

# ‘The calendar is just about up’: older adults with multiple chronic conditions reflect on death and dying

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## **ABSTRACT**

Drawing on data from in-depth interviews with 35 men and women aged 73–91, this article examines the ways in which older adults with multiple chronic conditions talk about and prepare for death and dying. While the focus of the original study did not include questions concerning the end-of-life, the majority of our participants made unprompted remarks regarding their own and others’ mortality. The participants discussed the prevalence of death in their lives as it related to the passing of significant others, as well as their own eventual demise. Additionally, the men and women expressed hopes and fears about their impending death, in particular with respect to prolonged pain and suffering, institutionalisation, and a loss of mental acuity and independence. Many of our participants also described their end-of-life plans, which included making funeral arrangements, obtaining living wills, and planning their suicides. They further reported a number of barriers to their planning for death, including a lack of willingness on the part of family members to discuss their wishes as well as a scarcity of institutional resources and support. We discuss our findings in relation to the extant research concerning older adults’ experiences of death and dying, as well as Glaser and Strauss’ (1971) theory of status passage and Marshall’s (1986) conceptualisation of authorship and the legitimisation of death.

**KEY WORDS** – Chronic conditions, death, dying, end-of-life planning, ageing, later life.

## **Introduction**

With the growing emphasis in gerontology and society alike on positive or successful ageing, topics such as death and dying are frequently avoided or neglected in the research (Clarke and Seymour 1999; Twigg 2000; Whitaker 2010). Indeed, there has been relatively little investigation of older adults’ attitudes towards death or their experiences of the dying body. Moreover,

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there has been a general tendency in the literature to ignore the experiences of adults who are ageing with multiple chronic conditions. Addressing these gaps in the research, the purpose of this article is to examine how older adults with multiple morbidities perceive and discuss death and dying. We draw on data from in-depth interviews with 16 men and 19 women aged 73+ who had a range of three to 14 chronic conditions (average of six). Although the focus of the original study was on the experience of having multiple chronic conditions and none of the participants were questioned about the topic, we found that death and dying were recurring and dominant themes in our interviews with the study participants. We employ Glaser and Strauss's (1971) concept of status passage to explicate our three key findings, namely: (a) death as pervasive and inevitable; (b) participants' hopes and fears for death; and (c) specific plans for death.

### Literature review

Defining death as the ultimate status passage, Glaser and Strauss (1971) have suggested that as individuals move through the lifecourse, they enter and leave numerous statuses, which may be, amongst other things, inevitable, desirable, scheduled, voluntary or controllable. Marshall (1986: 137) builds on the work of Glaser and Strauss, contending that 'an awareness of finitude' results in three social psychological processes that enable the individual to prepare for his or her death, thereby decreasing anxiety and facilitating acceptance of his or her mortality. To begin, 'legitimation of biography' (Marshall 1986: 139) entails reflecting on one's life history so as to achieve a sense of personal meaning, coherence and closure. In contrast, 'legitimation of death' (1986: 141) enables older adults to come to view their impending deaths as an appropriate, acceptable and desirable end to their biographies. Finally, 'authorship' or 'status passage control' (1986: 142) centres on the idea that individuals want to be in charge of their lives as they end. In this way, death and dying are actively rather than passively experienced processes through which individuals maintain and consolidate their sense of autonomous yet relational identities.

The research reveals that individuals who express a desire to talk about death or discuss end-of-life plans are often silenced and dismissed as being overly morbid (Clarke and Seymour 2010; Kjolseth, Ekeberg and Steihaug 2010; Seymour *et al.* 2004; Lloyd-Williams *et al.* 2007) by family members and health-care professionals who actively avoid the topic (Black 2007; Kahana *et al.* 2004). However, a number of studies have found that older adults often perceive their eventual demise positively or are at least open to discussing the issue. For example, in their interviews with 40 older adults who had advanced

heart failure and poor prognoses, Gott *et al.* (2008) found that some of their participants viewed death as a welcome release from intolerable suffering and others anticipated their ending as an opportunity to reunite with their spouses in the afterlife or to relieve their still living spouses from the burden of care-giving. Still other participants indicated that despite their poor health they did not contemplate their mortality but rather focused their attention and energy on the enjoyment of the present (Gott *et al.* 2008). Similarly, Nakashima and Canda (2005: 117) interviewed 16 terminally ill older adults, aged 65–103, and found that their participants were openly aware of and willing to discuss their mortality and were ‘consciously preparing for their coming death’. Describing how their participants used life narratives to construct meaning and a sense of resiliency in the face of death, Nakashima and Canda (2005: 119) reported that many of the individuals they interviewed continued to experience ‘positive personal development even while dying’. Finally, Ternstedt and Franklin (2006) conducted multiple, in-depth interviews with seven nursing home residents, aged 86–95, about their thoughts and feelings regarding death and dying. While four residents (three women and one man) conveyed a strong zest for life, one older man expressed indifference about dying, and two women suggested that they were longing to die as a result of loss of quality of life and personal unhappiness.

