Northern Ireland Assembly's Ad Hoc Joint Committee on the Mental Capacity Bill

Roundtable Evidence Session: 29th June 2015

1. I want to base my initial comments on two pieces of work in which I've been involved. The first was research that looked at the assessment of capacity and best interests in people with dementia who were admitted to medical wards where a question was raised about their ability to go home or whether they should go into long-term care. The second is the report of the Nuffield Council on Bioethics called *Dementia: Ethical Issues*. I should declare that I was on the working party which produced that report and I currently serve on the Council as Deputy Chair, so my advocacy of the report's recommendations should be seen in that light. I shall end with a very brief point about advance decisions to refuse treatment.

2. Thinking of residence capacity and our study of this, I'll start with a quick sketch. A lady with dementia lives alone at home and has been coping reasonably well, enjoying life, with the help of family and good neighbours. She develops an infection, which makes her behaviour more confused so there's considerable concern: she seems much more forgetful, she burns things, she leaves the door open, she gets lost when she goes out and eventually she wanders off in the middle of the night and gets picked up by the police near a *major* road and is taken into hospital. The diagnosis of an infection is quickly made and it's treated, but she's still confused. A question is raised about her ability to live independently at home. Does she have capacity to make this decision?

3. Very briefly, our research suggested that, in the main, assessments of capacity were often informally made, not recorded very well, and, for the most part, reflected the clinician's perception of what would be best for the person. In other words, the assessment of capacity was often conflated with judgments about her best interests. In particular, if she didn't appear to recognize **the risks** attached to going home, she was likely to be assessed as lacking residence capacity and the outcome was more likely to be that she would end up in a care home. The worry is that capacity assessments were based on likely outcomes rather than on the functional test required in the Mental Capacity Act 2005.

4. What do I mean by saying that the assessments of capacity were "informal"? Our observations were that judgements about capacity often reflected a host of influences rather than the result of a legal test. Perhaps she had been disorientated on the ward; a neighbour had told the story about her wandering; perhaps she's wet the bed and her daughter is worried about this; perhaps she's scored poorly on a formal test of her cognitive function. My suggestion is that none of these things in itself adds up to a formal test of residence capacity. But often *informal* information *like* this, or brief "chats" with the patient, contributed to the judgement that the person lacked capacity; and often what followed was placement in a care home.

5. All of this points to the crucial importance of **implementation**. To my mind, how this Bill is implemented will be the most difficult and repeating hurdle to cross.

6. The House of Lords Report on the Select Committee on the Mental Capacity Act 2005 noted the good intentions of the Act, but were critical of its implementation. It criticized *risk-averse* social workers and *paternalistic* clinicians. In addition, what we saw in our research was that many of these decisions are *just very complex*: complex because they involve significant judgements of value, involving values *diversity* and *conflicting* values. Consider, for instance, the judgement as to whether something is simply an "unwise decision" [Section 1(5)] or one in which the information is not being used and weighed appropriately [Section 4(1)(c)]. I note, moreover, the difference between this latter criterion in your Bill and the similar criterion in the MCA in England and Wales. Here, Section 4(1)(c) not only says that the information must be used and weighed, but also the person must be able "to appreciate the relevance" of the information (which could mean, be suitably *risk-averse*!). This may be helpful, but it may also simply make the judgement more complex. Part of the difficulty is that health and social care workers are strongly driven by the inclination to do the best thing, which influences their judgements about capacity and then their judgements about best interests.

7. The implementation of the Bill, once an Act, must be accompanied by a huge (and continuing) educational effort over the whole of the health and social care sectors. In addition, close attention *must* be paid to the drafting of the Code of Practice. In the case of a capacity such as residence capacity, with its implications for human rights (deprivation of liberty etc.), it *may* be useful to spell out (as in the case of testamentary capacity) the information that the person must be able to understand, recall, appreciate and use. We've suggested, for instance, that the relevant information concerns: **why** a change of residence is being proposed; **what** is being proposed; the **other options**; and the **likely consequences** of making any particular decision.

8. Another issue to emerge from our study was to do with the status of the family and the role of the Independent Mental Capacity Advocate (or IMCA). The IMCA has considerable powers, much as set out for the *independent advocate* in your Bill at Section 90. But we felt that there was a discrepancy between the statutory powers of the IMCA and the powers of the family where no IMCA was required. Families would go into meetings to decide on a loved one's best interests without access to "any health records" (Section 90(4)(a)) or any other "records relating to P's care, treatment or personal welfare" (Section 90(4)(b)). I guess that under your provisions, almost all the people I am thinking of – those lacking capacity because of dementia being placed in care homes – would be facing a possible deprivation of liberty (as in Section 36(1)(a)) and, hence should have the safeguard of an independent advocate (under Section 35 as per Section 86), which is a *good* thing. But we need to recognize that there might be examples where it could be argued that there was no actual deprivation of liberty and yet the person was still **vulnerable** in a manner that would warrant the use of an independent advocate. Think, for example, of someone on the *borders* of capacity where there's considerable pressure to accept long-term care.

9. Turning to the **Nuffield Council**'s report, there are two recommendations I wish to highlight. First, in Section 12 (Acts of Restraint), as in the MCA 2005, your Bill sets out that an act of restraint must be "a proportionate response" to the likelihood and

seriousness of harm to the person. The Nuffield Council recommended that "additional guidance" should be provided "to carers on when restraint might be considered to be "proportionate"" (Nuffield Council Recommendation 11, p. 108). In this connection, I note increased interest in the notion of "*forced care*", say for people in care homes with urinary and faecal incontinence, where care staff *on the ground* are left to decide what is "proportionate".

10. Secondly, the Nuffield Council's report made several recommendations covering research (18-20; page 142). I think the provisions in your Bill to do with research (Part 8) are sensible and standard. But the Nuffield Council report would suggest: first, "some form of (non-binding) advance statement on research participation which could influence decisions … after loss of capacity"; secondly, "that serious consideration be given to enable [Lasting Powers of Attorney] … to be explicitly extended to include decisions over research"; and, thirdly, that the Code of Practice "should include clear guidance on the procedures to be followed when capacity is lost during involvement in a research project covered by the Act…".

11. I wish to end by noting the relative lack of comment about advance decisions to refuse treatment. I believe these are covered under common law (Section 11(2)). But I cannot help anticipating legal battles over whether or not an effective advance decision to refuse electro-convulsive therapy, or even to refuse antidepressants and antipsychotic medication, might be regarded as "providing life-sustaining treatment" (Section 11 (4)(a)) or as acts which prevent serious deterioration in the person's condition (Section 11 (4)(b)). It may be **un**helpful not to give more guidance on these points.

12. Many thanks for your attention.

Julian C Hughes

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Homeward bound or bound for a home? Assessing the capacity of dementia patients to make decisions about hospital discharge: Comparing practice with legal standards

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ABSTRACT

Background: This article stems from a larger project which considers ways of improving assessments of capacity and judgements about best interests in connection with people with dementia admitted to acute hospitals with respect to decisions about place of residence.
Aims: Our aim is to comment on how assessments of residence capacity are actually performed on general hospital wards compared with legal standards for the assessment of capacity set out in the Mental Capacity Act, 2005 (MCA).
Method: Our findings are grounded in ethnographic ward-based observations and in-depth interviews conducted in three hospital wards, in two hospitals (acute and rehabilitation), within two NHS healthcare trusts in the North of England over a period of nine months between 2008 and 2009. Twenty-nine patient cases were recruited to the study. We also draw from broader conceptions of capacity found in domestic and international legal, medical, ethical and social science literature.
Results: Our findings suggest that whilst professionals profess to be familiar with broad legal standards governing the assessment of capacity under the MCA, these standards are not routinely applied in practice in general hospital settings when assessing capacity to decide place of residence on discharge from hospital. We discuss whether the criteria set out in the MCA and the guidance in its *Code of Practice* are sufficient when assessing residence capacity, given the particular ambiguities and complexities of this capacity.
Conclusions: We conclude by suggesting that more specific legal standards are required when assessing capacity in this particular context.

1. Introduction

Published figures on the impact of dementia in the UK make for sobering reading. It is estimated that 820,000 people in the UK currently have dementia with numbers projected to rise to over a million people by 2021 (Alzheimer's Research Trust, 2010). Dementia results in a progressive decline in multiple areas of functioning, including memory, reasoning and communication skills, as well as physical skills needed to carry out daily activities (Hughes, 2011). Recent estimates suggest that around 25 million or 40% of people in the UK have a close family member or friend with a diagnosis of dementia (Alzheimer's Research Trust, 2008). The cost to the UK economy has been estimated to be between £17 and £23 billion a year (Alzheimer's Research Trust, 2010; Department of Health, 2009).

The rising prevalence of dementia in the UK has had a significant impact on general hospital admissions. Studies suggest that in the population of older people in general hospitals the prevalence of dementia is between 13% and 26% (Inouye et al., 2006; Raveh, Gratch, Yinnon, & Sonnenblick, 2005). A recent policy guidance document reports that 40% of people in general hospitals in the UK have dementia (Department of Health, 2010). Older patients with dementia are more likely to require treatment in a general hospital for co-morbid health issues and are at a greater risk of requiring treatment for injurious falls, dehydration, malnutrition and infection than elderly patients without the diagnosis (Natalwala, Potluri, Uppal, & Heun, 2008; Van Doorn et al., 2003). For many dementia patients, a general hospital admission can be a 'determining event' that hastens the transition from home into residential care (Brindle & Holmes, 2005). In a longitudinal survey of publicly funded admissions carried out in the UK in 1995 and 1996, Bebbington et al. found that 52% of admissions to care homes came from hospitals (Bebbington, Darton, & Netten, 2001). McCusker, Cole, Dendukuri, Han, and Belzile (2001) showed that

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around 30% of patients over 65 years were admitted to long-term care in the 12 months following a medical admission. Reinforcing the recommendations of the National Dementia Strategy (Department of Health, 2009), improving effective hospital discharge for older people with dementia is highlighted as a priority in the delivery of quality care (NHS Confederation, 2010).

A significant number of older patients will be admitted to a general hospital from the community where they have been living independently or with community support. At the point of discharge they often express a desire to return home (Mackenzie, Lincoln, & Newby, 2008; Unsworth, 1996) even though their concept of 'home' may relate to a time in the past, without the dangers they have encountered in more recent times (Sikdar, 2006). Alternatively, health and social care professionals, along with relatives, may express concerns that home no longer represents the most suitable environment for the person's future wellbeing, with discharge into long-term residential care proposed as the 'safer' and more appropriate discharge option. Where such disagreements arise, this may trigger a formal assessment of the patient's capacity (Stewart, Bartlett, & Harwood, 2005). This is especially the case when, simply on account of the diagnosis of dementia, the person's decision-making capacity is called into question, despite the requirement in the Mental Capacity Act (MCA, 2005) that there should be a presumption in favour of the person having capacity. The outcomes of such assessments are of profound importance, both legally and ethically, as they determine whether individuals have legal capacity and can therefore exercise personal autonomy and have their wishes upheld, or whether they lack capacity and can be subjected, without consent and on the protective conditions prescribed by law, to the will of others.

