

'I live for today': a qualitative study investigating older people's attitudes to advance planning

Kritika Samsi BA MSc and Jill Manthorpe MA

Social Care Workforce Research Unit, King's College London, London, UK

Accepted for publication 24 June 2010

Correspondence

Kritika Samsi
Research Associate, Social Care
Workforce Research Unit
King's College London
Melbourne House
5th Floor, Aldwych
London WC2R 2LS
UK
E-mail: kritika.1.samsi@kcl.ac.uk

What is known about this topic

- The Mental Capacity Act 2005 provides a framework for planning and decision-making in case of loss of future capacity
- Older people approaching or following retirement are expected and encouraged to make plans under the framework
- Planning is generally seen as beneficial for all future eventualities

What this paper adds

- Tendency to plan is a personal life-long preference; the general public requires support in order to perceive benefits of thinking about future potential health problems
- Financial and funeral plans were common; less so health and social care plans
- Presence of family may result in people not recording their preferences but relying on family to act in their best interest

Introduction

The Mental Capacity Act 2005 (MCA), implemented in England and Wales in 2007, enshrines in law the right to set out advance plans and decisions should circumstances arise where decision-making ability may be compromised. Amongst other provisions, the Act enables

Abstract

This article reports investigation of prevalent understandings and systems of beliefs that underpin older people's attitudes towards making plans for their future. The Mental Capacity Act 2005 (MCA) enables adults with capacity to make plans and decisions in advance, to arrange proxy decision-making and provides safeguards for those who might lose the capacity to make decisions for themselves in the future. This study explored the attitudes of a diverse sample of 37 self-declared well older people living in the community in England about their views on drawing up statements of wishes and documenting their decision-making preferences. The study was conducted in early 2009. Findings revealed that most individuals had a personal tendency or preference towards planning, guided by personality, beliefs, living situation and the relevancy of planning to their situation. Financial plans and funeral arrangements were most commonly drawn up with an absence of health and social care plans, which participants tended to postpone considering. Housing and residential care were important for all. Overall, few participants had heard of the MCA and most were unsure where to turn for support. Participants appreciated support when discussing these issues; some turned to family, while others felt professionals were a more appropriate source of advice. The family doctor was cited as trustworthy and a potential place to begin inquiries. Conceptualising onset of certain debilitating conditions also encouraged participants to think about planning for them. This study has implications for public education campaigns and health-related information that could potentially impact on many older people who are interested in making plans but are unaware that legal safeguards and practical support are available to aid this.

Keywords: advance planning, dementia, Mental Capacity Act, older people

people to make their views known concerning finances, treatment and care (welfare) and to appoint proxy decision-makers. Its statutory Code of Practice provides a framework for practice and behaviour (Ministry of Justice 2007). Specifically, individuals can grant Lasting Power of Attorney (LPA), make Advance Decisions about care and treatment (AD) should capacity be com-

promised, and draw up statements of their wishes that professionals and others should take into account. Taken together this may be referred to as Advance Care Planning (ACP): obtaining 'the person's preferences regarding both the type of care they would wish to receive and the setting or location in which they wish to be cared for' (Exley *et al.* 2009). These options which rely on national legal frameworks feature in many parts of the developed world (O'Connor & Purves 2009). In the USA, Gillick (2010) reported that high-profile news stories of patient neglect or invasive treatment appeared to precipitate interest in living wills and advance directives.

Overall, the MCA encourages empowerment and protection of people, possibly relevant to the large number of older people fearing dementia (Gillick 2010) or those who have received a dementia diagnosis. ACP has particular implications for people with dementia because it straddles both physical and mental health-care and loss of decision-making capacity is particularly associated with loss of cognitive ability occurring progressively in dementia (Schiff *et al.* 2000, Hughes & Robinson 2006, Hertogh 2010). Despite this, there is limited evidence of ACP being fully integrated into routine practice and dementia care settings (Exley *et al.* 2009). With a diagnosis of dementia, an individual may reflect on future care, living arrangements, financial control and delegation (Atkinson 2007, p. 24). Professionals, however, may debate timeliness of introducing ACP; questioning when might be the appropriate moment to do so because specific options can only be considered when the individual still has capacity (NICE & SCIE 2006), but adjustment to the diagnosis may still be being experienced. Maintaining independence for as long as possible is valued by older people (Hayden *et al.* 1999); being involved in decision-making is known to have a positive impact on quality of life for individuals with dementia (Menne *et al.* 2009).