Much has been made of the concept of a ‘good death’, particularly within the hospice literature. Studies reveal that the majority of individuals define a good death as one that is free of prolonged physical suffering, pain and/or breathlessness (Broom and Cavenaugh 2010; Clarke and Seymour 2010; Gott *et al.* 2008; Howarth 1998; Lloyd-Williams *et al.* 2007; Singer, Martin and Kelner 1999; Steihauser *et al.* 2000; Vig, Davenport and Pearlman 2002). North Americans have been found to emphasise the importance of preparing for death and retaining a sense of control (Kelner 1995; Singer, Martin and Kelner 1999; Steihauser *et al.* 2000), thereby relieving their loved ones of the burden of having to make end-of-life care decisions in their place (Singer, Martin and Kelner 1999). Additionally, a review of the literature on ethnic diversity and end-of-life decision making by Kwak and Haley (2005) concluded that attitudes towards end-of-life decisions were deeply moderated by cultural values, demographics and awareness of treatment options. There are conflicting findings with respect to awareness as a quality of a good death with studies indicating that while some individuals would prefer to die suddenly or in their sleep (Clarke and Seymour 2010; Vig, Davenport and Pearlman 2002), others wish for a conscious death in which there is opportunity to surround oneself with family and friends and make farewells (Clarke and Seymour 2010; Kellehear 1990). Similarly, the research indicates that despite strong public and professional support for

home care, older adults differ in their preferences for place of death, with some preferring to die at home and others favouring a hospital or nursing home setting (Fried *et al.* 1999; Steinhäuser *et al.* 2000).

There is a body of literature that has found that resilience and selflessness in the face of suffering are also valued aspects of a good death. Cicirelli (1998) explored how acceptable or desirable 17 end-of-life options would be for individuals facing low quality of life as a result of a terminal or non-terminal health condition, finding that the majority of his respondents stressed the importance of striving to live well even when confronted with poor quality of life. Some of the hospice patients in Broom and Cavanaugh's (2010) study maintained that dying individuals should fight to remain alive and socially engaged to the bitter end even as they met their deaths with dignity, acceptance and stoicism, particularly for the sake of their loved ones. In this way, Broom and Cavanaugh (2010: 872) found that conceptualisations of the good death were imbued with moral overtones as their participants felt they must endeavour in their dying to 'alleviate the social sufferings of others', thereby leaving their family members with 'a departing gift of sorts'. However, some literature has revealed gendered differences with respect to responses to loss of quality of life. For example, in their interviews with 33 men and 36 women aged 65–93, Arber *et al.* (2008) found that older men often expressed 'self-oriented' attitudes as they focused on staying alive for as long as possible with little regard for the consequences of their decisions on others. In contrast, older women were 'other-oriented' as they opposed the use of life-prolonging medical technologies for themselves because they were primarily concerned about not becoming a burden on others. The women also indicated that they would be strongly in support of the use of these same technologies for their husbands, irrespective of the care-giving consequences for themselves.

Finally, the research has explored end-of-life planning attitudes and behaviours among older adults. End-of-life planning includes 'both formal activities, such as preparing a will to settle financial matters and specifying preferences for medical care, as well as informal activities such as discussing death with family members as well as engaging in various religious practices' (Ai, Hopp and Shearer 2006: 72). The research suggests that while many individuals think about the issues involved with death and dying (Garrett *et al.* 2008) and most people consider end-of-life planning to be important (Schrader, Nelson and Eidsness 2009), relatively few people actively take steps to organise their affairs or formally make their wishes regarding end-of-life care, death or dying known (Garrett *et al.* 2008; Schrader, Nelson and Eidsness 2009). That said, Lloyd-Williams *et al.* (2007) and Seymour *et al.* (2004) found that some individuals turned to end-of-life planning, such as making funeral arrangements, writing advanced care statements or wills, and

sorting their belongings, in response to their concerns about becoming dependent on and burdensome to their family members. Moreover, the research suggests that those individuals who engage in end-of-life planning tend to be older, of European descent, more highly educated individuals who have greater social support (Ai, Hopp and Shearer 2006; High 1993; Kwak and Haley 2005; McKinley *et al.* 1996).