Over the past 40 years a number of valuable empirical research studies have been conducted internationally and in the UK, which have attempted to conceptualise the notion of capacity and its assessment (Appelbaum & Grisso, 1988, 1995; Roth, Miesel, & Lidz, 1977; Weisstub, 1990; Wong, Clare, Gunn, & Holland, 1999; Wong, Clare, Gunn, Watson, & Holland, 2000). These studies, which have largely focused on capacity in relation to decisions about medical treatment and participation in research trials, have done much to inform and shape contemporary models of incapacity law and clinical practice worldwide. During this period in the UK important demographic and social changes, coupled with crucial mental health and capacity law reform, have led to an increased interest in capacity and its assessment generally (Suto, Clare, Holland, & Watson, 2005). In England and Wales, the MCA sets out broad legal standards against which mental capacity is now measured. Following its enactment, concerns surrounding older people and whether they are being deprived of their liberty in hospitals and care homes and should be made subject to Deprivation of Liberty Safeguards under the MCA (Department of Health, 2007; Ministry of Justice, 2008) have meant that assessments of capacity in relation, in particular, to deciding questions of residence should now receive closer scrutiny than ever before.

To date, little research has been conducted on how current legal standards are applied in clinical practice when assessing the capacity of older patients and whether they are capable of deciding where to live on discharge from hospital (Mujic, Von Heising, Stewart, & Prince, 2009, Shah, Banner, Heginbotham, & Fulford, 2009, Shah, Heginbotham, et al., 2009). Similarly, little judicial guidance is available through decided case law on how capacity should be determined in this specific context.[2] This is surprising given that discharge decisions relating to place of residence can present difficult practical and ethical dilemmas for clinical teams (Brindle & Holmes, 2005) and form some of the most common mental capacity issues for older people at the point of discharge from hospital (Mujic et al., 2009). As such, the way we assess a person's capacity to decide issues of residence on discharge from hospital is an increasingly important matter which clearly demands more attention.

The aim of this article, therefore, is to comment on how assessments of residence capacity are actually performed on general hospital wards in England and Wales, and to consider how such assessments compare with broad legal standards for assessing capacity set down in the MCA. Our findings are drawn from observations of capacity assessments carried out on three general hospital wards in the North East of England and form part of a larger research project which aims to improve the assessment of capacity and best interests for dementia patients on discharge from hospital when making decisions about going home or going into long-term residential care. Our comments here are grounded in ethnographic research involving ward-based observations, formal qualitative interviews, informal conversations and documentary analysis of medical and other ward-based records. Anonymisation and pseudonyms have been used to protect the confidentiality of all participants. We also draw from broader conceptions of capacity found in domestic and international legal, medical, ethical and social science literature. Future publications will highlight other areas of interest and data that emerged during this study, whereas the focus of this paper is on the legal issues that surround the assessment of the particular capacity to make decisions about place of residence.

We begin by outlining the current statutory framework for assessing decision-making capacity under the MCA. We then consider the 'functional' approach to capacity assessment adopted by the legislature in England and Wales and how this approach operates within the specific confines of the MCA. We then set out to identify, through analysis of research data, the extent to which current legal standards are being employed in general hospital wards when capacity assessments are made to determine placement or residence capacity of patients with dementia when they are discharged from hospital. We show that a more comprehensive, contextual approach to the assessment of capacity is needed in relation to decisions about place of residence for such patients owing primarily to the ambiguities and complexities involved in and highlighted by this particular capacity. In particular, identifying the relevant information that patients must understand in order to demonstrate decisional capacity is especially challenging for professionals (Wong et al., 1999). Our findings suggest that there is currently a wide inconsistency of approach amongst professionals when identifying 'information relevant to the decision' (Section 3 (1) (a) MCA) during the assessment of residence capacity. Given that 'the more information that the person must understand, and the more complex the nature of that information, the more impact it will have on the individual's capacity to understand' (Wong et al., 1999), we suggest that this particular aspect needs to be more carefully prescribed in this specific context. We therefore conclude by suggesting four key pieces of information that those falling within the confines of the MCA must understand, retain and weigh in the balance (as well as communicate) in order to demonstrate decisional capacity in relation to choice of residence following discharge from hospital.

2. The legal position

Routine assessments of patients' capacity to decide place of residence on discharge from general hospital are carried out by members of the multidisciplinary team (MDT) of social and health care professionals. It is rare for the courts to get involved in these decisions, even when the rationality of the patient's decision to return home is called into question and capacity becomes a 'live issue' (Brazier, 2007). Nonetheless, it is important to bear in mind that capacity is a legal concept and the courts are the ultimate arbiters of any disputes concerning its assessment. This must be the case, as capacity decisions can potentially

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[2] Since this article went to print, judgment in the case of *KK v STCC* [2012] EWHC 2136 (COP) (26 July 2012) has been handed down by Mr. Justice Baker which provides important guidance on how the courts approach the assessment of capacity to decide residence and care in relation to older people with dementia.

deprive people of their human rights and liberties and so such determinations must comply with legal (and ethical) standards and be justifiable in law (BMA and the Law Society, 2010).

In the jurisdiction of England and Wales, the MCA and its accompanying Code of Practice (Department of Constitutional Affairs, 2007) establishes a broad statutory framework through which decisions are made on behalf of adults who lack relevant decision-making capacity. Embedded within this framework, at Sections 2 and 3 of the Act, is a statutory definition and test for assessing capacity for the purposes of the Act.

A person lacks decision-making capacity in relation to a matter if at the material time he or she has ‘an impairment or disturbance in the functioning of the mind or brain’ (s2 MCA) which renders him unable to: (1) understand information relevant to the specific decision being made; (2) retain that information for as long as is required to make the decision; (3) use or weigh that information as part of the process of making the decision; or (4) communicate the decision made (s3 MCA). Where one or more of these four key abilities is absent, decisions can be made on behalf of the person if there is a reasonable belief on the part of the decision maker that capacity is lacking and what is being proposed is in the incapable adult's best interests.

The MCA adopts a ‘functional’ approach to capacity assessment, aligning itself with the approach recommended by the Law Commission when it reviewed the adequacy of the laws in England and Wales affecting mentally incapacitated adults in the early 1990s (Law Commission, 1995). The Law Commission considered three broad approaches to capacity assessment: the ‘functional’, the ‘outcome’ and the ‘status’ approach. Although of the three approaches recognised, the functional approach was and remains the most difficult to implement, nevertheless it has received the most informed empirical, clinical and legal support to date (Suto et al., 2005).

The functional approach asks whether the person being assessed has demonstrated that he or she can weigh up any foreseeable risks and benefits associated with the decision in order to arrive at a choice. The Law Commission described this as whether someone can understand the ‘nature and effects’ of relevant information (Law Commission, 1995). Relevant information is defined under the MCA as ‘information about the reasonably foreseeable consequences of deciding one way or another, or failing to make the decision’ (s3 (4) MCA). As such, it is the process of *how* the patient arrives at the decision and the extent to which the person's decision-making skills and abilities meet the demands of the situation (Grisso, 2003), rather than whether the decision is rational or sensible, that is the focus of the question.

The functional capacity test under the MCA operates subject to the assumption that an adult is presumed to have legal capacity to make personal decisions – including decisions about where to live and with whom – until proven otherwise (s1 (1) MCA; Appelbaum & Roth, 1981). For a number of elderly patients with cognitive and/or emotional impairments, a diagnosis of dementia may be enough to call this presumption into question. However, capacity cannot be established ‘merely by reference to a person's age, condition, or aspect of his behaviour, which might lead others to make unjustified assumptions about his capacity’ (s2 (3) MCA). So people with organic or psychiatric illnesses will not automatically be presumed incapable without further investigation into their understanding and cognitive abilities. This is a rejection of the status approach to capacity assessment, which would render a person incapable solely on account of his or her membership of a group or population with one or more particular characteristics (Suto et al., 2005). Such an approach has garnered little support in empirical research studies as it imperfectly assumes all populations (e.g. all people with dementia) are homogeneous and all decision making equally demanding (Suto, Clare, & Holland, 2002). The status approach has also been firmly rejected in law as being ‘out of tune with the policy aim of enabling and encouraging people to take for themselves any decision which they have capacity to take’ (Law Commission, 1995) and contrary to human rights principles; a position which is now reflected in the statutory wording of the MCA at Section 2 (3) mentioned above.

With the functional test, a number of important legal principles need to be emphasised. First, the capacity assessment process under the MCA is time- and decision-specific. Although the MCA recognises that a person's decision-making capacity can be permanent or temporary and may fluctuate, even over a short period of time, legal capacity is assessed at a particular point in time in relation to a specific matter. It may be that an assessment should be delayed if it is thought that capacity would return and this would accord with the person's best interests (s4 (3) MCA). Lawyers tend to refer to people as having ‘lucid intervals’ in which they may be able to demonstrate sufficient functional capacity for their decisions to become legally binding. If a person is incapable of making a particular decision at a material time, this does not mean he or she lacks capacity generally in relation to all matters; she simply lacks capacity in relation to the specific task in question (Re T [1992] 4 All E.R. 649). Accordingly, the law accepts that capacity is a quality which has a tendency to ebb and flow, but for legal purposes its assessment must be taken at a snapshot in time, in relation to a specific matter and is decided on an all-or-nothing basis (Buchanan, 2004).

Second, according to common law principles, capacity must be assessed in relation to the gravity of the decision being made (*Re T*). This does not mean that where decisions give rise to more serious consequences there will be a change in the test for capacity; but rather that a greater demand will be placed on a person's abilities in relation to the particular decision when the outcomes are particularly grave or risky (Wong et al., 1999). Once this principle is added to the first, i.e. that capacity is time- and decision-specific, it becomes clear that the particular information required to make the decision is vital.

It is important to note, too, that a person's ambivalence or evasiveness about questions of residence post-discharge does not necessary lead to a finding of incapacity. Lady Butler-Sloss in Re B (Consent to Treatment: Capacity), Re [2002] 1 F.L.R. 1090, at para. 35 stated that ambivalence about whether to receive medical treatment would only be relevant to the issue of capacity, ‘if, and only if, the ambivalence genuinely strikes at the root of the mental capacity of the patient’.

Further, unwise decisions do not, by themselves, lead to a finding of incapacity. It is irrelevant that the decision is considered unwise in the eyes of the majority, as long as it is broadly consistent with the individual's own value system. This is made explicit at s1 (4) of the MCA: “A person is not to be treated as unable to make a decision merely because he makes an unwise decision.” The MCA therefore rejects the ‘outcome approach’ to capacity assessment which focuses on the final decision made and renders a person incapable on the basis that any decided outcome is inconsistent with either conventional values, or is one with which the assessor disagrees (Wong et al., 1999).