One way to enable discussions about future planning would be to encourage all older people to consider health and social care plans as part of general long-term adaptation for retirement. However, generally, older people are not inclined to contemplate possible health and social care problems (Hill *et al.* 2007). Hill *et al.* (2007) reported that many of their sample of 91 older people living in England voiced ambivalence around planning for possible ill-health or disability associated with advancing age, exhibiting attitudes such as 'hoping for the best' and 'facing problems if and when they arose'. In medical settings too, there is evidence of this disinclination to plan. Schiff *et al.* (2000) reported that although some older inpatients felt that they would benefit from having drawn up an AD, few had done this. Many older people appear content that relatives make decisions for them if they are unable to do so, thus appointment of surrogate decision-makers has been rare (Gamble *et al.* 1991).

In the context of the MCA consolidating and extending people's rights to make AD and setting out safeguards, there is interest in whether these opportunities are being taken up. Studies examining attitudes and understanding of ACP have focussed on patients and healthcare practitioners (Atkinson 2007, p. 170) and therefore report experiences of what happened after an ACP was formulated. There is little research around attitudes and understanding of older people with no imminent health or care decisions in prospect. Indeed, such older people may not wish to consider this matter or may find the process difficult or distressing. Sykes & Hedges (2008) differentiated between perspectives that adopt the mindset: 'I have a problem, what shall I do?' and those which are more information-orientated: 'I have a problem, what shall I find out?' They suggested that, rather than researching options, some older people prefer to 'get on with it'. Other authors have observed that older people tend to seek out information in order to obtain answers to specific problems (Godfrey & Denby 2007). Alongside information-gathering by themselves, older people often seek guidance, help or advice, especially when it comes to governmental information and services (Darnton 2005, Gilroy 2005).

Aims

This study explored experiences, opinions and attitudes of older adults living in the community regarding planning for their future in context of the MCA. We wanted to identify thinking and beliefs that underpinned action or inaction, more specifically, to investigate how older people thought about future financial, health and social care decisions, potential sources of advice and support, and to discover if and how the MCA applied to the everyday lives of older people who considered themselves healthy for their age. This study was part of a larger research project (EviDEM MCA) investigating practice under the Act.

Method

Following ethical permission, participants were recruited from a variety of community-based sources: advocacy group for older people (12 participants), social club (10 participants), social group (three participants), support group for a particular health-problem (four participants) and special interest science group (two participants) in London. Members of these groups over the age of 50 were invited to participate in a study around decision-making in later life. Following interviews, some participants suggested that they had friends who might be keen to take part (six participants). All interested individuals were approached, the study presented to them, implications of taking part explained, assurances of con-

Box 1 Interview topic guide

1. Plans for managing your money
 - a. Will/Advance decisions/Lasting Power of Attorney
 - b. Any wishes you might have?
 - c. Why/why not
2. Plans for future care
 - a. Where you want to live
 - b. Why/why not
3. Medical plans or decisions
4. Would you make plans in the future
 - a. Under what circumstances or events?
 - i. About what if you had memory problems?
 - ii. Family/friends change/move
 - iii. If suggested by family and friends
5. Support from professionals
6. Have you heard of the following
 - a. Mental Capacity Act
 - b. Lasting or Enduring Power of Attorney
 - c. Advance decisions or Living Wills
7. If you have made plans/will make plans, do you think professionals will take any note of them?
 - a. Why/why not/any experiences
8. Have you have made decisions of behalf of someone else who was poorly or confused
 - a. Why/what happened/who encouraged you
 - b. How has this affected you
9. Have you discussed these issues with friends/family
10. If you decide to make plans, where would you go for information and/or advice

Confidentiality made and consent obtained. Interviews were conducted using a Topic Guide (Box 1) developed to answer the research questions and in light of the literature around planning for later life and the MCA. Most interviews took place in participants' own homes, lasting on average 30–45 minutes.