## **Methods**

The data for this article were drawn from in-depth interviews with 35 older adults (19 women and 16 men) who had multiple chronic conditions. We purposely selected participants who had a minimum of three chronic conditions including at least one of the following: arthritis, cataracts/glaucoma, back problems, heart disease and/or diabetes. These conditions were selected because they are the most prevalent chronic illnesses reported by older adults in Canada and are frequently linked to increased rates of disability and dependency (Statistics Canada 2006). Participants were recruited through advertisements in local newspapers and posters in public facilities. Additionally, we sent invitational letters of recruitment to potential participants using a database of individuals who had participated in a previous study concerned with chronic conditions in which the first author had been a co-investigator. During the initial contact, participants were asked to list existing chronic conditions to ensure they met the criteria for inclusion. Interviews were conducted at locations of the participants' choosing, primarily in their own homes. Participants were interviewed twice for an average of 2.4 hours and a total of 97 hours. The interviews were conducted by the lead researcher (the first author) and two graduate students (the second and third authors). The men and women were asked about their health histories, their current health statuses, their interactions with health professionals and family members, their feelings about and perceptions of their bodies, and their predictions for the progression of their various illnesses. Notably, we did not specifically ask the participants about death and dying, although, as we discuss below, these topics emerged in the majority of our interviews.

## *Sample*

Sample participants ranged in age from 73 to 91 years, with men averaging 78.6 years and women averaging 80.3 years. While participants had between three and 14 chronic conditions, most individuals reported having an average of six health problems, which most commonly included: arthritis

(28), back problems (26), heart disease (24), cataracts/glaucoma (14) and cancer (12). At the time of the interviews, all of the participants were living in their own homes or in retirement communities. The participants were diverse with respect to their marital statuses, incomes, educational attainment, work histories and countries of origin (even as the majority of our study members were of European descent). There was a noted difference between the men's and women's educational attainments and income levels. While the majority of the women reported having a high school or technical school education, men were equally as likely to have a high school or university education. Similarly, whereas most of the women could be classified as having a lower to middle-class income, and none of the women had an income that was higher than CAD \$55,000 a year, the majority of the men had middle to upper-class incomes, and five had a yearly income that exceeded CAD \$75,000.

### *Data analysis*

All interviews were digitally recorded and transcribed verbatim by trained research assistants. Following transcription, we analysed the data using Strauss and Corbin's (1998: 10) concepts of open and axial coding, which they describe as the 'the analytic process through which concepts are identified and their properties and dimensions are discovered'. The authors read and reread the transcripts to generate an initial codebook that included a death and dying category, which was further subdivided into the following axial codes: (a) death as natural and inevitable; (b) good and bad death; (c) end-of-life control; (d) legitimization of death; and (e) reasons for living. These five axial codes subsequently formed the three themes we examine in the following section. Namely stories regarding the inevitable nature of death informed our discussion of the pervasiveness of death and dying in older adults' lives, while mentions of good and bad deaths revealed some of our participants' hopes and fears about death. Descriptions of end-of-life plans and individuals' reasons for living or wishing to die underscored our last theme of participants' plans for death. During this multi-staged and complex process, we moved back and forth between the full interview transcripts and the coded data to ensure our interpretations were valid and contextualised in the participants' broader life histories and experiences as well as the extant literature and theorising about death.

### **Findings**

While they were not directly asked to discuss death and dying, 29 of the 35 participants (18 women and 11 men) in our study spontaneously brought up

the topic. In this article, we tease out the nuances of the 29 participants' unprompted reflections on death and dying, beginning with the dominant theme of death as pervasive and inevitable, followed by our participants' hopes and fears regarding their own passing and concluding with a review of their end-of-life plans.

*'Everybody's going to die': the pervasiveness and inevitability of death*

To begin, 25 of our participants described how many people in their social circles, including their spouses, friends, or family members, had passed away with a concomitant impact on their awareness of their own mortality. For example, a 75-year-old man who suffered from arthritis, back problems, a bowel disorder and heart disease recounted the following:

Last summer I went to nine funerals. This year I've been to three funerals. And it does affect you – profoundly . . . Like I've gone to so many funerals over the last three years – I mean people from late 40 s until their late 70 s. And you look around – we're all going there. I mean that's the ultimate destination, I guess. And you look around and say 'Well, the next one could be yourself.'

