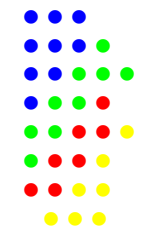


Planning in advance for long term care needs

Jill Manthorpe, Kritika Samsi
Social Care Workforce Research Unit
King's College London

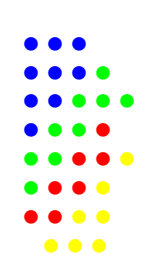
EviDEM Programme of Research –
Mental Capacity Act

Long Term Care Conference 2012



Overall study

- Five year research programme funded by National Institute for Health Research; due to end August 2012
- Looking at the implementation of the Mental Capacity Act 2005 in England and Wales, and how it applies to people with dementia and their carers



Mental Capacity Act 2005

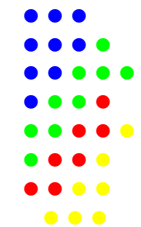
- MCA provides frameworks to enable people to make their own decisions in advance of problems such as dementia (loss of mental capacity)
- Enables people to plan in advance and nominate someone to have Lasting Power of Attorney, who can make decisions if required
- Decisions may include everyday decisions, as well as major decisions about care, treatment and finances

Making decisions about your health, welfare and finances...

Who decides when you can't?

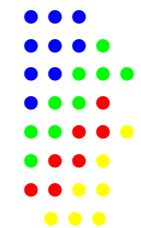


Long Term Care Conference 2012



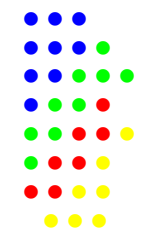
Research Question

How does the Mental Capacity Act support and enable planning among people with dementia living at home and their carers?



Methodology

- Qualitative longitudinal study
- Case studies of 12 people with dementia and their carers
- Living in their own homes
- Interviews every 6 months over 18 months
- Framework analysis used to develop categories



Interviews

Four main topics covered:

- Perceptions of the future

- Sources of support

This paper focuses on **Types of Plans** and
Carers' Perspectives

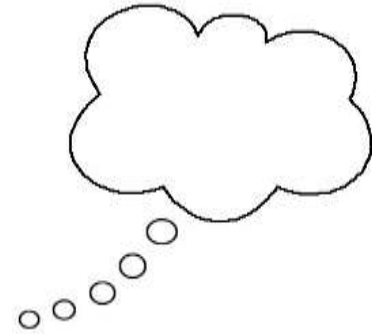
Types of plans

- Diagnosis of dementia was a marker for negative perception of future
- Most worried about outcomes in the future, especially care and support needs
- Despite this, few had formal plans in place
- Wills and funeral plans common
- Health and social care plans less common
- Discussions around health and social care plans had started but in haphazard ways
 - No record necessarily made



To plan or not to plan?

- Context of thinking about future care
 - Perceived and enacted support from family
 - Perceived support from healthcare professionals especially General Practitioner (family doctor)



“No”

Family could be relied upon to make decisions

“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, or if you needed treatment?

“I don’t know, my children would decide, yes. Well, I know my children don’t want me to move out of my home at all, they know what I want with treatment.”

– Male, age 80

Perceived and enacted support from family

“Yes”

Families would be left with difficult choice

“Yes, [I have] a Living Will, 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..”

– Female, age 85

‘Living will’ is term commonly used – legal term is ‘advance decision’

“No”

Healthcare professionals can be trusted to ‘do the right thing’

“I have a very good doctor, there is a group of doctors, and they are very good and the hospital is very good. Well my plan is – I have to work with my doctor and consultant – yeah that is the only plan, to work with my GP. And I mean if I need treatment, I wouldn’t want them to say don’t give her treatment or not because I am not one of those. I would leave it to them.”

– Female, age 78

Perceived support from healthcare professionals

“Yes”

If diagnosed with a debilitating illness

“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. Or, I think if a doctor told me that I had dementia, then yes I would be making plans in that case”

– Male, age 70

Carers' relationship with proxy decisions/plans

- Most carers uncomfortable making decisions about long-term care for their relative with dementia without their relative's involvement
- Spousal carers seemed to find it easier than adult children not living with parent with dementia
- General concern that plans/decisions may change
- Confused about the strength (legality) of formal plans binding them to provisions that may later be reconsidered

Person with dementia's relationship with decisions/plans made for them

- Common concerns that plans/decisions may change
- Those with spouse carers demonstrated greater confidence that wishes would be carried out
- Most were confident that clinicians and practitioners would abide by stated preferences/wishes

How would carers make proxy decisions?

Formal choices

What relative has formally stated in advance care plan

Mutual choices

What carer had discussed with relative with dementia when they had capacity

Retrospective choices

What relative's preferences and wishes would have been

Best interest choices

What is in their relative's best interest

Support for planning



- Very limited knowledge of sources information and advice
- Personalised information and advice cited as far more important than general leaflets and signposting
- Limited understanding and awareness of Mental Capacity Act and provisions to appoint Lasting Power of Attorney

Inequalities in experiences

- Those with family solicitors and knowledgeable family members reported feeling having more support and greater confidence
- Those with limited equity to leave as inheritance saw planning as less important and personal choices as less in their control
- Those with GPs they trust may not realise that they will not have the same GP if they move to a care home

Research gaps

- There is little research on economic inequalities in dementia support – why not?
- Are differences in support and assistance carried over to long term care settings? What compensates?
- What support is available to people with limited family contact or whose family contact (eg partners) decreases? Is anyone responsible?
- What is best way to keep a record of wishes and choices and to ensure these are transferred to care home settings? Is this the care home's role?

Disclaimer:

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Thank you!

- For further details

- Contact:

Jill.manthorpe@kcl.ac.uk

kritika.1.samsi@kcl.ac.uk