Interviews were recorded and transcribed verbatim. Transcripts were checked and inconsistencies rectified. The analytical approach adopted was framework analysis, being appropriate for applied or policy relevant research of this kind (Ritchie & Spencer 1993). This deductive, a priori approach begins analysis from pre-specified aims and objectives. Analysis comprised five stages: (i) familiarisation with data by repeated reading of transcripts, (ii) identification of themes in first few transcripts, assigning codes to them and initial development of a thematic framework, (iii) application of the thematic framework to other transcripts, (iv) addition of emerging themes to existing framework, and (v) mapping out the coding framework and interpretation of clusters of themes in relation to the research questions. Questions from the Topic Guide were used as a starting point and any emergent themes from transcripts were coded as responses to each question.

Face-to-face qualitative interviews were conducted with 37 participants, who had a mean age of 71.4 years, ranging from 53 to 86 years; most were female (30

people; 81%). In terms of ethnic groups, 21 participants described themselves as white British, six as black Caribbean, three participants each of African and Indian origin, two Guyanese, one Irish and one Scottish, reflecting London's diverse black and minority ethnic population (Manthorpe *et al.* 2009). Findings presented reflect the majority response and ethnic group differentiation has only been identified if relevant. Once themes were saturated, no further participants were sought. Names have been replaced to preserve anonymity but gender, age and individual ethnic group are included.

Findings

Four main themes were identified in transcripts relating mainly to questions from the Topic Guide: (i) individual inclination to plan, (ii) types of plans, (iii) reasons for planning or not planning, and (iv) support with planning. Direct quotes have been used and identifiable features of participants were removed.

Individual inclination to plan

A significant theme that emerged was that participants had individual and personal approaches to planning. A range of predisposing factors was identified, including disposition, belief systems and spirituality, participants' living situations, the current (2010) uncertain state of the economy, and their confidence and trust in medical practitioners. Some participants declared their personal tendency and preference to avoid planning for the future. They described attitudes like 'live for today', enjoy life to the maximum, not thinking much about the future, and not letting worries and problems affect life. Making detailed plans for the future had, therefore, not featured in their lives:

I live for today, tomorrow you die. It has been successful for me so far, I am 79 ... I enjoy good health and I go away every year and everything. (MCA OA 021, male, age 79, black Caribbean)

Some participants discussed this disinclination alongside spiritual beliefs and described feeling that only God knew the future. One participant spoke of her religious convictions and discussed having already organised and paid for funeral arrangements. However, apart from this and despite her concerns about finances, she had not drawn up a will nor any medical or social care plans. She did not feel that it was appropriate for her to interfere in God's work:

I don't care if I am dying tomorrow, I said to people look, if it is my turn that God said I should come and join Him, I said I am prepared, what is the use of worrying? (MCA OA 035, female, age 65, black Caribbean)

A significant sub-theme was identified from discussions with people living alone with no relatives. They spoke about being unable to appoint anyone to hold LPA or to ensure wishes and preferences were carried out because they had no direct or even distant next-of-kin. They highlighted that their friends being elderly themselves compromised their ability to act as effective attorneys. This particular group described the strongest intention to plan:

What the Government have to realise is as I get older my friends get older, so at the moment I am waiting to find out if one friend is going to be buried, another friend has Alzheimer's and so it goes on and on and on and on, no way can I ask a friend my age. Younger friends lead very busy lives and they have got family problems of their own. (MCA OA 012, female, age 84, white British).

A small group of participants said that they did not have any finances or valuable personal effects to leave their children and hence viewed planning as irrelevant to their situation. They conceptualised plans in terms of financial transactions or for functions of inheritance and appeared to find it difficult to think about planning for health and personal welfare as matters that might affect them.