Another man, aged 76, who had arthritis, back problems, chronic fatigue syndrome and heart disease, described how his father's early passing had rendered him aware of the finitude of his own life at a relatively young age:

My dad died when he was 54 from pancreatic cancer . . . I remember when I turned 54 . . . I really felt as if, not scared but aware of the fact that what my dad had passed away from, it could hit anybody at any time and every year I lived beyond that was a plus. But I try not to think about it really, just take each day as it comes and, you know, hope that you see another one.

In this way, many of our participants had begun to confront death on a regular basis and asserted that the ubiquity and closeness of death made them appreciate life that much more.

Moreover, many participants emphasised the need to recognise and accept death as an inevitable, if not desirable, status passage. For example, seven individuals (four men and three women), none of whom were actively religious, were philosophical and contended that because of the inescapable fact of death, one should not worry about the future. A 73-year-old woman, who had arthritis, heart disease, kidney disease and polymyalgia, stated that witnessing two family members' struggles with cancer and rheumatoid arthritis had made her more accepting of her physical decline and eventual demise: 'You know, you just accept it. I told my sister, "If anything happens to me," I said, "When I'm gone, I'm gone. I don't want any of you to think about it. That's life."' Thus, these individuals were fatalistic about the inevitability of death and accepting of their mortality. Although

the majority of our participants recognised and were at peace with the finitude of their lives, four women also stressed that they did not yet feel ready to move through the last status passage as they made comments similar to those of a 78-year-old woman who suffered from arthritis, back problems, glaucoma and a neurological disorder. She contended: ‘Not that I’m afraid of death. But this life is good and I don’t want to go now . . . I mean when I die, I die. But not yet. I’m not ready.’ Therefore, acceptance of mortality did not translate into a passive or disengaged response to living.

At the same time, nine people (five men and four women) described how their awareness of their impending death was augmented by their advanced ages or the fact that they had terminal illnesses (two participants). That said, these individuals often reflected on the fact that while death was certain, the timing of their passing remained unknown. For example, a 78-year-old woman who had diabetes, heart disease and a serious and debilitating case of Crohn’s disease put it this way: ‘How long have I got? I don’t know. My days are numbered. The best years are all behind, they’re not ahead. But I can’t do anything about it—whatever is going to happen is going to happen.’ Likewise, a 75-year-old man with a number of chronic conditions including arthritis, back problems, heart disease, urinary incontinence and a terminal illness asserted:

MSA [Multiple System Atrophy] is a terminal disease . . . but it’s hard to judge how long I have to live. I wouldn’t guess more than a couple years at the rate I’m deteriorating . . . The outlook is kind of grim. One doesn’t like to consider one’s imminent death but I guess I have no choice but to take it as it comes.

These participants were pragmatic about their mortality and demonstrated awareness of their prognoses, which had been made all the more evident to them by virtue of the physical realities of having multiple chronic conditions in later life.

Interestingly, four participants (one man and three women) conveyed a sense of surprise that they had lived as long as they had as they made comments similar to those of an 86-year-old woman, who had arthritis, back problems and heart disease, and who had experienced a stroke during heart surgery:

I never thought I’d live this long . . . My parents died very young . . . my parents both died in their early 60s. And I just never thought that I would last that long somehow . . . Because I’d had this heart surgery, I really rather thought that I would go quite quickly.

As well as being amazed by their longevity relative to the experiences of their parents or other loved ones, these participants often expressed gratitude, if not pride, over their good fortune. A 79-year-old woman, who had arthritis,



back problems and Parkinson's disease in addition to a family history of terminal neurological disorders, put it this way:

No women in the family lived beyond 65 for some reason . . . I consider myself very lucky in that all the women in our family were dead before me, before my age. You know? Like my grandparents, etcetera, and my mother, they were all dead at 65 and here I am darn near 80.

In addition to their thoughts about their own impending deaths and perhaps a reflection of the pervasiveness of mortality in their social networks, our participants often discussed death in an off-hand and light-hearted way. Many of the participants casually interspersed their stories with references to the deaths of their friends and loved ones, while others made humorous remarks. For example, a 79-year-old man who had a bowel disorder, diabetes, heart disease and glaucoma joked: 'In the morning I have my two cups of coffee and I read my paper all the way through to see who died just in case my name is on there.' Still others perceived a blithe attitude towards mortality to be an essential coping mechanism when dealing with long-term chronic and/or terminal illness. For instance, a 79-year-old woman, who had arthritis, back problems, glaucoma and heart disease, had this to say of an encounter she had had with her physician:

I mean we're all gonna die very soon, so let's have a good time while we're here and laugh at it. That's another problem with doctors – they don't laugh at dying. You know, the doctor gave me a prescription for two more years. And I said to him, 'You think I'm gonna last that long?' He said, 'Well, yeah if I have anything to say about it.' And I thought, 'Oh for God's sake, I'm joking.'

