it because 'once you're dead, you're dead', and you will know nothing about it.

Despite the desirability of dying suddenly alone at home, there were a number of apparent contradictions to be found within participants' responses. Fiona, for example, liked the idea of a quick pain free death, but after saying she had no fear of dying alone she went on to say, 'my worst fear is just being found by (my daughter)'. Fiona saw her daughter on a regular basis and the likelihood was that her daughter would find her body if she died at home. The effect that such a discovery would have on her daughter worried Fiona.

For some participants the possibility of their body not being found for a while was troublesome. Jackie expressed a preference for a quick death but had reservations about the length of time it might take for her body to be discovered. Jackie said:

The way my husband went is the way I'd like to go, suddenly,  
yeah...when you hear tales of people not being found for months

on end...It's like nobody cared to look...that would be a bit distressing...if it was just like three days, that would be, yeah, I wouldn't mind that.

Jackie's response to this worry was to have milk delivered to the door, saying 'the milkman would see that there was milk there and know that there was something wrong...that's my insurance policy'.

David, Grace and Archie all thought that their neighbours would notice if they were not going about their usual business and that their neighbours would investigate. Grace was a familiar figure in her neighbourhood as she was often out jogging, and she believed that her next door neighbour would notice and take action if her curtains were not drawn back. David and Archie both lived in neighbourhoods where people kept an eye on each other. David said:

It's happened on a couple of occasions, when I've decided not to get up in the morning. You know, I thought I'd have a lie in. You can't have a lie in round here, they come knocking on your door. Are you all right David?...I'm under surveillance, which is fine...you need nosey neighbours.

Not all neighbourhoods were like this, however. Rosalind usually said hello to her neighbours when she saw them on the street, but did not think anyone would notice if they did not see her for a long time. She said, 'It would probably be quite a while before anyone knew anything had happened'. Both Michael and Emily thought that they could lie dead for a week or two before their bodies were found, but they did not see this as a problem.

## **Hospice at home nurses**

The nurses who took part in the study were of the opinion that people should be accompanied when they are dying, although that is not always what happens in their experience. The possibility that someone may prefer to be alone when dying was not something that they had ever discussed before. James, who had completed his nurse training only a few months prior to taking part in the study, said 'I don't think it's ever come up in any of my training, that actual question, should someone be alone or with someone when they die?' The hospice at home nurses worked with patients considered to be in the last 12 to 16 weeks of their lives, and their role included the provision of support and care for people to die at home if that was what they wanted. Generally speaking, for someone to be enabled to die at home it was necessary for them to have family and friends who could look after them when the professionals were not present. It was particularly problematic when the dying person lived alone, because 'there's more safety issues if there's not someone living there with them' (James). Such issues included matters of security and access to the home for professionals when the patient may be unable to come to the door, and also issues such as the risk of falls or loneliness for the person living alone.

A big risk the nurses perceived was that the person would die alone for, as Brenda said, 'I don't like the thought, I don't think anyone should be alone to die.' The resources were not available to provide workers to spend 24 hours a day with a person who lived alone, although: 'Normally you've got a good indication that someone's deteriorating so, by the point of nearly dying, they probably have someone with them, because we get, like, night-sits in' (James). Often patients 'come to realise that they cannot manage at home' (Karen) and

will be admitted to a care home for their last days of life. On other occasions family members who have moved away will return to provide the necessary care. Despite this, however, the nurses had all worked with patients who had died alone at home.

The nurses believed that, provided they had the capacity to make a decision, it was for the patients who lived alone to decide whether they wished to stay at home when they were dying; as Jenny said 'at the end of the day it's their choice. We do our best to support them'. It was important to the nurses that they should do their best to ensure that a dying person who lived alone understood the risks involved, including the risk of dying alone. They worried about their patients' vulnerability when they were on their own and about what could happen to them, but despite this Jenny thought 'being on your own is achievable.'