Again, in the case of B, Lady Butler-Sloss highlighted the importance of not conflating the concepts of capacity with best interests in the context of deciding whether a person has sufficient capacity to decline medical treatment. She said at para. 100:

> *“it is most important that those considering the issue [of whether a person has sufficient mental capacity] should not confuse the question of mental capacity with the nature of the decision made by the patient, however grave the consequences. Doctors must not allow their emotional reaction to or strong disagreement with the decision of the patient to cloud their judgment in answering the primary question whether the patient has the mental capacity to make the decision.”*

Finally, existing common law tests of testamentary capacity (Banks v Goodfellow (1869-70) L.R. 5), capacity to gift, (Re Beaney (deceased) [1978] 2 All E.R. 595), marry, (Sheffield City Council v E & S [2005] 1 F.L.R. 965), to litigate, (Masterman-Lister v Brutton & Co and Jewell & Home Counties Dairies [2003] 3 All E.R.) etc., which have developed more specific, contextual legal standards in the courts, are not replaced by the MCA. Instead, when the courts interpret such cases in the future they are given wide discretion to adopt the MCA test ‘as they think fit’ in these contexts (MCA, Code of Practice, para. 4.33), allowing the various elements of what a person needs to understand and weigh in relation to each specific test to survive the more standardised requirements of the MCA. It is important to highlight the existence of these specific common law capacity tests since we shall argue that similar, more specific standards should be applied when assessing residence capacity on discharge from general hospital.

3. Methods

3.1. Epistemological perspective

The perspective of constructionism underpinned our study design and methods. Constructionism suggests that each individual constructs his or her own perception of reality and that researchers subjectively reinterpret the accounts of study participants (Gergen & Davis, 1985; Schwandt, 2000).

3.2. Study design

Ethnographic research methods were chosen to complement the exploratory nature of the research and to provide detailed and rich description of concrete events and interactions (Hammersley & Atkinson, 1995). Ethnography has its roots in anthropology and the study of cultural interactions within small groups and societies. This is an approach with an established tradition in medicine to explore the cultures of those delivering and the recipients of medical care (Pope, 2005). Institutional ethnography allows the study of strategic issues and problems in institutions, such as hospitals, and the practical implementation of key legislation at ward level (ten Have, 2004). The provisions of the MCA had been disseminated within hospitals for seven months prior to the start of the research. Ethnographic observation and qualitative interviews sought an in-depth understanding of how decisions about capacity and judgements about best interests were arrived at in connection with whether or not a patient should be discharged either home or to long-term care.

3.3. Ethical issues

Ethical approval was gained from the NHS regional ethics committee (Newcastle and North Tyneside 2 Research Ethics Committee Ref No: 08/H0907/50). In line with the MCA, where it was deemed that a patient lacked capacity to consent, a personal or nominated consultee was approached to seek a view concerning the person's participation in the research (MCA s32 subss. (2) and (3)). People who lack capacity are often excluded from research, but we considered the views and experiences of this often unrepresented group as critical in terms of addressing the research question and maintaining a person-centred approach (Kitwood, 1995). We also operated a process of continuous consent (Woods & Pratt, 2005) in order to ensure that patients with borderline capacity to consent to participate in research were included in the study whenever possible. All staff consented to be observed, and where selected, to participate in qualitative interviews. To maintain confidentiality, all transcripts of fieldwork notes, observations and interviews were anonymised. Only the key researcher (MP) can identify individual participants.

3.4. Ethnographic fieldwork

Fieldwork was conducted over nine months between June 2008 and June 2009 (incorporating a three-month analysis period after 6 months). Data collection (by MP) took place over 111 days supervised by JB.

3.4.1. Study population and participant sampling strategy

Three care of the elderly wards (acute and rehabilitation) in two hospitals within two NHS healthcare trusts in the North of England were selected to reflect differences in ward case mix and organisational culture. Since we proposed a comparative case study analysis we used a purposive sampling strategy that involved developing a variable sampling matrix in order to ensure a diverse range of participants (Strauss & Corbin, 1998). Unlike random sampling in quantitative research, a purposive sampling strategy does not seek statistical representativeness of the sample selected. Rather, cases are selected in order to highlight the generalisability of cases to theoretical propositions. The process of purposive case selection identified similar cases in each participating ward on the basis of mental capacity. Using ward records and informal conversations with members of ward staff the key researcher identified patients who appeared to have mental capacity to make decisions about their discharge, patients who appeared to lack capacity and some for whom it was unclear about their capacity to make discharge decisions. Within each of these three groups, cases were selected to illustrate different medical reasons for admission, living arrangements, previous use of formal homecare services and levels of social support. Analysis and case selection went hand in hand in order to ensure that each cell of the sampling matrix was populated with at least one case. Case identification ceased in each ward once data saturation was achieved and no new and different cases were identified.

3.4.2. Fieldwork observations

To understand what influenced capacity and best interest decisions, detailed field notes captured key ward-based interactions and events involving the whole range of health and social care professionals, people with dementia and their families. These included routine activities such as consultant-led ward rounds, MDT meetings, case conferences and discharge planning meetings, as well as more informal interactions. Patients' medical records were also reviewed.

3.5. Interviews

Qualitative interviews were conducted with patients (N = 29), a nominated family member (N = 28), and a broad range of healthcare professionals, including both senior and junior doctors (physicians and psychiatrists), nursing staff (qualified and non-qualified, senior and junior, including a psychiatric liaison nurse), occupational therapists, social workers, a physiotherapist and an Independent Mental Capacity Advocate (IMCA) (N = 35). Interviews with patients and family members occurred around the time of discharge and, where possible, three months after discharge. The purpose of these interviews was to access personal experiences, thoughts, understanding and values. In addition, interviews with professionals specifically explored participants' understanding and knowledge of the MCA and how capacity and best interests were usually assessed up to the point of discharge. All interviews were used by the researcher as an opportunity to clarify and ‘validate’ emerging themes in her observations and interpretations. All interviews were digitally recorded, transcribed verbatim and checked prior to analysis.

3.6. Focus groups

To supplement the hospital-based fieldwork and access a broader range of perspectives and experiences, a series of focus groups were held in the period between April and May 2009 with three groups of healthcare professionals (N = 22) and one group of three carers with two staff members from the voluntary agency which supported them. In addition to hospital specialists, the professional focus groups included general practitioners (including a trainee) plus social workers, occupational therapists, nurses (including an assessor for nursing home placement), psychologists, a care home manager and a chaplain with expertise in the field of dementia care. The focus groups were asked to consider three hypothetical cases derived from the observation data and to discuss how capacity and decisions about best interests might be improved. The groups were facilitated by two members of the research team, one leading and the other taking observational notes (JB, JCH, HG, and MP). Discussions were digitally recorded, transcribed, and included in the overall analysis.

3.7. Analysis

From transcripts of fieldwork notes, interviews, focus groups and memos the key researcher synthesised the decision-making process for each case. These ‘case studies’ facilitated case comparisons using the constant comparative method (Glaser & Strauss, 1967). Memos, which focused on individual emergent themes or concepts, were written in order to explore and develop the data (Charmaz, 2006). Transcripts of the primary data and ‘case studies’ comprised the ‘data’ for analysis in data workshops (MP, JB, and JCH) where key themes were identified and a coding frame developed. NVivo software (NVivo, 2010) was used to manage the data.

4. Results

Analysis of the 29 cases revealed a number of important issues relating to how assessments of capacity to decide residence were being carried out in practice compared with current legal standards under the MCA. Our key findings below have been grouped under headings which reflect three main themes emerging from our data, namely: whether a functional approach to capacity assessment was routinely adopted by professionals; whether such assessments were being carried out in a formal or informal way on general hospital wards; and whether the information given to patients by professionals during the assessment process (being information that the patient was required to understand and weigh in order to communicate a decision) was ‘relevant’ information in the context of this particular capacity assessment.

4.1. A functional approach to capacity assessment

4.1.1. Functional versus outcome

Although on the whole professionals seemed to appreciate that a statutory definition and functional test for capacity existed in the MCA, not all adopted the statutory approach in practice. Relevant information was not always clearly identified and varied between cases. It was not always clear how the information was used to test the person's recall, understanding and ability to weigh matters up before communicating a decision. One social worker provided a clear example of how he approached a formal assessment of capacity to decide residence on discharge from hospital:

> “*Well I don't do the MMSE*[3] *or anything like that – that's nursing or social workers from old age psychiatry – I'm more about where are you? Who are you? Tell me a wee bit about yourself. Tell me a little bit about your family, your past history. Do you know why you are here? You know, erm, what are your wishes for the future? If they're married, tell me about your wife, you know, and if they're able to give me that information then in the main we're talking about someone who has capacity.”* Interview: 02sJ-0206, lines 49–55: Social Worker.

The narrative derived from this social worker's approach would yield some information relevant to a functional assessment of capacity (e.g. if the patient recalls and understands why he or she is in hospital), but other aspects of the interview would be irrelevant (e.g. some details – albeit not all – about the patient's spouse and family); and there are some things the person (arguably) ought to know to make a capacitous decision with respect to place of residence, such as his or her requirements (if any) for assistance, which would not necessarily be covered.

For patients with a diagnosis of dementia or cognitive impairment, where there was uncertainty regarding their capacity, we observed that professionals routinely made assessments that were outcome-driven rather than based on an assessment of mental function. Professionals from a range of disciplines, as shown in the following two quotes, explained how it could be difficult to unpick whether a patient lacked insight into his or her situation, and therefore could not weigh things up properly, or whether the patient was simply being unwise, in which case the decision should be respected.

> *“I think this is an interesting issue around capacity, I think quite often capacity is used, or the issue around capacity is used, as a basis for saying that somebody's made a decision that you don't agree with yeah … [*Later in the interview*]…I mean the difficulty thing is, like I say is about the unwise decision if it's difficult knowing sometimes whether somebody has been able to process the information and make a wise decision, make a capacitated decision or whether in fact they haven't been able to analyse it. I think that's quite difficult sometimes but if you know your patient well enough you can generally judge that.”*
> Interview: 01BsB-0808, lines 192–194 and 351–356: Occupational Therapist (OT).

> “*….erm then it comes down to that thing of whether it's an unwise decision but one made with a full understanding of the risks, or whether it's, you know, a decision, you know and completely no insight what the problems may be, what the consequences are and I think that's when you start to get very concerned about somebody's capacity to make decisions.”*
> Interview: 01AsO-2111, lines 66–70: Consultant.

Where assessors did not agree with patients' decisions, they were prone to interpret the decision as lacking insight and, thus, the decision maker as lacking capacity. Furthermore, ‘best interests’ was often considered by the MDT irrespective of whether or not the patient had the requisite capacity. Issues surrounding ‘best interests’ and ‘risks’ appeared to be prominent factors in the assessment of capacity in the context of dementia.

Although we observed that professionals from both health and social care professed to understand the need to respect unwise decisions, putting this into practice appeared problematic. This seemed especially true for junior nursing staff who appeared more risk-averse; and also for the nursing staff who had developed a closer relationship with the patient on the ward and perhaps felt more accountable for the patient's future welfare. Consultants, and to some extent professionals from social work and psychiatry liaison services, seemed to be more comfortable with the concept of the unwise decision and capacity. As such, how legal standards under the MCA were perceived and implemented in practice varied, not only between the different professional groups observed, but also between individuals practising within those professional groups.