While the woman's levity indicated her own comfort with passing and the discussion of her mortality, her physician's response betrayed his discomfort and perception of death as an enemy.

*'Let me pass away peacefully': hopes for and fears about death*

Even as our participants frequently described the inevitability of death, they also discussed their hopes and fears about their approaching demise. To begin, approximately half (eight men and six women) of our study members expressed apprehension about the prospect of having a prolonged death, which they considered to be a particularly bad form of passing. A 76-year-old man, who had arthritis, back problems, a bowel disorder and heart disease, recounted a story about his mother's dying process as an example of what he feared most with regards to his own future: 'My mom had a stroke when she was 86. She died when she was 89 . . . Her mind was sharp but she couldn't talk. She was totally paralysed . . . That's no life . . . It was just so sickening.' In addition to dreading being 'trapped' in their bodies, many participants also expressed abhorrence towards the possibility of suffering and being in pain

for a long period of time. For one woman, aged 86, who suffered from back problems, heart disease and the effects of stroke, the fear of being in long-term and unremitting pain had already become a terrible reality:

My spine is extremely painful. There's nothing they can do with that . . . So the shorter [my wait to die] the better. And I'm not the only one who thinks that. There are a lot of people here that if you sit down and talk to them, they say with a sigh that they're just waiting. Someone described this [retirement home] as God's waiting room . . . I just hope that one day I won't wake up.

As the above woman stated, many of the individuals we spoke to wanted a swift, painless death, such as dying in their sleep or from a sudden heart attack, as they made comments similar to those of an 80-year-old man who, in addition to having arthritis and heart disease, had had two minor strokes, and was fearful that he would experience another, more debilitating stroke. He asserted: 'I'm worrying about my health. I'm not worrying about death. I don't mind going phew quick like that. That's okay. But I don't want to lie [in the hospital] for five, six months, a year . . . with no future.'

One-third of our participants (seven men and three women) also spoke of the onset of dementia preceding death as an especially horrifying way of dying. The men were particularly fearful of the possibility of losing control over their bodies and minds. For example, an 80-year-old man, who had arthritis, back problems, chronic fatigue syndrome and severe depression, stated:

I would hope that my mind doesn't go before my body. This is the sad thing about the man I was talking about – that his mind is going and his body is relatively okay, except for some slight tremor. That I think is probably the worst thing that could happen to me.

Similarly, having to be institutionalised as a result of the failure of the body or the mind was described by one-third of the participants as another form of bad death. A 78-year-old woman, who had Crohn's disease, diabetes and heart disease, and who was currently living independently in her own apartment, put it this way:

If my health stays like this, I can cope until the day I am gone. But I hope it doesn't get any worse – like the diabetes, my eyes right? And then also, some people have had their legs amputated. So, oh God, no I hope it doesn't get any worse . . . I've visited some people in the nursing homes and I don't want to end up there. I don't want to. And yet, you can't burden your kids because if it comes to that you need a lot of attention and they can't give it to you. And God forbid I wouldn't want to get dementia either.

Having witnessed the often painful endings of loved ones or the demeaning existence of institutionalised older people, these participants were well aware of how much worse their quality of life could become in the future.

While our participants often described trepidation over becoming burdensome, six men were particularly concerned about how their declining health might threaten their masculine sense of self as autonomous and powerful individuals. For example, having always considered himself to be extremely self-sufficient, a 79-year-old widowed man, who suffered from back problems, a bowel disorder, glaucoma and heart disease, had this to say: 'I don't want someone else to come around and have to look after me, wash me, clean me, carry me around. It's not my idea of what I want to do.' In this way, he feared not only dependence but also a loss of dignity as he became increasingly reliant on others for his basic needs. Likewise, a 75-year-old man, who suffered from arthritis, cancer, chronic obstructive pulmonary disorder (COPD), glaucoma and heart disease, and could no longer walk, drive or engage in activities for prolonged periods of time, was worried that further losses to his independence would deprive him of the ability to end his life in a manner of his own choosing:

Stroke, not a stroke that cripples me but a stroke that cripples my brain – that worries me. If I was to have a stroke and have to go to the hospital, how could I get my pills to end it? That worries me. Becoming completely dependent on other people taking care of me, I don't want that. I just don't want it.

In this way, for many of the men in our sample, a bad death was defined in terms of a loss of autonomy that challenged their view of themselves as active, independent and masculine individuals.