Paula echoed Brenda's thought that no one should be alone when they are dying, but went on to reflect: 'whether that would be for me or the patient.'

Jenny described an experience that all the nurses were able to recognise:

Working years ago in the in-patient unit where there can be families around the bed, we've probably called them in actually, saying we think that it's imminent, and, family have been there quite a long time, and they've just gone off to have a cup of tea and the patient will die. And some patients do just want to be on their own. So, to be on their own is probably what that person wanted.

Shona suggested that people who are dying may have a measure of control over the moment at which death occurs: 'I think people just choose when they want

to go, if they want to go by themselves, I think, I don't really think we have a say in it. I think it's the person that's dying has that decision.'

## **Discussion**

The people living alone who took part in this pilot study were a heterogeneous group of people, with diverse interests and backgrounds, but they had three things in common in addition to the fact that they lived alone: they all had family with whom they had differing levels of contact, they were all active in the world outside their homes and they had all at one time lived with others as adults. None of them, in other words, lived as individuals isolated from wider society (Kellehear, 2009).

Participants spoke about their mediated experience (Giddens, 1991), and how the later years and deaths of family members and friends had helped to form their own views; they did not only experience bereavement on the loss of the person about whom they cared, but they also experienced the process of that individual's dying. How they interpreted that experience had an impact on the ways in which they thought about their own future deaths and the processes involved in dying.

All participants stated that they liked their independence and liked being alone for the freedoms it gave them. This does not necessarily mean that they would have chosen to live alone; Michael and Emily were the only participants who said that living alone was a better experience for them than living with their spouses or partners. However, all participants had created new identities, whether post-

bereavement or post-divorce, as people who valued their independence and liked living alone (Garthwaite, 2015; Giddens, 1991).

Most of the participants' social contacts took place outside their homes, so they needed to be able to go out in order to maintain this contact and their independence. A situation where participants would be unable to take an active part in the outside world thus represented a serious threat to the individuals' sense of independence, however the inability came about. How participants responded to this potential threat differed.

Seven participants thought that, should their independence be threatened, they would take steps to secure the care and support that they needed in order to maintain their life and live as comfortably as possible in the circumstances. This might not be their ideal choice, but if necessary they would accept their changing situation and adapt to the need for care (Lloyd et al., 2006). During the interview, for example, Rosalind began to reframe her identity as someone who liked her independence, but who needed social contact even more. As Rosalind pointed out, human beings are surprisingly adaptable and just as, after the loss of their partner or spouse, participants created new identities for themselves as independent people who enjoyed living alone, so they would be able to adapt these identities to their new circumstances (Garthwaite, 2015).

Four participants, however, talked about the possibility of ending their lives rather than putting themselves in the situation where they are looked after by other people. For these individuals death was perceived as less of a threat than the idea of moving into a care home, or of needing 24 hour care and support (Davis-Berman, 2011). This fear of losing control of their own lives gave a sense of legitimacy to the idea of participants' dying, whether that death was to come

about by natural means or through suicide or assisted suicide (Howarth, 1998). Although none of them talked about feeling that their life was already complete (van Wijngaarden et al., 2015), for these participants pre-emptive suicide would be a way of avoiding a long drawn out death and of attaining the kind of dying that they might prefer at some unknown point in the future (Hardwig, 2009; Heinrich et al., 2011). For this small group of participants taking charge of when they will die could be one way of trying to ensure a good death for themselves at a time when their life is complete and to avoid what they perceive as unnecessary suffering (Meier et al., 2016).