4.1.2. Contrasting case studies

These points can be highlighted by comparing two cases — ‘Mr. Collier’ and ‘Mrs. Gardiner’. As with three-quarters of the patients in our study, both patients lived alone in their own homes prior to admission. On discharge from hospital, one returned home and one was

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[3] The mini-mental state examination (MMSE) is a much-used formal screening tool of cognitive function. It mainly tests memory, but also other cognitive abilities such as reading, writing and drawing. Scores under 24/30 may indicate dementia; but even scores of 27/30 or below may indicate a decline in cognitive function (Folstein, Folstein, & McHugh, 1975; Hodges, 2007).

discharged to residential care. Like approximately half of the patients, both underwent a formalised capacity assessment. Mrs Gardiner's case was, however, unique amongst the 29 cases observed in that the definitive decision maker in her case was a social worker and not a member of the hospital's clinical team.

These cases were chosen to represent two contrasting approaches to capacity assessment. However, they embody many of the factors for the two-thirds of cases in which the patient's capacity was unclear. Whilst these particular cases provide clear examples of either ‘functional’ or ‘outcome-driven’ assessments, in many of our cases there was ambivalence about the patient's mental capacity in relation to hospital discharge.

4.1.2.1. Mr. Collier. In the case of Mr. Collier, there were grave concerns about his safety at home, where he lived alone. The home was untidy. He smoked in bed and his diet was poor. Many of the healthcare professionals involved in his care found it difficult to engage with him, which made it difficult for them to assess his capacity. Ultimately, the lack of engagement was taken to signify a lack of capacity (although not everyone in the team agreed with this) and, despite the patient continuing to express a wish to return home, reluctantly he accepted a trial placement in residential care. At follow-up, he expressed unhappiness because he felt ‘tricked’ by the social worker and doctors into accepting a trial discharge; but there had been no review or sign of any attempts to get him home. One aspect of this case, therefore, is that it shows the importance of the decisions being made given the risk of an ensuing deprivation of liberty. However, it also signals the reluctance of staff to accept the implications of a functional assessment, as shown by this quote from an OT involved in Mr. Collier's care.

> *‘I don't think they've done a formal capacity assessment with him yet [right]. His MMSE was something like 28 out of 30, or 30 out of 30 ….He can relay the information back and he would, technically – which is why I have a bit of an issue with the whole capacity thing. I mean I understand that, I get that you have to have measures in place so that people can, you know, if they have capacity they make that choice, and I understand that people have different, you know, what I class as ‘tidy’ might not be what somebody else classes as ‘tidy’ or whatever, but there must be like a cut-off point where he just clearly isn't coping at home.’*
> Interview: 02sC-1305, lines 262–274: Occupational Therapist (OT).

This is a clear demonstration of the thought that outcomes (e.g. Mr. Collier living at home in a very untidy state) should determine decisions about where Mr. Collier should live rather than a functional assessment of his decision-making capacity. In addition, there appeared to be tensions between preserving the rights of the individual, and protecting wider society (Larkin, Clifton, & de Visser, 2009). For example, at the MDT meeting, when discussing Mr. Collier's behaviour of smoking in bed, the team talked about the risks to the patient, but also to neighbours if the house were to burn down. Hence, the concepts of risk and risk management play an important role in the assessment process vis-à-vis placement. This approach resonated with the majority of cases that we observed.

Indeed, several healthcare professionals, as recorded in the fieldnotes extract below, expressed the opinion that the issue of capacity was almost secondary to the issue of the discharge outcome – in this case safety – when it came to discharge planning.

> *‘…after we finished recording[the interview] she [Psychiatry Liaison Nurse] said that her main point was that it's not really – her “motto” as she put it – was does it matter if the patient has capacity? Really the issue is, is the patient going where they want to go and is everyone happy with it? If that's the case then does it really matter if that patient has capacity?’*
> Fieldnotes: 2-35-0106, lines 216–220.

4.1.2.2. Mrs. Gardiner. The case of Mrs Gardiner, on the other hand, is a good example of where a functional approach to the assessment of the patient's capacity was carried out. Although the patient's decision to return home was considered unwise by the MDT the patient was, nevertheless, found to be capable of making the decision. This assessment was encouraged by a pilot proforma being used on the ward to assist capacity assessments, which closely reflected the criteria of the MCA. The result was that descriptions of the formal assessment were lengthy, well documented and closely followed the statutory requirements of the MCA. In the quote that follows from a doctor involved in Mrs. Gardiner's care, it is acknowledged that there were doubts about the wisdom of the outcome, but the functional assessment of capacity won the day.

> *‘Yeah she was deemed to have capacity and she ended up going home although there's quite a lot of concerns from the nursing staff about how she would manage at home. As far as I know she hasn't come back in again (laughs) erm, erm, but, I think, you know, this, that's the difficulty if you do deem someone that does have capacity erm it's, that you do have to be able to let them make unwise decisions or decisions that may well not be erm sort of what you think is the most sensible decision if they are able to make the capacity about going home….* [later in interview]*…So yeah I'm not sure whether there was doubts about her capacity as such but just whether home was the best, best, best place for her.’*
> Interview: 02AsA-0104, lines 125–131 and 152–154: Registrar.

4.2. Formal and informal capacity assessments

Professionals were observed to adopt informal and formal processes of capacity assessment in practice. These appeared not always to be two separate processes, but could be concurrent or interchangeable. Professionals described informal assessments of capacity as processes that occurred over a period of time and involved gleaning information from various sources, which then fed into the overall capacity assessment. This was often referred to as having a ‘holistic view’ of the patient. It might involve, for instance, an OT home visit, the result of which would be fed into the assessment process to form a general picture of the patient's capacity. It should be noted that such a visit might either be used to inform judgements about the patient's functional ability to weigh things up, or it might encourage an outcomes approach to the assessment of capacity: if the home visit went badly, but the patient still said he or she wished to go home, it might be presumed that this was in itself a marker of incapacity.

Analysis of the 29 patient cases revealed that informal assessments were routinely carried out during ward rounds. Patients were often assessed numerous times, informally, over a prolonged period of time before the decision about their capacity became ‘formalised’. Formal assessments involved conversational exchanges between the patient and the assessor with questions about home-life, reasons for the current admission, the patient's feelings and their expectations concerning the future. Judgements were then made as to whether the patient had given responses that seemed reasonable. Such assessments were still heavily influenced by the more informal, general observations of the MDT, which had been gathered over a prolonged period of time. The following extract illustrates this approach:

> *“You get a feeling about people's general capacity, but then … if a decision is being taken or being made or about to be taken, I think then we'll be slightly more specific about going to the patient and actually exploring the issues in more depth. So I think there's a gut feeling and then sort of you know hopefully, I think it mainly comes about if there's conflict or if there's concerns that we investigate that further by sort of direct questioning.”*
> Interview: 01AsO-2111, lines 24–31: Consultant.

Capacity assessments were not always, therefore, routinely carried out, especially when patients failed to voice their opinions and instead complied with what was being suggested. Evidence from the medical records of our cases suggests that formal assessments were only completed for approximately half of the 29 patients. The reliance on informal processes can again raise the concern that the functional nature of capacity assessments is not being grasped by those working on the front line. And there is evidence that more formal assessments only occur when there is disagreement.

> *'But I don't feel that it happens in real life really. I don't, I think if the MDT and the patient's relatives decide that they should, that their level of requirement is that they might need care, I don't feel that we do assess their capacity if they just kind of, if patients are placid as you call it, if there's no big objection if they're not saying loudly 'I want to go home' then I don't feel that on a routine basis that we assess their capacity to agree with us, we only assess their capacity if they don't.'*
> Healthcare professional focus group 1; lines 835–840.

4.3. Understanding information relevant to the decision

The nature and extent of the information that the patient should be deemed to understand in order to demonstrate decisional capacity varied between cases. The inability of patients to recall earlier conversations with staff on the ward, or confusion around where they were or who the nursing staff were, would on occasions lead to patients being assessed as incapable of making decisions about their future choice of residence. The relevance of such facts to a functional assessment of capacity to decide about place of residence remains questionable.

> *'You know for some people it's actually very straightforward: they plainly don't have capacity because they can't remember, you know, anything. They don't know where they are, they think they're at home, they think I'm their daughter, you know they think they still live with their mother, you know things that are plainly not true and they plainly, even when we treated [the] medical problem, they plainly do not, cannot understand or retain relevant information about the home situation so then it's easy to make a decision that they don't have capacity and then we can make a best interests decision.'*
> Interview: 01-BsQ-1212, lines 71–78: Consultant.

The following extract from fieldnotes suggests that professionals are not always explicit when presenting information to patients or exploring the potential of long-term institutional care.

> "*The consultant said that he had a feeling that the patient might be "up for it", referring to residential care. He also said that they should be honest about it, they should say what it is. He didn't say the word 'euphemism', but he was saying was that they would always say "a bit more care", "somewhere where you can get a bit more help". He said, at the end of the day, what they [the patients] were going into was an institution. I don't think he was suggesting that they would say that it was an institution to the patient, but I think, in his words, what he was saying was that they should say "We're thinking about a residential nursing home for you." So I thought that was really interesting that the consultant felt that the MDT aren't always that explicit when they're exploring opinions of the patient and they do use terms like 'somewhere where you can get a bit more care' and it just may not be very clear to patients that it's being put to them or suggested to them that one of those options is residential care, rather than returning to their original home.*"
> Fieldnotes: 39-080609, lines 297–308: from MDT meeting.

5. Discussion

Decisions to return older people with dementia home, when they possess fluctuating or declining mental functioning, are particularly troubling for professionals. Evaluative decisions required in this type of capacity assessment are often complex and the anticipated risks unpredictable. Throughout our observations and interviews, anxious parties voiced concerns about potential wandering, injurious falls and fire hazards, eating inappropriate or out-of-date food, the inability to manage finances properly and exploitation by carers, relatives and strangers (Waugh, 2009). Even when an elderly person demonstrates the ability to understand and weigh risks, placing a vulnerable person back into a home environment, with uncertain and interminable risks, both to themselves and potentially to others, is a huge responsibility for the decision maker, exposing those concerned to the risk of legal liability when things go wrong.

Clear tensions exist in our current legal model between the notions of autonomy and risk. The MCA's aim of empowering people so that they make decisions themselves wherever possible in the least restrictive environment is balanced incongruously against the need to protect the allegedly or actually incapacitated person and others from the effects of risky or even negligent decisions. At the point of discharge from hospital, professionals are simultaneously responsible for upholding patients' rights to make autonomous decisions wherever possible (under the principles of the Act) whilst protecting patients and others from the effects of hazardous discharge decisions (Larkin et al., 2009). Our observations of clinical practice suggest that professionals struggle to reconcile these competing aims effectively, so that capacity assessment outcomes are often couched in terms of risk and prevention of harm.