Another third of our participants (three men and six women) were also concerned that the process of their dying, and in particular a prolonged death, would impose a burden on their families or on state resources. Already being cared for by his wife, a 75-year-old man, who had arthritis, back problems and urinary incontinence, and who was undergoing chemotherapy for cancer, worried about how his deteriorating health might further affect his family:

I don't see myself becoming independent. If anything at all, I will become more and more dependent . . . I think my greatest concern is how I am going to end up. What is going to happen with me? Am I going to be in a nursing home? Am I going to be a burden on my children and my wife? I wish things would end soon . . . I'm not going to get better. If anything, I'm going to get worse . . . I wish that the end would come sooner rather than later.

In contrast, an 82-year-old widowed, childless woman, who had arthritis, a bowel disorder, cancer, heart disease and macular degeneration, feared becoming a burden on individuals with whom she was not emotionally bonded, either her estranged extended family or employees of the state:

I would hate that [going into a nursing home] but whatever has to be, has to be. I'd hate that I'd have to burden somebody. That would be the hardest part . . . I wouldn't

depend on my family to look after me. I don't think they would anyway . . . I wouldn't want to be dependent on them. I wouldn't want them to give up their time for me.

Others, like the following 80-year-old man, who had arthritis, heart disease and had suffered a number of strokes, were adamant in their assertions that government resources would be better spent on younger individuals who they perceived to be more worthy candidates of expensive treatments because of their longer life expectancies:

If there's no future, no going back to normal, there is no sense to lie in the hospital too long. That's a waste of money for the government and for the family members. There's no sense in wasting the money and the time. There are other patients who need the beds, they should take the beds, rather than men like me who don't have any future – who are too sick or too old.

The notion that their generation was using up a disproportionate amount of health-care resources through their death and dying processes was articulated by a number of participants. One woman, aged 87, who suffered from a bowel disorder, diabetes, heart disease, the effects of stroke and urinary incontinence, expressed this sentiment with particular bluntness as she maintained the following:

We're all living too long. And a lot of the people I talk to, they don't want to be living. And here we are taking all the things up from the health service, all the time, and doctors and money that it involves. And for what? And for your generation, or my daughter having to look after me, that's a big worry to me, if something happens that my daughter has to look after me. I just don't want that at all. And, so that's why I feel that we really should [be able to have] euthanasia, and have a choice.

Thus, many of our participants openly described aspiring for quick, painless deaths that were not the result of prolonged suffering or dementia and that did not impose undue burden on their families or on health-care resources more generally.

*'I don't want to suffer and I don't want to be a nuisance': planning for death*

Building on their perceptions of death as something to be faced and accepted, half of our participants (seven men and ten women) stressed the importance of planning for their future demise. For example, an 80-year-old man, who had arthritis, back problems, chronic fatigue syndrome and severe depression, and whose wife had recently passed away, asserted the following:

I think people need to prepare. None of us like to think about that. We think that we're kind of immortal but I think that people need to prepare for their funeral and choose what it's going to be. Everything from the church to a local pub.

Eleven participants (five men and six women) discussed their plans for death in terms of attending to practical matters such as making funeral

arrangements, obtaining living wills or establishing a trusted loved one as their power of attorney. In doing so, these individuals, and particularly the women in our sample, were endeavouring to be as little of a burden as possible to their remaining friends and family members. An 80-year-old woman, who had recently experienced deterioration in her physical condition as a result of advancing arthritis, fibromyalgia and a degenerative disc disease, had this to say:

I'm getting ready, you know. I'm trying to get my things in order . . . because you never know when you're going to go . . . I just don't want to be a nuisance to anybody . . . It would be so much easier on the family too if they didn't have to go through this.

Fifteen participants (seven men and eight women) were striving to actively control a largely uncontrollable status passage by making practical plans for their end-of-life. For example, a 75-year-old man who had arthritis, cancer, COPD and heart disease stated:

I've lived my life my way as much as possible. I'm going to die my way as much as possible. And I'm going to age my way as much as possible. I mean, obviously I can't control everything, you know? But as much as I can control I will.

Thus, the participants were asserting their autonomy and exerting 'authorship' (Marshall 1986: 142) over their demise.

Seven participants (three men and four women) intended to maintain maximum control over their dying as they had specific plans for ending their lives when they deemed that their quality of life was no longer tenable and they felt ready to go. Responding to a question regarding how he would handle further declines in his health, a 79-year-old man, who had arthritis, a bowel disorder, back problems, prostate cancer and urinary incontinence, put it bluntly:

If [the cancer] holds off for another five or six or seven years, then you have five or six or seven years that you can control it, and then the calendar is just about up. So then the hell with it! Go home and get the gun out and blow your brains out.