Living alone increases the chances of dying alone at home, and all but two of the participants addressed the idea of their own possible deaths alone at home. In general, if this meant a sudden death with little suffering then people were in favour. However, contradictions were evident between individuals' personal wishes and their concerns about how other people might be affected by such a death, and what other people might think or do (Lloyd et al., 2006), for example, Fiona's belief that her daughter would be distressed by finding her mother's dead body or other participants' anxieties that their bodies might not be found for an extended period of time. Participants did make some efforts to alleviate these anxieties; Jackie had milk delivered in the hope that the milkman would notice if she did not take the milk bottles into the house, in a similar manner to participants in an earlier study (Lloyd-Williams et al., 2007). Grace, Archie and David all had neighbours whom they believed would take action if they did not draw back their curtains (Lloyd-Williams et al., 2007), but did not consider that their neighbours might not notice the undrawn curtains or might be away from home. For these participants the feeling of anxiety was caused,

not by the idea of death itself, but by other factors related to the circumstances of the death which would be out of the participant's control.

In voicing their concerns participants revealed themselves as engaging in a process of reflexivity, by which they developed desired futures (Giddens, 1991). These desired futures made reference not only to participants' own wishes, but also considered the feelings and wishes of others in their social circle. In doing this individuals exhibited themselves as embedded in networks of interdependence which, even for those who lived alone, informed and facilitated their actions (Burkitt, 2016; Elias, 1978). However, unless the individual decides to end their own life, as four participants thought they might at some point in the future, it is unlikely that they will have control over the timing of their dying. Their engagement in relational reflexivity is therefore unlikely to lead to autonomous action (Burkitt, 2016; Hague, 2011).

The nine participants in this study who engaged with the idea of dying alone did not consider this to be something to worry about. There were aspects of the process that caused them some concerns, but the notion of being alone at the point of death was not one of them; this was even considered desirable as it suggested dying swiftly and without suffering. This suggests the possibility that when individuals think about their own deaths, as opposed to the deaths of others, the factors which count as important are different. This is consistent with findings of a review on the good death conducted by Meier et al. (2016), which reports that perceptions of what counts as a good death may vary between those who are dying, their families and the professionals involved in their care. For the person who is dying and for their family members, a death while asleep is a good one, suggesting perhaps a lack of suffering. However, the presence of



family is of greater importance to the family than it is to the dying individual (Meier et al., 2016); dying alone is not necessarily a problem for the person who is dying.

The nurses who took part in the study all believed that no one should die alone, which is consistent with previous research on nurses' views (Field, 1984; Fridh et al., 2009; Gunther and Thomas, 2006; Hadders et al., 2014; Izumi, 2006; James et al., 2010). They were, however, prepared to discuss the issue and suggested themselves that the desire to see no one die alone might be more for the nurses' own benefit or that of the patients' relatives, than for meeting the needs of the patient. They were able to provide examples of the deaths of patients for whom they had cared, which suggested to them that dying people may have a measure of control over the timing of their own death and that some may choose to die when they are alone. Lack of previous discussion of the issue may relate to the idea that not being with a patient is counterintuitive for those working in a profession devoted to the provision of care (Royal College of Nursing, 2014).

## **Conclusion**

This group of participants were not only willing to talk about death; they were also willing to talk about it in relation to themselves (Chapple et al., 2015). For some participants who provided feedback on the interview process the opportunity to speak openly about possible future infirmity and how they might die was welcome; some even felt that researchers were not direct enough in their questions about dying.

Threats to their independence were viewed as serious by all participants. Death itself, however, was not viewed as such a serious threat and for some individuals was considered preferable to accepting care from others. Participants in this pilot described themselves in terms that prioritised notions of independence and agency, appearing to have few qualms at the thought of dying alone. Anxieties were, rather, focused on the processes and experiences which would precede that death or on how their family members might experience their death. Several participants had plans to end their own lives, should they deem it necessary, expressing a strong idea of being autonomous agents. However, it is important to remember that the participants were not imminently facing their own deaths and that they might change their minds.

The hospice at home nurses expressed their belief that no one should die alone, but acknowledged that this may be more for their own benefit, as their professional experiences suggested that some people prefer to be alone as they approach death. The findings therefore suggest that the concept of dying alone needs to be reconsidered. While this is a small-scale study its findings do suggest that dying alone may be more of a problem for those who survive a death, rather than for the person undergoing the death.

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