Types of plans

When participants described existing arrangements made, financial plans were most common. A will was frequently mentioned, followed by granting Enduring Power of Attorney (the earlier Power that applied to financial decisions alone and not health and welfare decisions), setting up joint bank accounts, taking out health insurance, and consolidating investments and bank accounts. A tendency to plan for financial security did not necessarily mean that individuals planned for other aspects of future care as well. For example, one participant talked of her household insurance, health insurance, income protection plans and financial arrangements. Despite making difficult decisions for her late mother through final stages of cancer, she had not considered making plans of this nature but expressed interest in them when raised during the interview:

I am hoping that I won't be looked after [in a care home], but yes I will wait until I cross that bridge, I think.

Interviewer: Is there a reason you have avoided thinking about it now?

No, I have not thought about it, perhaps I need to think about it, I was just interested in getting the money sorted, but you are right, I do need to think about it, haven't heard about it before. (MCA OA 016, female, age 59, British Indian)

Funeral arrangements were also discussed, ranging from a separate bank account for funeral costs, to more

elaborately planned procedures, including hymns they would like sung at the ceremony. Participants portrayed their reasons for making funeral arrangements as being in the best interests of their relatives:

I thought what sort of coffin, what sort of service and I thought no, I don't want the boys [adult children] to have to do that, they don't know what hymns I like, so I have done the lot. If people can't get to the crematorium, I have even done a memorial service in their local church and I made the boys laugh, I have paid for the choir [laughter] and what hymns I would like played there ... But I must admit that has only come, I hadn't thought of it before ... I felt so numb when I was trying to arrange [husband's] funeral. No I don't want the boys to have to do that. (MCA OA 011, female, age 78, white British)

Housing and residential care appeared to be significant discussion points for participants. Most had spoken to partners, family members and close friends about this. Some described how much their home meant to them emotionally and that they hoped to stay in it until the end; others spoke of their willingness to move into residential care in order to relieve their children of the responsibility of caring. It appeared, however, that few were aware of the complex administration of the social care system in England and did not understand that they could state their preferences or how the MCA could support these:

Hopefully I will probably die [in own home] because I don't want to go into a home, unless I have to, or into an old people's bed-sit with a warden.

Interviewer: Have you made any written formal plans to ensure this?

No, I think that automatically would happen with the council.

Interviewer: Have you made any provisions to prevent being moved into a home?

No, I don't know how I can. (MCA OA 023, female, age 68, white British)

There was an absence of health and social care plans in the formats permitted under the MCA and most participants admitted not having thought about these. They seemed interested with the idea when it was introduced during the interviews and asked for information afterwards. This was in contrast to many financial arrangements in place around joint accounts, direct debit for bills, powers of attorney and wills.

To plan or not to plan?

No straightforward reasons emerged why people chose to make plans or not. Instead, a complexity of predis-

posing factors was identified that tended to evoke two separate responses from participants. These factors included (i) perceived and enacted support from family, (ii) onset of certain conditions, and (iii) postponement of decision-making for an unspecified future.

Perceived and enacted support from family

A majority of participants talked about their disinclination to plan as they felt their spouse or children who knew them best would be able to make decisions on their behalf. Members of the white British group primarily talked about support from their spouse or partner, failing which they were keen to make their own plans and decisions. Tendency to rely on family members was most prevalent amongst members of the black Caribbean group who described networks of family members they could rely on to make the right decision for them:

Well I have got children, I have two daughters, two sons, and they will look after me, well they are looking after me at the moment you know.

Interviewer: What about if you had to move somewhere else, or if you if you needed to be looked after?

