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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.

Keywords: Capacity assessment, best interests, Mental Capacity Act 2005, dementia, hospital discharge, residence

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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/YouGov, 2008). The cost to the UK economy has been estimated to be between £17 and £23 billion a year (Department of Health, 2009; Alzheimer's Research Trust, 2010).

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% (Raveh *et al.*, 2005; Inouye *et al.*, 2006). 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 (Natawala *et al.*, 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 and 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 *et al.*, 2001). McCusker *et al.* (2001) showed that 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 (Unsworth, 1996; Mackenzie *et al.*, 2008) 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 *et al.*, 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 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 conceptualize the notion of capacity and its assessment (Roth *et al.*, 1977; Weisstub, 1990; Appelbaum and Grisso, 1988; Appelbaum and Grisso, 1995; Wong *et al.*, 1999; Wong *et al.*, 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 *et al.*, 2005). In England and Wales, the *Mental Capacity Act 2005* (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 (Ministry of Justice, 2008; Department of Health, 2007) 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 (Shah *et al.*, 2009a, Shah *et al.*, 2009b, Mujic *et al.*, 2009). Similarly, little judicial guidance is available through

decided case law on how capacity should be determined in this specific context.¹ This is surprising given that discharge decisions relating to place of residence can present difficult practical and ethical dilemmas for clinical teams (Brindle and 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

¹ 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.

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 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/Law Society, 1996).

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 and 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’ (s 2(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 *et al.*, 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 (s 4(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 and 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, 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, 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 MMSE² 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

² 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 et al., 1975; Hodges, 2007).

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 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. But 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 30He 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 *et al.*, 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, 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 (Verkooijan H., *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, 2009).

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 *et al.*, 2009a). 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, 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 (Jones, 2005, Cowan, 2007). 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.

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There are no conflicts of interest.

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