In law, the boundary between capacity and incapacity is not static and can advance or retreat depending upon the gravity of the decision or the risks that the outcome of any decision may present to the person or others. In a treatment context, this means that when more serious, life-threatening or irreversible treatment decisions need to be made, then a patient must demonstrate a greater degree of capacity before their wishes are respected. In the context of capacity to decide to return home on discharge from hospital this would mean that a greater degree of capacity would need to be demonstrated by a person who wished to return home to risky home placement. The difficulty with this approach is that treatment decisions, even bad ones, give rise to largely predictable risks. Patients who refuse surgery for breast cancer will risk strongly impaired survival rates (Verkooijen et al., 2005). Doctors can predict, with varying degrees of accuracy, how quickly a cancer will spread and the likely symptoms that the patient may encounter should this happen. Often patients will be presented with a broad spectrum of potential risks and outcomes, the physical impact of which will most often be borne by the patient alone. Regardless of whether a prognosis is correct, as the potential risks are identifiable there is the perception that they can, therefore, be contained and managed. So even when a patient's treatment refusal is morally repugnant to others, society can, at a push, deal with it; the law and the patient's autonomy can be upheld because the risks are contained and firmly within our sights. Risky home placements, on the other hand, give rise to hazards that are illimitable; they are more uncertain and therefore less manageable. For those who make capacity assessments, it is much more difficult in this specific situation not to let those uncertainties influence the outcome of any assessment of capacity, especially when those decisions have the potential to harm third parties.

It has been argued that the law creates too sharp a boundary between those who possess capacity and those who do not, which fails to deal adequately with those who rest at the margin of decisional capacity (Herring, 2009). It is at the margins where the difficult assessments lie and where evidence suggests that capacity assessments can be subjective, idiosyncratic procedures where the outcomes are often unpredictable and inconsistent. As Kapp notes 'the various parties generally "bumble through", extra legally as best they can. They do this based on informal, working clinical judgments about capacity and the cooperation (or complicity, depending on one's attitude to the propriety of "bumbling through") of willing and available family members, friends, and health care and social care providers.' (Kapp, 2002). Yet the legitimacy of our current legal model relies heavily on health and social care professionals making accurate and reliable 'neat, clean, dyadic (either/or) distinctions between decisional capacity and incapacity' (Kapp, 2002). In reality, capacity is rarely seen in such black and white terms and operates at the margins in varying shades of grey.

Our observations of clinical practice (albeit on only a few wards in one part of the UK) reflect this analysis. Informal assessments of a patient's capacity, based on a collection of subjective judgements, are routinely made by the MDT or by relatives, often over extended periods of time. During this process legal standards are not always applied, or are applied selectively, in order to arrive at a solution or outcome that is considered 'best' for the patient. This raises the question whether current legal standards are sufficiently robust to evaluate this particular capacity effectively or whether the assessment of a person's capacity to make decisions about whether to return home from hospital requires more specific legal standards, greater interventions and safeguards. We suggest they do. Although limited safeguards exist under the MCA when local authorities and NHS trusts are making decisions about a change of accommodation for a patient who lacks capacity, in that they are now required to appoint an independent mental capacity advocate (IMCA) to represent that individual if there are no family or friends to support them, no independent safeguards exist when family members are present. Older people with a diagnosis of dementia are in a particularly vulnerable position, especially at the tail end of life when it is easy for their voices not to be heard. To restrict (or even deprive) older people of their liberty by deciding that they should spend the rest of their lives in institutional care, against their wishes, potentially violates one of the most fundamental human rights – that of personal liberty – and is a decision which calls for robust legal standards and close clinical scrutiny (O'Keefe, 2008).

Since the MCA came into force in 2007, a programme of mandatory training for local authorities and NHS Trusts has been rolled out across England and Wales. Early studies suggested that some NHS trusts may have been slow to implement training policies. In 2009, a small pilot study conducted by Shah et al. found that fewer than 50% of the consultant old age psychiatrists surveyed reported that the MCA training in their trusts was mandatory (Shah, Banner, et al., 2009). Whilst this figure represents an early snapshot of training in one sector of the NHS, and may not represent current trends, more recent studies have begun to focus on the efficacy of such training amongst NHS and social care staff generally and whether it produces any discernible benefit to participants. In 2011, Willner et al. conducted a study that aimed to assess the extent of knowledge of the MCA amongst new recruits to a NHS Trust by means of a true/false questionnaire (Willner, Bridle, Dymond, & Lewis, 2011). Their findings revealed no significant differences in performance between staff who reported having previously received training on the MCA and those who had not, giving rise to concerns about how much information is being retained by participants in MCA training. There are also problems meeting the specific training requirements of such a diverse group of health and social care professionals and IMCAs who are required to understand key provisions of the MCA in their respective roles (Cowan, 2007, Jones, 2005). Although our findings suggest that even the use of a simple proforma (for example in the case of Mrs Gardiner) can lead to a better understanding of the Act and more comprehensive record of assessment, which is more closely aligned to the legal standards of the MCA, few such interventions were evident in practice during this study. Instead, assessment practices were largely idiosyncratic in their approach and varied considerably between cases. Professionals were left to determine which information they considered material or relevant to the decision and how much information was to be imparted to the patient during the assessment process. This had an important influence on the outcome of any assessment since it tended to yield subjective and unpredictable outcomes.

6. Conclusion

We conclude our study, therefore, by proposing that a more specific test should be adopted when assessing capacity to decide where to live on discharge from hospital, given the inherent complexities that this particular decision presents. This would mean that in this specific context, what the patient is required to understand and weigh – the 'relevant information' that is material to the decision – would need to be more precisely drawn, just as more specific legal standards are applied when assessing capacity in other contexts, as in testamentary capacity.

We propose that patients (who are in hospital) would be assessed as unable to make a decision about where they will live after their discharge from hospital if, in accordance with the MCA, they were unable to understand, retain, weigh and communicate the following information:

- Why they have been in hospital (hence, this must have been explained to them);
- The social arrangements that are being proposed for them on discharge, i.e. whether they will be returning home or moving to another place of residence and with whom they will be living, if anyone, (hence, these things should have been discussed with them);
- The ways in which it is being suggested they will or might require help (if at all) after their discharge from hospital and the care options they would have available to them (hence, the relevant issues and options, including the justifiable concerns of others, must have been discussed with them);
- Those persons and services able and willing to provide help and the nature of the help that can be provided (hence, this must have been discussed with them).

It may be that the person has been told that they require adaptations to their home and twice-daily visits from homecare and it is this information that they would be required to understand, retain, weigh up and communicate; but they may reject that these things are required and still have capacity if they have demonstrated the required functional ability.

The above recommendations are based on the premise that when assessing an individual's capacity the amount and relevance of the information given to individuals, to allow them to make a decision about a proposed course of action or its alternatives, will have a direct bearing on the outcome of the assessment. Assessing a person's capacity to decide where to live will usually require the assessor to have a great deal of information concerning the patient's past and current living arrangements, their current and future care needs and the person or people who may be willing to meet these needs. Only by gathering this information can the assessor present the various options, alternatives and risks associated with a particular choice of residence to a patient so that they can understand and weigh those factors in the balance in order to demonstrate decisional capacity and make an informed choice. Healthcare professionals charged with making such decisions must, therefore, ensure that patients with dementia are provided with all of the relevant facts on which they will be assessed and judged. This must be done in a manner that is meaningful, which conveys the underlying purpose and aim of the assessment process. By adopting more specific criteria as regards to what is 'relevant information', it is hoped that future discharge decisions can be made more openly, in a way that is more defensible in terms of both the ethical and legal frameworks within which care is provided.

Our study has highlighted a number of practical and conceptual tensions faced by professionals when assessing the capacity of dementia patients to make decisions about where to live on discharge from hospital. It has also drawn attention to the need to re-examine current legal standards when assessing capacity in this context. We have ventured to suggest ways in which current legal standards can be enhanced. There is clearly also a need, however, for additional empirical study to test the effectiveness of our proposals and to clarify the issues raised in this article. We are aware that, at present, there is little or no quantitative evidence regarding the assessment of capacity to choose a place of residence. At best, therefore, future research might involve 'mixed methods', to include qualitative and quantitative research in order to test the feasibility and acceptability as well as the effectiveness of our recommendations.

7. Conflicts of interests

There are no conflicts of interest.

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A Relative Safeguard? The Informal Roles that Families and Carers Play when Patients with Dementia are Discharged from Hospital into Care in England and Wales

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ABSTRACT

In general hospitals, decisions are routinely made by health and social care professionals to discharge older people with dementia, who lack capacity, into long-term institutional care. There are few independent procedural safeguards that monitor how those professional 'best interests' decisions are made. Instead there is an assumption, implied by the Mental Capacity Act 2005 (MCA), which governs decision-making on behalf of incapacitated adults in England and Wales, that relatives will act as informal caretakers of patients' interests and will challenge professional decisions where necessary. This article examines whether this is the case in practice and the factors that may prevent relatives from carrying out this safeguarding role effectively. Our findings stem from a qualitative (ethnographic) study which captured observational data on acute and rehabilitation hospital wards in two hospitals within two NHS healthcare trusts in the North East of England. Our results show that relatives struggled to safeguard the rights of incapacitated patients with dementia when professional residence capacity and best-interests decisions were made about living arrangements and relatives were often ill-equipped or unsuitable to carry out this safeguarding role. Without better information-sharing and more robust independent procedural safeguards in the MCA, the rights of older patients with dementia are not being adequately protected during the hospital discharge process.

I. INTRODUCTION

In general hospitals in England and Wales, decisions are routinely made to discharge older patients with dementia who lack decisional capacity, either back home or into long-term institutional or supported care settings. Multi-disciplinary teams (MDTs) of health and social care professionals will usually assume this decision-making responsibility, unless formal welfare proxies (often relatives) have been appointed as court deputies or under Lasting Powers of Attorney.

Since 2007, the Mental Capacity Act 2005 (MCA) together with its associated Code of Practice (Code) (Department of Constitutional Affairs, 2007) has provided the principal legal framework that governs decision-making on behalf of adults who lack capacity in England and Wales. Under the MCA, adults lack capacity when they have a permanent or temporary 'impairment of, or disturbance in the functioning of, the mind or brain' that prevents them being able to make particular decisions.[1] Where this is the case, as long as a decision-maker has a 'reasonable belief' that what is being proposed is in an individual's best interests and is, as far as possible, the least restrictive of that person's rights and freedoms, then acts can be done and decisions made for the incapable person, without consent and without the decision-maker incurring legal liability.[2]

To date, there has been only limited analysis of how professionals conform with the MCA when residence capacity is assessed and when decisions are made to discharge dementia patients from hospital and relocate them into long-term institutional care (Emmett et al., 2013; Williams et al., 2012). Most often, these decisions are made within the privacy of clinical and social care teams, unless patients are 'unbefriended' and there is a duty to appoint an Independent Mental Capacity Advocate (see below) or there are concerns that older people may be deprived of their liberty[3] in hospitals or care homes, which triggers the additional scrutiny of the Deprivation of Liberty Safeguards (DOLS) under the MCA (Ministry of Justice, 2008). For the majority of patients however, there is little independent scrutiny of how residence capacity assessments and best-interest decisions are made by professionals on discharge (Bartlett and Sandland, 2013). Instead, the onus is on those professionals involved in a person's care to exercise professional duties to keep the person safe and to comply with the statutory requirements of the MCA when making discharge decisions. Professionals are almost completely self-regulating in this regard; there is no equivalent to the independent second opinion safeguarding of the Second Opinion Appointed Doctor (SOAD)[4] under the Mental Health Act 1983 for example, and no independent tribunal review processes.