I don't know, my children would decide, yes. Well, I know my children don't want me to move out of my home. (MCA OA 018, male, age 80, black Caribbean)

There were, however, participants who perceived support from their families as reason to make arrangements. They felt that setting out their plans would relieve their families of the responsibility of making decisions on their behalf:

Yes, [I have] a Living Will (a common lay term for an advance decision), my doctor, my lawyer, the children know, the point of my doing that is, say I was like a cabbage somewhere, do we pull the plug? Well which one [of my children] has to decide? I don't want any of mine to do that; I would hate to have to do it myself. (MCA 013, female, age 85, white British)

Onset of certain conditions

One likely reason for making plans was the onset of a debilitating illness of some kind. Dementia was discussed as one of these conditions, when participants speculated that there might be little chance of recovery and the prospect of losing capacity to make decisions was heightened:

If I made plans in the future, well I could think of an event immediately that would save me the trouble, if my doctor tells me I have only six months to live, something like that. But I think if a doctor told me that I had dementia, then yes, I

would be making plans in that case, but I can't think of anything else which would precipitate that. Well it is all I can think of at the moment, there may well be others you know, or if I have a sudden debilitating illness I suppose, like muscular dystrophy. (MCA OA 010, male, age 70, white British)

Postponing plans

Although a large proportion of participants acknowledged during the interview that planning may have beneficial effects, they were keen to postpone making any plans themselves for when they got older, in worse health or when it seemed 'more appropriate' to do so. One physically disabled participant described how remaining in her own home was very important to her independence and sense of self:

Because if I get worse – I live alone – if I can't manage – what am I going to do? Fall about the house? I don't want to go into a home.

Interviewer: Would you consider making a plan?

Maybe later, yes, yes, because I don't want to go into a home, not now after everything I have had, I don't want to go into a home.

Interviewer: Yes, of course, so at what point would you make plans?

When I couldn't walk about as much; when I couldn't do things like put the kettle on or whatever. (MCA OA 036, female, age 63, white British)

Support for planning

Participants were also asked about the level of support they felt was available to enable them to make plans and decisions for later life. Participants were first asked about their familiarity with and understanding of key terms and phrases, such as MCA, LPA and living wills (the legal term being AD but this term was not widely understood).

None of the participants had heard of the MCA specifically, despite some understanding that principles of the Act were respected in health and care settings. Some appeared to have an understanding of LPA, knowing that it involved appointment of a trusted person to manage your affairs when one was unable to do so. However, few appeared aware of the change in terms since the introduction of the Act and assumed the Enduring Power of Attorney meant the same as the LPA. Living wills/AD's were rarely understood, and, in some cases, associated with what participants called 'clinics in Switzerland' and euthanasia. These participants assumed that living wills could not be honoured by medical professionals because assisted suicide is illegal in the UK:

Well, at the moment they can't, can they, because it is illegal in this country. But I tend to think doctors do take it into their own hands and I think they probably helped my mum. And having seen the way my father died I am quite grateful, not at the time I wasn't, but just to stop her suffering. I think in those cases it is when someone is in terrible pain with absolutely no help, yes I think they should ... (MCA OA 014, female, age 72, white British)

Participants on the whole appeared unsure where to turn for support with planning. Financial advice and support appeared easier to come by and participants knew where these could be accessed. Having reliable financial advisers to give sound advice was described positively and participants appeared reassured by them:

No, I have a financial adviser so he keeps up to date with everything, and, you know, he is very good – like certain policies that I used to have that he felt that I should cash them in, you know, because I have become ill, he said it is no use carrying on with them, so he has advised me to keep a certain life[style], car, and things like that – but certain policies I was paying in monthly and that and he said it is not worth it at the moment so that is very good. (MCA OA 037, female, age 53, British Indian)

The role of the local family doctor or General Practitioner (GP) appeared to be crucial. Some participants were unsure they could rely on their GP, reporting not always seeing the same GP and feeling not particularly supported by the primary healthcare team. Others felt they could rely on their GP for advice about making plans and that these would be honoured. They were confident in the GP's information and advice regarding living wills/AD's.

When asked whether any local information and advice agencies would be helpful, white British participants said that they were likely to visit local branches of Age Concern (now Age UK), whereas black Caribbean participants appeared reluctant to share personal information with these voluntary agencies. Some from the latter group considered these as less appropriate for their needs and catering more for the majority population. They felt that if they wanted to make plans, they were more likely to consult family members and friends who would direct them to appropriate agencies/people rather than talking to strangers.