Others had more carefully planned measures in place for the eventuality of compromised health and loss of quality of life. An 80-year-old woman, who had arthritis, back problems, COPD and glaucoma, and whose deceased husband had been a doctor, admitted:

I used to look after the drugs for my husband and . . . when he died I saved some of these things and they're well expired by now but they're in a little box in my storage room. I always thought if I got ill or had a stroke and I couldn't recover I would take the pills.

For these individuals, suicide was a rational, active choice that they intended to exercise when they felt the timing was right, rather than an indicator of suicidal ideation or pervasive depression.

Despite the importance they placed on planning for death, seven of our participants described a number of barriers that they had encountered while trying to formalise their wishes. Some of the participants had difficulty discussing their end-of-life plans with their loved ones, and made remarks similar to those of a 75-year-old woman, who had arthritis, back problems and fibromyalgia, and who had raised her granddaughter by herself:

[My granddaughter] is having some difficulties because at this point, I'm almost 75, so I'm talking about pre-paying a funeral and making arrangements. And she's having difficulties with that... She almost freezes right up about that... I just thought, 'No I'm not going to stress you with it. I'll just go ahead with it and when you're ready to talk about the plans I've made then I'll tell you about the plans that I've made.'

As well as unreceptive family members, other participants described frustration over the lack of institutional support and resources for end-of-life planning. An 86-year-old woman who, as a result of back problems, heart disease and residual effects of stroke, experienced chronic and severe pain, spoke of her aggravation over her low quality of life:

I'm not talking about somebody young because if you've got some disease, maybe something could come along that would cure it – but when you're of a certain age, I really think [euthanasia] should be possible. I gather you've got to have a doctor's permission and most doctors won't touch you with a ten-foot pole. They should. There are an awful lot of people I've chatted to here who don't want to continue living. But they're like me, they don't know what to do about it. There's nothing you can do. I don't want to take an overdose of anything because I don't know whether it would be successful and that would be worse. So, I'm not depressed about it, you just accept these things.

While the above woman desired control over her status passage, her efforts were stymied by a lack of knowledge of how to end her life in a painless and effective manner as well as the fact that she did not have access to health-care professionals who were willing and legally able to assist her.

## **Discussion and conclusions**

In this paper, we have described the death and dying stories and perceptions of older adults who had multiple chronic conditions. Our study was originally conceptualised as an investigation into the lived experience of having multiple chronic conditions in later life. As such, we did not set out to specifically study attitudes towards death and dying and, moreover, had not even considered that these issues would emerge in our interviews. Nevertheless, our interviews with our participants revealed that these topics were an important and underlying aspect of what it was like to live in a chronically ill, ageing body. As a result of their complex and numerous health issues, our

participants were frail and experiencing considerable and often distressing declines in their functional abilities. Additionally, their advanced ages meant that as many of their family and friends had begun to pass away, they encountered death on a regular basis. Indeed, their proximity to death by virtue of their multiple morbidities and their advanced ages as well as the changes in their social networks culminated in a profound 'awareness of finitude' (Marshall 1986: 137) that perhaps distinguished them from other older adults.

Although our participants emphasised the inevitable nature of the status passage they were facing, namely death, they also stressed how their demise was desirable (Glaser and Strauss 1971). For some, like the findings of Gott *et al.* (2008), and Ternstedt and Franklin (2006), death was perceived as a welcome, if not longed for, end to their suffering and to their being a burden on their spouses and other family members. Others, while stressing the importance of acceptance and dignity in the face of death, found that the pervasiveness of death in their social circles and the inevitability of dying made them grateful for each remaining day they had. In this way, we were struck by the resilience and selflessness that many of our participants displayed irrespective of their chronic health issues and social and physical losses.

At the same time, our participants had clear ideas regarding the definition and experience of a good or bad death. Echoing the existing research (Broom and Cavanaugh 2010; Clarke and Seymour 2010; Gott *et al.* 2008; Howarth 1998; Lloyd-Williams *et al.* 2007; Singer, Martin and Kelner 1999; Steinhäuser *et al.* 2000; Vig, Davenport and Pearlman 2002), our study participants wished their deaths to be quick and free of prolonged suffering and pain. Already experiencing physical misery and loss of independence and having witnessed the deaths of others, many of our participants were acutely aware of the fact that their suffering was invariably going to worsen. Their stated fears about growing ever more dependent or enduring physical or mental incapacitation with a resultant threat of institutionalisation were grounded in life experience and their corporeal realities. It is for these reasons, perhaps, that our participants did not describe awareness as a necessary aspect of good death, unlike the participants in the study by Vig, Davenport and Pearlman (2002), as they preferred to pass on without further pain or physical losses, which might entail sedating medication in the future. Similarly, unlike the research by Fried *et al.* (1999) and Steinhäuser *et al.* (2000), place of death was not an issue described by the men and women we spoke to, who rather emphasised independence and swiftness as preferred characteristics of death.

