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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.**

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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.

## **INTRODUCTION**

In general hospitals, 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.<sup>1</sup> 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.<sup>2</sup> It is by evidencing this 'reasonable belief' that professional decision-makers will be afforded a statutory defence against legal liability for what would otherwise be a non-consensual, and therefore unlawful, touching or interference with the incapable person concerned under both domestic and European law.<sup>3</sup>

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, Poole, Bond and Hughes, 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<sup>4</sup> 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) <sup>5</sup> 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'.<sup>6</sup>

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 <sup>7</sup> (Cowley and Lee, 2011). IMCAs have a statutory right to access patients' relevant health and social records when carrying out this statutory duty <sup>8</sup> and must undertake mandatory training in their role and the provisions and application of the MCA and Code amongst other things.<sup>9</sup>

IMCAs also have the duty to '*to raise questions or challenge decisions which appear not to be in the best interests of the person*'.<sup>10</sup> 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*' <sup>11</sup> 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.<sup>12</sup>

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 to that can be 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 participant's real names and anonymisation 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.

## **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. This approach facilitated naturalistic enquiry of the subject and can be characterised 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, 2001; Pope, 2005). The principles of institutional ethnography facilitates the study of strategic problems and issues in institutions and the practical implementation of key legislation (ten Have, 2004).

### **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 nine months between June 2008 and June 2009 (including a three-month analysis period at six months), 111 days of ward-based field data was 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 seven months prior to the commencement of research.

#### 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 which characterised 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 fieldnotes, 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 formalised 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 three 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, as well as to incorporate further emergent themes throughout the study. All interviews were digitally recorded, transcribed verbatim, checked and anonymised prior to transcription. Informal discussions with all key stakeholders were captured and recorded in researcher fieldnotes.

## 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 anonymised.

## 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 synthesised into 'case studies' of decision-making processes relating to judgements 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 judgements and discharge.

Although 29 patient cases were involved in this research, in the analysis for this paper 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 1 briefly summarises 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.

< insert Table 1 about here >

## **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 and 'comparison of concepts' in the spirit of constant comparison methodology (Glaser & 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 (Keywood, 2003; Charles, Gafni and Whelan, 1997).

*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, line 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 133-135: 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 (Efrainsson, Sandman, Hydén and Rasmussen, 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’... And then we kept saying to my mother, ‘have they taken you for a walk? are you having...?’ I mean she had an Occupational Therapist or something, but I don’t know what she done with her, I don’t know what they do, I don’t know what she did with her.*

Interview: 131008, line 707–716: 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 judgements 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. And as I said, .. those important bits of information were missing and if I'd seen that, I wouldn't have been quite so stroppy, my daughter wouldn't have been so obstinate and it would have been a better procedure and now when I think about it, since I talked to the GP, I wonder if that nursing assessment is correct...*

*(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 931–938, 945–953 and 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 'medicalised' 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,' 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 128–149: 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 261-276: 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 difficult it was for her to deal with her husband's sudden admission to hospital and 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 and assisted her with meals and day-to-day tasks. 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). 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.

In Mrs Baker's case, her family felt that her confusion and tiredness were caused by delirium associated with her UTI rather than any long-term cognitive decline. They also felt that their



mother was being discharged from hospital too quickly and would have benefitted from further hospital rehabilitation and care.

*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.

## **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, Tavis and Safewright, 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 (Greener, Poole, Emmett, Bond and Hughes, 2012; Emmett, Poole, Bond and Hughes, 2013). 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, Mbamalu and Hinchley, 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, Poole, Bond and Hughes, 2013).

It is vital, therefore, that older people who lack capacity are adequately represented and safeguarded during any decision-making process (Boyle, 2011; Boyle, 2008) and robust legal standards and close scrutiny of those decisions is carried out (O’Keefe, 2008). This is especially important given the seriousness and complexity of the decisions being made and the fact that 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 recognised trend in medicine and law to empower family members in professional welfare decision-making processes involving incapable patients (Bopp and Coleson, 1996). In the United Kingdom, public and patient involvement in health decision-making remains at the heart of government policy for modernising 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 judgements 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 (Selwood and Cooper, 2009; Boyle, 2011; Bopp and Coleson, 1996; Keywood, 2003; Manthorpe, Samsi and Rapaport, 2012).

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, Clare, Luke and Holland, 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). 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, Clare, Luke and Holland, 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.

## **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 (Liberty, 2012; House of Lords Select Committee, 2014). 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, Rapaport, Harris and Samsi, 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 of the MCA 2005.
2. Sections 1(5) and 1(6) MCA 2005 and see MCA Code of Practice, para. 5.13.
3. Section 5 of the MCA 2005 and Article 8 European Convention on Human Rights and Fundamental Freedoms 1950 (ECHR).
4. Article 5 ECHR
5. Second Opinion Appointed Doctors (SOADs) are appointed under Part IV Mental Health Act 1983 as a second opinion safeguard when compulsory treatment is administered in certain situations to detained patients under Part IV for mental disorder without consent.
6. 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.

7. Section 35 MCA 2005 and see MCA Code of Practice, para. 10.76.
8. MCA Code of Practice, Chapter 10, Summary.
9. Section 35(6) MCA 2005
10. MCA Code of Practice, para.10.20.
11. MCA Code of Practice, para. 10.4.
12. Regulation 7, The Mental Capacity Act (Independent Mental Capacity Advocates) (General) Regulations 2006 (*SI 2006/1832*); see also in Wales: Regulation 7, The Mental Capacity Act 2005 (Independent Mental Capacity Advocates) (Wales) Regulations 2007 (*2007 No. 852 w.77*)

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Table 1: Key Patient Characteristics

<b>Patient</b>	<b>Age</b>	<b>Living arrangements prior to admission</b>	<b>Relative</b>	<b>Discharge destination</b>	<b>Diagnosis of dementia</b>
Mrs Miller	90	Alone, Sheltered Accommodation	Nephew	Nursing Care	Y
Mrs Wright	91	Alone, home	Daughter	Residential Care	Y
Mrs Butler	74	Alone, home	Daughter	Residential Care	Y
Mr Fisher	82	With wife, home	Wife	Residential Care	Y
Mr Coleman	82	With wife, home	Wife	Nursing Care	Y
Mr Day	91	Alone, home	Son and daughter in law	Deceased	Y
Mrs Tanner	85	Alone, Sheltered Accommodation	Daughter and son	Nursing Care	Y
Mrs Baker	89	Alone, home	Daughters and son	Home	N
Mrs Carter	90	Alone, Sheltered Accommodation	Daughter	Residential Care	Y
Mrs Salter	88	Alone, home	Daughter	Residential Care	Y
Mrs Woodward-Jones	80	Alone, home	Friend	Residential Care	Y
Mrs Parker	78	Alone, home	No-one	Nursing Care	Y
Mr Shepherd	89	Alone, home	Daughter and son	Nursing Care	Y
Mr Collier	74	Alone, home	Daughter	Residential Care	N
Mr Tyler	83	Alone, home	Daughter	Residential Care	Y
Mr Ryder	87	Alone, home	Son and daughter in law	Nursing Care	Y