Discussion

Limitations of this study include the diverse nature of participants, although large variation within the sample reflects the ethnic diversity of London and other major cities in England. No attempt has been made to compare groups as differences would be superficial and differences between these groups have been identified only if

they appeared significantly relevant to the emergent finding. These merit further investigation as do stratifications across age, gender, sexuality, socioeconomic and health status.

This study explored attitudes of older adults living in the community and likelihood of them taking the opportunity to make advance health and personal welfare plans in accordance with the principles of the recently implemented MCA. Overall, most participants expressed some interest in the new legal framework, although whether this translates to action remains to be seen.

Disposition driven

A key finding of this study is that making prior health and personal welfare arrangements tended to be affected by individual disposition and attitudes to life. These various attitudes tend not to be reflected in information or publicity from health and social care settings, where planning is often conveyed as unproblematic. Not all participants felt planning was necessary or beneficial and in cases of those who had planned, professionals appeared not to have instigated this. This tendency to be a life-long planner or otherwise is reflected in another study (Hill *et al.* 2007), which classified people as 'non-planners', those who always planned, those whose plans got knocked off course, and those who started making provision for retirement only later in life; highlighting that planning for later life was not a natural consequence of growing older. This present study is also in line with others' findings. Financial and funeral plans were more common than deliberated actions in relation to other areas of decision-making (Hill *et al.* 2007), with later researchers reporting that participants find conceptualising ill-health particularly challenging (Sykes & Hedges 2008). Some older people appear to feel that planning is irrelevant to them as they have little to leave their children; reflecting an earlier study where those on higher incomes were more likely to make plans than others (Hayden *et al.* 1999). Attention should perhaps be drawn to the difference between attitudinal research of this kind and what might actually transpire in the future (de Boer *et al.* 2010). In this regard, the role of researchers and educationalists in promoting awareness of concepts such as MCA, ACP and LPA is worth mentioning.

Awareness and legal literacy

A lack of awareness of specific principles of the MCA was also identified, which may have contributed to poor planning. Some, however, gave 'commonsense' definitions of terms. More importantly, participants were unsure where support and advice could be accessed. Financial advice was easier to obtain (Hill *et al.* 2007),

which some found relevant to their situations and prospects. Most had sought the assistance of a solicitor to draw up a will, although some had done this independently through forms acquired from post offices or stationers. The role of commercial businesses in encouraging and enabling older adults to plan for later life was reflected in responses from participants who described feeling reassured by financial advisers and help from solicitors. It is also worth noting the role of research in promoting and spreading awareness; most participants asked for more information from the researcher who then provided publicly available leaflets of information and sources of advice participants could later read and access.

Poor legal literacy may have also contributed to the lack of formal or written health and personal welfare statements of wishes, as found in other studies (Doron & Werner 2008). While discussions with family were a common reason for reassurance that the 'right thing' would be done, this study also found that older people are keen to avoid becoming a 'burden' on their family, specifically on their children (Gott *et al.* 2004), despite which plans had not been made to avoid this. Expressions of interest in making plans, stating wishes and AD's also highlighted that publicity about the MCA has not reached all levels and groups of the older population. Envisaging the potential threat to autonomy of a debilitating illness might be a way of encouraging people to make plans, if they felt that this was appropriate; this could potentially be used in public education campaigns. However, in the context of the continued ethical debate about the validity of advance directives for people with dementia who may lack capacity in the future (de Boer *et al.* 2010), this suggestion for publicity campaigns may be counterproductive. The failure to recognise that one might benefit from information about choices may have resulted in this need remaining latent (Darnton 2005). Independent care advisers, as suggested by Counsel and Care (Burke 2008) may be able to inform older people of their rights and the choices available to them both in the immediate present but also for the future.