Given their wish to not suffer, it is unsurprising that many of our participants described death as a status passage over which they endeavoured to

exercise a measure of control. For some, this control was expressed in terms of making plans such as getting rid of possessions or arranging wills. Others, like the ‘activists’ in Kelner’s (1995) study, articulated strong desires to be in charge of their end-of-life health-care decisions, including the retention of the power and means to hasten their demise. This latter group of individuals were thereby planning to voluntarily pass through the status passage of death at a time and using methods of their own choosing rather than waiting for nature to take her course. In this way, most of our participants were engaging in the authorship (Marshall 1986) of their deaths and were confronting the end-of-life as autonomously as possible, similar to the previous research conducted with North American participants (Kelner 1995; Singer, Martin and Kelner 1999; Steinhäuser *et al.* 2000).

Although there were relatively few gendered differences in our findings, the men’s and women’s varying responses to the loss of autonomy warrant further comment. As we have previously noted, for the men, loss of independence and concomitant threats to masculinity tended to be paramount. Thus, more men emphasised being in control of their own destinies, including their deaths, and expressed derision over the possibility of becoming helpless. Given the emphasis placed on autonomy, control, invulnerability and power within hegemonic masculinity norms (Prentice and Carranza 2002), the men’s responses to increasing physical decline are unsurprising. In contrast, and similar to Arber *et al.* (2008), we found that more women articulated negative perceptions of what their declining health would mean for others. Specifically, the women spoke more often than the men of not wanting to burden others and, therefore, of the importance of planning for their demise. In this way, the women’s responses to their growing physical deterioration reflected the privileging of selflessness, care-giving for others and family orientation as valued markers of femininity (Prentice and Carranza 2002).

Many of our participants were actively legitimating their impending deaths (Marshall 1986) in a variety of ways. For some, death was to be expected by virtue of their familial health and mortality histories or the experiences of their friends who had already passed on. As has already been noted, some participants, especially the women, also conceptualised and legitimated death as a means of sparing their loved ones the burden of having to engage in care-giving. Finally, some of our participants legitimated their deaths as a means of preventing themselves and others from becoming a drain on already limited health-care resources. Internalising ageist assumptions about the devaluation of older adults and the use of productivity and social engagement measures of one’s social worth, these individuals argued that younger people were more deserving of comprehensive health care.



Our paper adds to the literature on death and dying in later life by drawing attention to the unique experiences of frail, older adults who are coping with the physical and social realities of multiple chronic conditions. Because of the complexities of their health issues, their frailty and often almost unbearable suffering and their advanced ages, our participants were highly aware of and willing to discuss death and dying. The fact that they spoke so extensively about death and dying, even though we did not specifically question them about the topic, underscores the importance of the issue for frail older adults. Clearly, we had internalised assumptions about the taboo nature of death and dying by not even considering that it warranted attention in our interviews. Thankfully, our participants felt comfortable enough to disregard any uneasiness we might have unwittingly displayed or our lack of forethought about the importance of mortality to their experience of multiple chronic conditions as they clearly gave voice to an issue that was obviously at the forefront of their minds.

Limitations to this study include the small, convenience sample as well as the fact we may not have fully explicated the topic of death and dying because of its exclusion from our formal interview schedule. While the participants had diverse ages, incomes and levels of education, none identified as homosexual and the majority were of European descent. In the future, it will be important to focus research on the experiences of gay, lesbian, bisexual or transgendered older adults as well as individuals of different racial-ethnic and religious groups. It would also be beneficial to investigate the experiences of rural older adults who might further lack health-care resources and to hone in more specifically on advanced old age when health issues tend to become more prominent and limiting.

In conclusion, we have become strongly aware of the importance of providing a space for older adults to speak about their thoughts, feelings and concerns regarding death and dying rather than assuming that these are undesirable and unmentionable topics. Many of our participants were isolated in their planning for death as they faced unreceptive family members and health-care professionals who were uncomfortable discussing their wishes for end-of-life. It is imperative that researchers, health-care providers and society at large tackle our collective reticence to allow older adults to reflect on end-of-life so that their passing may be as autonomous, dignified and honouring as possible.

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