There does however appear to be an implicit assumption within the MCA that friends, family, carers, and others who are in a position to be consulted about the incapacitous older person, and who are presumed to have that person's best interests in mind, will safeguard an older person's interests and rights where appropriate. This assumption is derived from the fact that when close relatives are not present, so there is no one else with whom it would be 'practical or appropriate' to consult when long-term residence decisions are being made, additional 'independent safeguards' are thought necessary under the Act, via the appointment of an Independent Mental Capacity Advocate or 'IMCA'.[5]

The IMCA's role is to support and represent a person during the discharge process and to offer views or information which must be taken into consideration by the decision-maker when determining the best placement for the older person concerned[6] (Cowley and Lee, 2011). The IMCAs have a statutory right to access patients' relevant health and social records when carrying out this statutory duty[7] and must undertake mandatory training in their role and the provisions and application of the MCA and Code amongst other things.[8] IMCAs also have the duty 'to raise questions or challenge decisions which appear not to be in the best interests of the person'.[9] The IMCA Regulations state that the IMCA will have the same rights to challenge decisions made as if they were made by individuals '(other than the IMCA) engaged in caring for [the incapable person] or interested in his welfare'[10] and considerable guidance is offered in the MCA Code of Practice on how challenges can be brought, via complaints procedures or by referrals to the Court of Protection where appropriate.[11]

Since the suggested assertion is that a person with no relatives requires some alternative means of safeguarding, which is provided by the IMCA, the question then arises whether the safeguarding by relatives (and other non-professionals) offers the same degree of protection potentially provided by IMCAs; for if this is not the case and relatives are not able to provide the same level of safeguarding as IMCAs, then there would seem, counterintuitively, to be a lack of equity, in that those who do not have relatives to consult or represent them could potentially receive an increased level of safeguarding than those who do.

It is from this premise that we set out to explore, through our data, the informal role of relatives during the discharge-planning process and the extent to which they do, in fact, fulfil an effective safeguarding role when decisions are made to discharge older patients with dementia from hospital either back home or into long-term care. It is through this enquiry that we hope to develop a clearer picture of how the MCA is being implemented in practice and the extent to which the current statutory framework of the MCA is effective in safeguarding the rights of incapacitated older people.

Whilst this article focuses on practice in England and Wales, the issues discussed are of wider international significance, as relatives take on equally important roles in decision-making involving adults who lack legal capacity in other developed legal jurisdictions.

Excerpts in this article do not bear participants' real names and anonymization and pseudonyms have been used to maintain confidentiality. For the purposes of this study and for ease of reference, we have broadly defined the term 'relatives' to include both blood-relatives (as the term is conventionally understood), as well as non-blood relatives, partners, friends.

II. METHODS

1. Study Design

Ethnographic research methods underpinned this study which explored how capacity assessment and best-interest decisions were carried out in relation to hospital discharge for people with dementia (for an overview of the project, see Poole et al., 2014). This approach facilitated naturalistic enquiry of the subject and can be characterized by the researcher participating to varying degrees in the daily lives of those they are studying over an extended period of time through watching, listening, and asking questions. Ethnography has an established tradition in the exploration of medical culture (Brewer, 2000; Pope, 2005). The principles of institutional ethnography facilitate the study of strategic problems and issues in institutions and the practical implementation of key legislation (ten Have, 2004). We took a critical realist position in that we presumed there was an objective world shaped by our human words and actions (Sayer, 2000). We used a variety of ethnographic approaches (observation, interviews and focus groups) in order to make sure we captured as many different perspectives as possible. During the observations, the researcher (MP) acted as a non-participant observer so that, insofar as this is possible, she might avoid influencing the environment she observed.

2. Ethical Considerations

Ethical approval was granted by NHS regional ethics committee (Newcastle and North Tyneside 2 Research Ethics Committee Ref No: 08/H0907/50) to undertake the ethnographic exploration of capacity assessment and best-interest decisions in relation to hospital discharge for people with dementia.

3. Ethnographic Fieldwork

Over a period of 9 months between June 2008 and June 2009 (including a 3-month analysis period at 6 months), 111 days of ward-based field data were collected. Fieldwork was undertaken on three general elderly care wards, in two hospitals within two NHS healthcare trusts in the north-east of England. Fieldwork centred on the care and discharge process of 29 patient cases and how this was facilitated by their relatives and the many staff providing their care. The provisions of the MCA had been disseminated in hospitals for a minimum of 7 months prior to the commencement of research. Table 1 shows the demographic details and background information of the 29 participants.

4. Study Population and Sampling

Participating wards were selected based on specialism and case-mix (care of the elderly and ortho-geriatric care, including acute and rehabilitation settings). The broad inclusion criteria adopted in the study reflected the naturalistic approach to enquiry and the underpinning patient-centred ethos of gaining perspectives of patients with dementia regardless of advancement of the condition. Therefore both patients who were able and unable to consent to participation were included. Personal and nominated consultee agreement was obtained for those patients whom the researcher considered unable to provide written consent. A member of the clinical team made the initial approach to the patients, which the researcher then followed up. Contact with relatives was established through the patients.

Cases were then theoretically sampled (Silverman, 2005) to ensure participants represented a broad range of characteristics including: reason for admission; living arrangements; formal and informal support networks; capacity decision and discharge outcome. The sample also extended to represent key events and interactions

Table 1. Demographic and background details of 29 participants in study

Age	83 (range 69–92)
Gender	Female = 16; Male = 13
Ethnicity	White British = 28; White European = 1
Location	Acute =20; Rehab =9
Average Length of Hospital stay	Acute ward = 35 days (range 13–59 days) Rehabilitation ward = 87 (range 29–157 days)
Mini-Mental State Examination (MMSE) scores[a]	Range 6–30
Diagnosis of dementia	$n = 20$

[a] The mini-mental state examination (MMSE) is a formal clinical screening tool of cognitive function. Scores under 24/30 may indicate dementia; but even scores of 27/30 or below may indicate a decline in cognitive function (Folstein et al., 1975; Hodges, 2007).

which characterized cases such as discharge planning meetings; home visits and input from psychiatry services.

Ward staff consented to be observed, and professionals were purposively sampled for an additional qualitative interview.

5. Field Observations

A funnel-based approach (Walsh, 2012), starting with broad observations before concentrating on specific events, enabled the researcher to gain an understanding of day-to-day life on the wards, and then focus on specific cases and processes influencing capacity and best-interest decisions around residential capacity. Ward-based interactions were documented in detailed field notes, capturing a broad range of observations. However, events observed in MDT meetings and discharge planning meetings/case conferences were identified as instrumental in the processes of discharge decision-making, and key to this analysis. Detailed review of patients' medical records supplemented direct observations, enabling unobservable data to be captured, and allowed exploration of how key capacity, best interest, and discharge decisions were formally documented.

6. Interviews

In total, 92 formalized qualitative in-depth interviews were conducted with all stakeholders. The 35 interviews with health and social care professionals represent perspectives from a broad range of disciplines and include: senior and junior doctors (physicians and psychiatrists); nursing staff (qualified and non-qualified, senior and junior, and psychiatry liaison); social workers; occupational therapists, a physiotherapist, and an IMCA. Twenty-nine patient interviews and 28 interviews with a nominated relative were conducted at the point of discharge and at 3 months post-discharge where possible. The interviews allowed participants to describe their personal experiences and views of hospital discharge decisions. In addition, professionals were more specifically asked to discuss understanding of the MCA in practice and judgements on residential capacity and best interest decisions. Topic guides were iteratively developed after initial field observations to incorporate further emergent themes throughout the study. All interviews were digitally recorded, transcribed verbatim, checked and anonymized prior to transcription. Informal discussions with all key stakeholders were captured and recorded in researcher field notes.

7. Focus Groups

A series of focus groups were conducted between April and May 2009 to incorporate a broader range of views, values and experiences. Participants were asked to suggest if and how residential capacity and best-interest decisions could be improved through discussing hypothetical vignettes derived from the ward-based data. Three groups of health and social care professionals ($n = 22$) and one group of three carers plus two voluntary agency staff members participated. Professional participants were represented by: general practitioners (including a trainee); social workers; occupational therapists; nurses (including a nursing home placement assessor); psychologists, a chaplain; and a care home manager. Two team researchers (one leading, one taking notes) facilitated the groups (JB, JCH, HG, and MP). With consent of the participants, discussions were recorded, transcribed, and anonymized.

8. Analysis

Analysis of coded transcripts was conducted through a series of data workshops (MP, JB, and JCH). This facilitated the development of a coding framework for all data, from which themes emerged. Emergent themes were further developed through the use of memos leading to key concepts in the data (Charmaz, 2006). Data was managed using NVIVO software (NVivo, 2010). For each of the 29 cases, the multiple sources of field data were synthesized into 'case studies' of decision-making processes relating to judgments on capacity and discharge. Using constant comparative methods (Glaser and Strauss, 1967), case studies were then analysed highlighting similarities and differences. This allowed common themes and key differences to emerge between cases, indicating examples of good practice or potential areas for improvement in the processes of assessment of residence capacity, best-interest judgments, and discharge.

Although 29 patient cases were involved in this research, in the analysis for this article we focus on the 16 cases in which families were formally acting on behalf of patients who were assessed to be lacking sufficient capacity to undertake their own discharge decisions. Table 2 briefly summarizes some of the key characteristics of the 16 patients judged by healthcare professionals to lack capacity to make their own discharge decision. The table illustrates a diverse range of relatives involved in best interest decisions, highlighting different family relationships. This also includes cases in which relatives undertook sole responsibility or part of a 'group' decision.

III. RESEARCH FINDINGS

The extracts we use here are taken from a few of our cases, using pseudonyms in order to illustrate the perspectives and experiences of relatives, patients, and healthcare professionals. These cases were selected from our data as they provide contrast

Table 2. Key characteristics of 16 patients assessed to lack capacity on discharge

Patient (pseudonyms used)	Age	Reasons for admission	Living arrangements prior to admission	Relative	Discharge destination	Diagnosis of dementia
Mrs Miller	90	(Acute) confusion; shoulder pain	Alone, Sheltered Accommodation	Nephew	Nursing care	Y
Mrs Wright	91	Fall – fractured humerus	Alone, home	Daughter	Residential care	Y
Mrs Butler	74	Fall – fractured femur	Alone, home	Daughter	Residential care	Y
Mr Fisher	82	Minor surgery (planned procedure)	With wife, home	Wife	Residential care	Y
Mr Coleman	82	Chest infection/ collapse/ fall. fractured femur	With wife, home	Wife	Nursing care	Y
Mr Day	91	Increased confusion; generally unwell	Alone, home	Son and daughter in law	Deceased	Y
Mrs Tanner	85	Suspected fall	Alone, sheltered accommodation	Daughter and son	Nursing care	Y
Mrs Baker	89	Chest pain, dizziness and unwell.	Alone, home	Daughters and son	Home	N
Mrs Carter	90	Fall. Increased confusion. Suspected urine infection	Alone, sheltered accommodation	Daughter	Residential care	Y
Mrs Salter	88	Suspected fall	Alone, home	Daughter	Residential care	Y
Mrs Woodward-Jones	80	Fall; increased confusion	Alone, home	Friend	Residential care	Y
Mrs Parker	78	Fall	Alone, home	No-one	Nursing care	Y
Mr Shepherd	89	Fall; fractured femur	Alone, home	Daughter and son	Nursing care	Y
Mr Collier	74	Fall – head injury	Alone, home	Daughter	Residential care	N
Mr Tyler	83	Fall and suspected chest and urine infection	Alone, home	Daughter	Residential care	Y
Mr Ryder	87	Fall, chest infection; community acquired pneumonia, increased confusion	Alone, home	Son and daughter in law	Nursing care	Y

and 'comparison of concepts' in the spirit of constant comparison methodology (Glaser and Strauss, 1967). The extracts allow us to explore the broad themes that emerged from the data. It should be noted that Mrs Parker's case was the only one in our study where an IMCA was appointed as the patient was considered 'unbefriended' whilst in hospital.