Gatekeepers to information and advice

Participants rarely discussed receiving advice about future options from medical or legal professionals. Although this could demonstrate reluctance of older people to question people in authority (Burke 2008), no participant described such discussion being initiated by medical or legal professionals. GPs were potentially the only universally available external source of advice or information in this area and they were generally, but not always, trusted sources. If there is a move to promote making arrangements for possible difficulties in making decisions, GP's might be the most appropriate people to

initiate this discussion routinely with all patients. Others suggested that they would be likely to consider options if someone in a position of authority encouraged them, suggesting that poor legal literacy leads to under-confidence in articulating decisions and statements of wishes. Advocacy or voluntary sector services may help in this regard as they serve as gatekeepers for information and may be in a better position to time such discussions appropriately (Samsi *et al.* 2010).

Publicity and information approaches

Housing was a key issue for participants, either in terms of staying at home until death or willingness to move to a care home in order to relieve others of the burden of responsibility. Public education campaigns promoting advance planning may benefit from addressing practicalities of either decision and may improve public understanding of care options. Finally, a specific campaign to offer advice and information to people with no next-of-kin may be welcomed. The MCA has already made provision for a specific independent advocacy service for 'un-befriended' people who lack capacity to make decisions about an accommodation move or serious medical treatment (see Manthorpe & Samsi 2009). The lack of awareness of this provision may have implications for people with no next-of-kin to have greater confidence that their wishes will be heeded and to encourage them to articulate their choice and plans.

Despite publicity around the MCA, lack of awareness amongst participants highlighted that perhaps intended messages are not reaching the general population. While older people are less likely to target primary sources of information, such as government agencies (Sykes & Hedges 2008), a public education campaign with key messages might target relatively healthy older adults. These messages could foster legal literacy, explaining perhaps that healthcare practitioners are obliged to pay attention to plans that are set out; that health and social care plans may be as important in terms of quality of life as financial and funeral plans; and that planning may be beneficial prior to the possible onset of serious impairment. Incorporating the notion that setting up surrogate decision-making systems may benefit the family as well as older people themselves may make this idea attractive to some older people.

Given the results of one survey which indicated that people were as concerned about the way in which they die as they were fearful of death (Bowling *et al.* 2009), the lack of planning found in this study is significant. In the light of findings that planning appears to be largely driven by individual disposition, stronger public messages are clearly required regarding the availability of resources to set out advance plans and decisions and

the benefits this may have. Presenting the facts and ethos of the MCA, for instance, may encourage people to be aware of their rights, as well as alert them to the possibility that considering health and personal welfare plans may be as important as financial plans.

Acknowledgements

We are most grateful to participants for their time and co-operation and to group facilitators who helped us with contacting participants.

Disclaimer

This study has received financial support from the National Institute for Health Research (NIHR) Programme Grants for Applied Research funding scheme. The views and opinions expressed therein do not necessarily reflect those of Central & North West London NHS Foundation Trust, the NHS, the NIHR or the Department of Health.

References

- Atkinson J.M. (2007) *Advance Directives in Mental Health: Theory, Practice and Ethics*. Jessica Kingsley Publishers, London.
- de Boer M.E., Hertogh C.M.P.M., Droes R.-M., Jonker C. & Eefsting J.A. (2010) Advance directives in dementia: issues of validity and effectiveness. *International Psychogeriatrics* **22** (2), 201–208.
- Bowling A., Iliffe S., Kessel A. & Higginson I.J. (2010) Fear of dying in an ethnically diverse society: cross-sectional studies of people aged 65+ in Britain. *Postgraduate Medical Journal* **86**, 197–202.
- Burke S. (2008) Information, advice and advocacy – power to all the people. In: N. Churchill (Ed.) *Advancing Opportunity: Older People and Social Care*, pp. 112–122. The Smith Institute, London.
- Darnton A. (2005) *Common Good Research: Communicating with Older People: Desk Research Key Findings for Communicators*. Central Office for Information, London.
- Doron I. & Werner P. (2008) Facts on Law and Ageing Quiz: older people's knowledge of their legal rights. *Ageing and Society* **28**, 1159–1174.
- Exley C., Bamford C., Hughes J. & Robinson L. (2009) Advance Care Planning: an opportunity for person-centred care for people living with dementia. *Dementia* **8** (3), 419–424.
- Gamble E.R., McDonald P.J. & Lichstein P.R. (1991) Knowledge, attitudes, and behaviour of elderly persons regarding living wills. *Archives of Internal Medicine* **151**, 277–280.
- Gillick M.R. (2010) Advance care planning: an American view. In: J.C. Hughes, M. Lloyd-Williams and G.A. Sachs (Eds) *Supportive Care for the Person with Dementia*, pp. 263–270. Oxford University Press, Oxford.
- Gilroy R. (2005) Meeting the information needs of older people: a challenge for local governance. *Local Government Studies* **31** (1), 39–51.
- Godfrey M. & Denby T. (2007) *Older People Accessing Information and ICTs*. Centre for Health and Social Care, University of Leeds, Leeds.
- Gott M., Seymour J., Bellamy G., Clark D. & Ahmedzai S. (2004) Older people's views about home as a place of care at the end of life. *Palliative Medicine* **18**, 460–467.
- Hayden C., Boaz A. & Taylor F. (1999) *Attitudes and Aspirations of Older People: A Qualitative Study*. Research Report No. 2. Local Government Centre, University of Warwick, Coventry.
- Hertogh C.M. (2010) Advance care planning and palliative care in dementia: a view from the Netherlands. In: J.C. Hughes, M. Lloyd-Williams and G.A. Sachs (Eds) *Supportive Care for the Person with Dementia*, pp. 271–281. Oxford University Press, Oxford.
- Hill K., Kellard K., Middleton S., Cox L. & Pound E. (2007) *Understanding Resources in Later Life; Views and Experiences of Older People*. Joseph Rowntree Foundation, York.
- Hughes J.C. & Robinson L. (2006) General practice perspectives: co-ordinating end-of-life-care. In: J.C. Hughes (Ed.) *Palliative Care in Severe Dementia*, pp. 116–125. Quay Books, London.
- Manthorpe J., Iliffe S., Cornes M., Moriarty J., Bright L., Clough R. & OPRSI (2009) Ageing cities: public health approaches to creating a mentally healthy London for older citizens. *Journal of Public Mental Health* **8** (3), 20–27.
- Manthorpe J. & Samsi K. (2009) Implementing the Mental Capacity Act 2005: Challenges for commissioners. *Journal of Integrated Care* **17** (3), 39–47.
- Menne H.L., Judge K.S. & Whitlach C.J. (2009) Predictors of quality of life for individuals with dementia: implications for intervention. *Dementia* **8** (4), 543–560.
- Ministry of Justice (2007) *Mental Capacity Act 2005: Code of Practice*. Department of Constitutional Affairs, London [WWW document]. URL <http://www.dca.gov.uk/menincap/legis.htm#codeofpractice> (accessed 21 July 2010).
- National Institute for Health and Clinical Excellence & the Social Care Institute for Excellence (2006) *Dementia – supporting people with dementia and their carers in health and social care* [WWW document]. URL <http://www.scie.org.uk/publications/misc/dementia/index.asp> (accessed 12 April 2010).
- O'Connor D. & Purves B. (Eds) (2009) *Decision-making, Personhood, and Dementia: Exploring the Interface*. Jessica Kingsley, London, 224 pp.
- Office of Public Sector Information (2005) *The Mental Capacity Act 2005*. London [WWW document]. URL http://www.opsi.gov.uk/acts/acts2005/ukpga_20050009_en_1 (accessed 12 April 2010).
- Ritchie J. & Spencer L. (1993) Qualitative data analysis for applied policy research. In: A. Bryman and R. Burgess (Eds) *Analysing Qualitative Data*, pp. 173–194. Routledge, London.
- Samsi K., Manthorpe J. & Rapaport P. (2010) "As people get to know it more": experiences and expectations of the Mental Capacity Act 2005 amongst local information, advice and advocacy services, social policy & society [in press].
- Schiff R., Rajkumar C. & Bulpitt C. (2000) Views of elderly people on living wills: interview study. *British Medical Journal* **320**, 1640–1641.
- Sykes W. & Hedges A. (2008) *Opportunity Age Information Indicators Feasibility Study*. Working Paper number 47. Department for Work and Pensions, London.