Themes have been grouped under three headings, namely: the different informal roles that relatives play during discharge from hospital (including the assumption of a caretaking or safeguarding role); the potential barriers that may prevent relatives from carrying out an effective safeguarding role during discharge planning; and those positive factors which helped relatives to safeguard the interests of dementia patients during discharge.

1. The Informal Roles Relatives Play during Discharge from Hospital

Relatives were observed to play a number of informal roles during the hospital discharge process, both in connection with the patient concerned and when interacting with health and social care professionals on hospital wards and elsewhere (Charles et al., 1997; Keywood, 2003).

A. Relatives as Advocates, Information-gatherers and Caretakers

Frequently relatives took on informal roles assisting older patients with daily living, facilitating communication between the patient and health and social care staff, which enhanced an older person's welfare and decisional abilities on hospital wards (Boyle, 2013). Relatives acted as advocates for patients who were too ill or confused to articulate their own views and wishes:

> INT:…my wife's done most of the talking you see 'cos I've been in hospital. She's done most of the talking. (Interview: 021208, lines 142–143: Patient (Mr Coleman)).

During their interactions with health and social care professionals, relatives also acted as information gatherers, questioners, observers, and prompters:

> INT: And…I don't actually…I don't, I don't see it as a discharge thing. I see it as a monitoring, a monitoring situation. The assessment is yes, where is Mum now? Okay, where is Mum now? Right, next week, anything else to add to that? Oh, ah, she's incontinent, didn't know that. Mobility; oh she can't walk, oh, that's the first I knew of it! (Interview: 031108, line 642–659: Relative of Mrs Salter).

Such an approach reflected the inquisitorial role performed by the IMCA in our study:

> INT: my role is to, is to just investigate all the circumstances and try and find out as much as I can really, I call it 'have a dig around' (laughs) (Interview: 080709, lines 133–35: IMCA interview for Mrs Parker)

However, not all relatives we observed were proactive information-gathers, often reluctant to interfere with hospital protocols or to question professional views

(Efraimsson et al., 2006). Also, while the IMCA had a statutory right of access to a patient's medical and social care records, which provided her with important background clinical and social information concerning the patient, relatives often found it difficult to access clinical information in hospitals. This may have been due to issues surrounding patient confidentiality, poor communication by professionals or relatives simply not knowing where to access the required information:

> INT: … Every time I used to go and see the doctor to see if I could see the doctor… 'well I don't really know, you'll have to ask the nurses, I'm just the..' you know, and I thought 'just terrible'…' (Interview: 131008, line 707–709: Relatives of Mrs Baker).

In the cases we observed in our study, there were several examples of relatives attempting to safeguard the interests of older people with dementia by making informal challenges to professional discharge decisions. However, a number of personal and procedural barriers prevented relatives from pursuing those challenges effectively.

2. Potential Barriers to Effective Safeguarding

A. Lack of Information and 'Signposting' by Professionals

Although we observed that decisions about discharge were made in other contexts (such as ward rounds, informal meetings between staff, patients, and relatives), we found that discharge planning meetings (otherwise known as case conferences) often provided the formal venue for best-interests decision-making prior to discharge.

However, relatives were not always aware of the purpose of those discharge planning meetings, which were not always properly signposted by professionals as being relevant to discharge placement. Mrs Salter's case illustrates this well.

Mrs Salter. Mrs Salter was an 88-year-old widow. She lived at home prior to her admission to hospital with memory problems and a suspected Urinary Tract Infection (UTI). She wanted to be discharged home and her daughter initially supported her in this decision. Mrs Salter was assessed to lack capacity and was ultimately discharged from hospital into long-term care.

Here Mrs Salter's daughter suggests that there was a lack of information and clarity around her mother's discharge planning meeting:

> INT: … you used the term 'planning for discharge' quite a bit. The hospital hasn't. They answered: 'we've got a planning meeting about your Mum' (Right) and its only been recently, once we decided that it was a nursing home, that the word discharge has come into the … it's an interesting factor that suddenly the word discharge comes as opposed to … ; it should really I think, should have come a bit earlier you know, 'we are doing an assessment so that we can discharge your Mum into the best possible place … (Interview: 031108 lines 1291–1304 Daughter of Mrs Salter).

Several relatives also expressed concerns that they had not been given enough timely information by professionals to be fully informed and prepared for discharge planning meetings. As such, they felt that they were not adequately prepared to make informed judgments about where patients should live on discharge, or to challenge professional views when they felt this was necessary:

> She [daughter] needed all of the information regarding her mother to make an informed decision and that she didn't think she had all of the information and at various junctures she felt like everyone else was in the know and that she wasn't… (Fieldwork notes: 031108, lines 27–29: Mrs Salter).

Mrs Salter's daughter describes how clinical information surrounding her mother's mobility and incontinence – issues that she had not appreciated before the discharge planning meeting – were presented as a series of 'bombshells' during the meeting, giving her little time to assimilate the information:

> INT: Oh it's like a series of Mount Everests.… what didn't happen at that meeting, which should have, was the discussion of the care issues, – the care package that was inadequate and… if those had been put forward to me beforehand, the nursing diagnosis would have been different and I'm concerned now that that diagnosis is wrong – that it is inadequate.
>
> (later in the interview)
>
> MP: So do you feel you were included enough in the process or… ?
>
> INT: I was included enough, but I wasn't clued up enough (Interview: 031108, lines 931–947; 967–969: Daughter of Mrs Salter).

B. Conflicts of Interests

The ability of relatives to represent and safeguard a patient's best interests was also called into question when conflicts of interests arose between relatives and patients. In the extract below, one junior doctor alludes to the difficulties faced by Mrs Salter's daughter who had to uncouple her own interests (that her mother's home, which she saw as her inheritance, was to be used to pay for a private care home placement) from the best interests of the patient:

> INT: But I guess the other thing that. I mean its all kind of complicating when there's funding involved. (Right) We then found out eventually that they had to pay part of the cost of a nursing home… (Ah)… .and that probably was the reason why erm she [daughter] was having quite a lot of difficulty in coming to terms with it, cause her Mum had a house and if you have a house you have to sell the house… (Right) Do you understand what I'm trying to say to you? (Sure). So it's not that straight forward sometimes. (Staff Interview: 201108: lines 380–400. F2 Doctor in case of Mrs Salter).

C. Inequalities of Power

Older or less assertive relatives found it difficult for their voices to be heard in the discharge-planning process or to influence and challenge discharge outcomes, even when they thought this was necessary. Inequalities of power in the decision-making process were occasionally the result of a relative's perceived deference to professional opinion or hospital procedures, or the desire to conform to the views of stronger-willed, more coercive family members. The result was that many relatives appeared to be ill-equipped to safeguard patients' best interests.

Mr Coleman. The elderly wife of Mr Coleman, an 82-year-old patient with dementia, explained the difficulties she encountered when faced with a sudden decision that Mr Coleman was to be discharged from hospital into long-term residential nursing care. This extract suggests how easy it can be for decisions to become 'medicalized' by professionals when they are privy to clinical information that relatives are not party to, with the result that relatives can suddenly become excluded from the decision-making process:

> INT: I mean when we were sitting having the meeting in the hospital, there was the nurse and the somebody – a social worker I think, lovely, talking away. 'yeah we'll get him home Mrs Coleman' you know and 'we'll get you this and we'll get you that' and I was over the moon, brilliant, and then the [nursing] sister walked in, and I don't know her name, and she said er 'you can't look after him', 'pardon', 'you can't look after him,' I said 'but why?' 'well you know he's got short term [memory loss],' I says, 'well I know that' [mmh mmh] 'I know but he's got to be turned over three times through the night', 'what', 'he can't turn himself over'. So straight out of my hands then.
>
> MP: and why did he have to be turned over do you know?
>
> INT: I've never found out yet [right] I asked five different people in [hospital site 1], four of them didn't even know what I was on about. I think they thought my memory was going you know [right] that's the way I felt… (Follow-up Interview: 160309, lines 61–76: Wife of Mr Coleman).

Mr Coleman's wife expressed her regret that she had not 'stuck up for' her and her husband more during the planning meeting and advocated more effectively in what she perceived was in accordance with her husband's previous wishes and therefore, his best interests – but it was now 'too late':

> INT: He hated it, you see him and I made a promise years ago that neither of us would put the other one in a home… and then as I say it was taken out of my hands so… I mean I broke my heart, he broke his heart but what could we do he was there
>
> MP: sure and was it your… son-in law who took the decision?
>
> INT: Aha yeah
>
> MP: And did he talk about it with you or did he?
>
> INT: No no, it was the same as the funeral (laughs) I did nothing at all about the funeral, they just took over and that was it. No as I said I says, I think when you get to 80 you become invisible… (Follow-up Interview: 160309, lines 128–49: Wife of Mr Coleman).

These findings can be contrasted with the approach of the IMCA in the study who viewed her role as the 'last line of defence' for patients prior to discharge and that it was her legal duty to step in and question clinical opinion, in spite of the perceived professional hierarchy in hospital:

> INT So basically the IMCAs opinions have to be listened to by the decision-maker because it's legal, so therefore if the IMCA says the person should have another try at home, they really have to say…, well it would be difficult to not do it [right].
>
> MP So could it overturn a consultant's decision or..?
>
> INT I think it probably could actually. I mean I think that it's, legally, they have to take it into consideration and if you're very sure that you think that this person should be able to be allowed to go home and try again then I would say that that's what happens and it has happened…. So it actually has happened that people have gone home – not always worked but erm,…but that doesn't mean that it shouldn't have been tried [sure]…(IMCA interview: 080709, lines 261–76: IMCA for Mrs Parker).

D. Emotional Burdens

Relatives also struggled to carry out effective safeguarding roles at a time when they were often coming to terms with the emotional stress and burdens associated with their close relative or spouse being suddenly admitted to hospital, and the potential impact that any discharge decision would have on their own lives.

Again, the elderly wife of Mr Coleman later reflected on how she felt she was emotionally burdened and 'in over her head' when it came to supporting her husband's interests at this critical time:

> INT: I used to sit with him 'til about half three [right] so I mean I was doing that every day in the hospital from September until he went into the home [right] I went there every day.. you know and it's a lot of driving and it's a lot of you know anxiety..
>
> (Later in interview)
>
> INT:..but I suppose what has to be will be isn't it you know [absolutely] it's no good regretting it now but and as [name of friend] says everybody has got a time over their head and when that time comes [yes] regardless of what…I says I know but I could have made him happier, I says even he if had to go then, you know, I could have made him a little bit happier, so there you are (laughs). (Follow up Interview 160309, lines 294–301 and 313-318: Wife of Mr Coleman).

3. Factors which Assisted Relatives to Safeguard the Interests of Older Patients with Dementia

Mrs Baker. Mrs Baker's case is chosen as an example of how relatives can influence best-interests decisions and safeguard patient interests more effectively during the discharge process. Mrs Baker's case was unique in that it was the only case in which a patient was allowed to return home in accordance with her wishes when she was judged to lack residence capacity. Mrs Baker's situation was also exceptional in that she had the support of a large, close-knit and vocal family who defended her wishes to return home and who (critically) agreed to implement a 'rota' of homecare following her discharge from hospital. The family's intervention, in this sense, was pivotal to the decision to allow Mrs Baker to return home.

Mrs Baker was 88 and prior to her admission to hospital lived in her own bungalow with the help of professional carers and her family who lived locally. She was admitted to hospital with a UTI and was assessed as being on the borderline of lacking capacity to decide where she should live. The professional decision to discharge Mrs Baker home was facilitated in no small part by her family's tenacious and persistent questioning of hospital professionals and their familiarity with hospital processes (one of the daughters worked in the NHS hospital where Mrs Baker was being treated). This suggests the possibility (at least) that social class and education might play an important role in the degree to which relatives can offer effective support and advocate for older people. Ultimately, Mrs Baker was given 'the benefit of the doubt' by her consultant who decided to take the 'path of least resistance' by allowing her to return home with increased support provided by her extended family.

A. Empathy and the Family Dynamic

It was clear that Mrs Baker's children regarded their mother as a strong, matriarchal figure whose views should be respected. Here Mrs Baker's daughter and son-in-law describe the moment that Mrs Baker was brought into the discharge-planning meeting and told she would be able to return home. Although the outcome of the meeting was positive (in that Mrs Baker was allowed to return home as she wished), her anger at being excluded from the decision-making process during the meeting is unequivocal. As her daughter explains:

> INT: …we're all sitting here, it's like the X-Factor. There's four of us sitting there and they wheel her in [to the planning meeting] and you're saying to her 'this is what we decided on your behalf'. Now she was as good as gold, - I think you (researcher) were the last to leave, – as soon as you went out the door she went absolutely ballistic.
>
> MP: Really, what was her response?
>
> INT: She said, 'thanks very much!' She says, 'family; you make me sick the lot of yous' and was in temper and she walked through the door and we got (son's name), the brother, (he's the favourite you know), we says, 'you see to her'. 'Open that bloody door' she said…and he said 'mam' he says, 'I can't, you're in the way'. 'Open the door or you will go through it!'. And she stormed off to her bed…So we went in to try and talk her round. 'Just get away the lot of you, family, yous are a load of rubbish'
>
> [and later in the interview]
>
> INT: …. if you look at it from her point of view, we're all there…this is a woman who's been independent all her life, she has this few months of illness, she comes in and we're all deciding what's going to happen to her. We knew, and we told the social worker but it was completely disregarded.

> INT: Well look what our (son's name) said; he said 'if that was me' he says 'and I come in and me daughters had arranged my life, I would say 'well you know what you can do' you know..
>
> ….
>
> INT: and then we told the social worker immediately afterwards when she went back on to her ward and she said 'ah she'll forget'.
>
> INT: No she doesn't forget.
>
> INT2: She doesn't forget (Interview: 131008, lines 362–382 and 417–444: Relatives of Mrs Baker).

In spite of Mrs Baker's physical and mental decline in hospital and her increasing reliance on others for day-to-day support, her family believed that she had retained the capacity to make her own choices about living arrangements. This was quite exceptional in our study. Often relatives were inclined to think that patients with dementia did not have the capacity to make their own decisions, and were doubtful of their ability to make residence choices even when they were assessed as competent to do so.

B. Confidence and the Availability of Resources

Although Mrs Baker's family felt that they were unable to challenge clinical opinion in a formal manner – 'give us some kind of guidelines, we're not qualified to make medical decisions' – their close-knit and supportive family dynamic meant that they were in a position to advocate effectively for Mrs Baker and assist her return home. While we observed the same concerns and deference paid by relatives to the wishes of older patients in other cases we observed (Mrs Coleman, for example), this was rarely married with the confidence to advocate effectively, nor the resources – or at times the inclination – to offer the same level of support to the patient at home.

IV. DISCUSSION

Capacity assessments and best-interest decisions regarding living arrangements, although they may be a routine part of general hospital discharge planning for many professionals, are rarely straightforward in practice. Frequently, decisions about changes of accommodation will be made suddenly in an older person's life, during 'the crisis of hospitalisation' (McAuley et al., 1997) and often when a patient's cognitive abilities and health are fluctuating. Professionals have the difficult job of weighing and ranking complex clinical needs alongside competing personal, social, and ethical factors, where issues of risks (to the patient and to others) will often weigh heavily in any placement decision made (Emmett et al., 2013; Greener et al., 2012). Family and close friends – most often the primary carers in older patients' lives – may wish to assert their own personal agendas, so that conflicts of interest can arise between patients and their caregivers (Brindle and Holmes, 2005). Typically, older people with dementia fade into the background during this decision-making process, while others decide on their relocation into permanent care (Dwyer, 2005). Moreover, decisions about hospital discharge and living arrangements are inextricably linked with diminishing community services and finite hospital resources, where 'effective bed management' and 'improving patient throughput' have become common bywords in hospital discharge planning (Banerjee et al., 2008). This can lead to ill-conceived capacity assessments being carried out by professionals on busy hospital wards and best-interests decisions that fail to comply with the legal standards of the MCA (Emmett et al., 2013).

It is vital, therefore, that older people who lack capacity are adequately represented and safeguarded during any decision-making process (Boyle, 2011, 2008) and robust legal standards and close scrutiny of those decsions is carried out (O'Keeffe, 2008). This is especially important given the seriousness and complexity of the decisions being made and because the majority of older people with dementia will not be able to access complaints procedures themselves without the help and support of others (Boyle, 2011).

Over the past two decades, there has been a recognized trend in medicine and law to empower family members in professional welfare decision-making processes involving incapable patients (Bopp and Coleson, 1996). In the UK, public and patient involvement in health decision-making remains at the heart of government policy for modernizing the National Health Service (Department of Health, 2004). Recent reforms of incapacity laws in England and Wales have similarly done much to elevate the legal rights of relatives, so that they can now participate more fully in health and welfare decisions involving their incapable loved ones on a formal and informal basis. Whilst such involvement acknowledges that good familial and social networks certainly shape the perception of what is best for incapable patients (Keywood, 2003) – and therefore who better to help make these judgments than the older person's family members and close friends? – cautionary lessons from practice suggest that an over-reliance on relatives to safeguard the rights of incapacitated adults can sometimes lead to an erosion of the rights of incapable people and occasionally to their financial and physical abuse (Bopp and Coleson, 1996; Boyle, 2011; Keywood, 2003; Manthorpe et al., 2012; Selwood and Cooper, 2009).

These matters are particularly troubling when relatives are expected to function as caretakers of the rights of incapacitated older adults when residence decisions are being made. In their study of a pilot IMCA service in 2009, Redley and colleagues questioned whether the best interests of vulnerable incapable older adults could be adequately represented by relatives when IMCAs were excluded and when complex decisions surrounding a change of residence were being made. They stated:

> These can involve complicated issues, such as the client's assessed needs, local funding criteria and the local availability of appropriate residential places. An experienced advocate working as an IMCA may well be better placed to represent someone through this process than a family member or friend for whom this is an exceptional experience (Redley et al., 2009).

These concerns are echoed by Keywood, who identifies the difficulties relatives face accessing health and social care services when they are untrained or unsupported in that role (Keywood, 2003). Peel and Harding's research shows that family carers frequently find service provision for dementia sufferers 'confusing' or 'impenetrable', so that navigating 'the system' can often become more difficult than carrying out their primary caring role (Peel and Harding, 2013). Our own observations, albeit from a limited study carried out in a specific setting, suggest that family and close friends also struggle to deal with the emotional burdens associated with discharge planning (Stoller and Pugliesi, 1988) and lack timely information to make well-informed decisions about placement choices for patients at crucial planning meetings (Redley et al., 2009). Our findings also suggest that not all relatives have the temerity to question professional opinion, especially given that most relatives will lack an understanding of the medical and legal construct within which capacity assessments and best-interests determinations are made. Relatives also struggle to uncouple their own best interests from those of the care recipient (Keywood, 2003). Whilst this is understandable, particularly in the context of residence decisions, where relatives may need to juggle a myriad of new personal, emotional, and financial responsibilities surrounding discharge, these issues can often conspire to mean that relatives are not always best placed to promote the best interests of vulnerable older adults when residence decisions are made and they may be ill-equipped to act as effective caretakers of those interests.

V. CONCLUSION

Certainly, these findings have important implications for the wider concerns surrounding access to justice, the adequacy and availability of independent safeguards under the MCA and the protection of the human rights of incapable adults generally (House of Lords Select Committee, 2014; Liberty, 2012). Without the assistance of well-informed, supportive relatives to initiate hospital and local authority complaints mechanisms, who could pursue challenges to the Court of Protection where necessary, many older patients with dementia will simply be unable to instigate these challenges and appeal mechanisms themselves (Manthorpe et al., 2009). When the onus is placed on care-recipients and the discretion of their relatives to initiate complaints procedures and challenges in this manner, those procedures and informal safeguarding mechanisms appear to be little more than patchy, arbitrary measures that fail to deliver the protection and access to justice that vulnerable incapable older adults and their families and carers need and deserve.

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NOTES

1 Sections 2 and 3 MCA 2005.

2 Sections 1(5) and 1(6) MCA 2005 and see MCA Code of Practice (Code), para. 5.13.

3 Article 5 European Convention on Human Rights and Fundamental Freedoms 1950, 4.XI.1950.

4 A Second Opinion Appointed Doctors (SOAD) is appointed under Part IV Mental Health Act 1983 as a second opinion safeguard when certain compulsory treatment for mental disorder is administered to detained patients under Part IV without consent.

5 An IMCA is a new statutory advocate role introduced by the MCA. Section 36 MCA enables the Secretary of State and Welsh Ministers to make regulations as to the functions of IMCAs. The IMCA represents those who lack the capacity to make important decisions about serious medical treatment and change of accommodation where they have no family and friends available to consult. The IMCA assumes the traditional advocacy role of supporting and representing a person's wishes and feelings so that they will fully be taken into account, together with the new role of providing assistance for challenging the decision-makers when the person has no one else to do this on their behalf.

6 Section 38(5) MCA 2005 and see MCA Code, para. 10.4.

7 MCA 2005, s. 35(6).

8 MCA Code, para. 10.18.

9 MCA Code, para. 10.4.

10 Regulation 7(2), The Mental Capacity Act (Independent Mental Capacity Advocates) (General) Regulations 2006 (*SI 2006/1832*); see also in Wales: Regulation 7(2), The Mental Capacity Act 2005 (Independent Mental Capacity Advocates) (Wales) Regulations 2007 (*2007 No. 852 w.77*).

11 MCA Code, para. 10.32–39.

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