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**Citation:** Cliff, C. & Mcgraw, C. (2016). The conduct and process of mental capacity assessments in home healthcare settings. *British Journal of Community Nursing*, 21(11), pp. 570-577. doi: 10.12968/bjcn.2016.21.11.570

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**Link to published version:** <https://doi.org/10.12968/bjcn.2016.21.11.570>

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**The conduct and process of mental capacity assessments in home healthcare settings: A qualitative study exploring the experiences and perceptions of nurses and allied health professionals.**

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## **Abstract**

**Background:** The assessment of capacity to consent to treatment is key to shared practitioner-patient decision making. It is the responsibility of the person closest to the decision being made to carry out the assessment.

**Aim:** To examine the factors that influence mental capacity assessments in home healthcare settings and identify the facilitators and inhibitors to the conduct and process of assessments as perceived and experienced by generalist nurses and allied healthcare professionals.

**Methods:** Semi-structured interviews with a purposive sample of community nurses, community physiotherapists and community occupational therapists in one NHS Trust in London. Data were analysed thematically.

**Findings:** Five key themes were identified: patient factors, family influences, staff factors, team factors and environment factors. Whilst some appear germane to both hospital and home healthcare settings, others are unique to - or manifest very differently in - home healthcare settings.

**Conclusion:** The findings suggest the conduct and process of mental capacity assessments in home healthcare settings is an inherently complex endeavor.

## **Key Points**

- Healthcare practitioners must encourage and empower people to share decisions about their treatment and care
- The key factors that influence mental capacity assessments in home healthcare settings include patient factors, family influence, staff factors, team factors and environment factors
- The social context in which mental capacity assessments occur make the conduct of these assessments an inherently complex endeavor in community settings
- Interdisciplinary working provides opportunities for community practitioners to support less experienced colleagues by providing relevant learning experiences

## **Key Words**

- Decision making
- Mental capacity
- Assessment
- Facilitator
- Inhibitor

## **Introduction**

Healthcare practitioners must encourage and empower people to share decisions about their treatment and care (Nursing and Midwifery Council, 2015; General Medical Council, 2008; College of Occupational Therapists, 2010; and Chartered Society of Physiotherapists, 2012). Whilst people have the right to make what others might regard as an unwise decision, there are occasions when a person's refusal to consent to treatment will raise concerns about their decision making ability. The assessment of capacity to consent to treatment and care is considered a fundamental component of shared practitioner-patient decision making (Etchells et al, 1999).

In England and Wales, the Mental Capacity Act (MCA) 2005 provides the legal framework for assessing a person's capacity to make decisions. The purpose of the MCA is to empower individuals to make their own decisions and to keep those who lack capacity at the centre of decision making. The Act is underpinned by five key principles (See Box 1) and gives clear instructions for assessing whether a person lacks capacity to make a particular decision at a particular time (known as the two stage – diagnostic and functional – test) (See Box 2). If the person is found to lack capacity then a best-interest decision may be made on their behalf. Accurate and timely assessment is important to ensure those who suffer a loss of autonomy are identified and appropriately supported.

Examples of people who may lack capacity include those with a brain injury, a mental health condition, dementia, a severe learning disability, or impaired

consciousness at the end of life. Approximately two million people in England and Wales are thought to lack capacity to make decisions for themselves (Social Care Institute for Excellence, 2009). Many will be cared for in community settings due to new models of chronic disease management and policies supporting patient preferences to die at home. Given the MCA states that it is the responsibility of the person most closely involved in the decision being made to carry out the mental capacity assessment, the issue of capacity is one that is relevant to practitioners from a wide range of disciplines and includes not only specialists working in mental health but practitioners providing generalist services such as district nursing and community rehabilitation.

Evidence suggests shared decision making is not always optimally achieved due to difficulties experienced by practitioners carrying out mental capacity assessments (Mental Health Foundation, 2012). These difficulties include deficiencies in practitioner knowledge about the principles and legal responsibilities of the MCA. For example, a survey of 86 emergency care practitioners judged only 67% of doctors and 10% of nurses correct in their knowledge regarding capacity to consent or refuse treatment (Evans et al, 2007). Similarly, qualitative interviews with 32 care home staff found considerable variation in understanding of the terms and principles of the MCA (Manthorpe et al, 2011).

As much as these studies are important in understanding the education and training factors that might contribute to suboptimal decision making, somewhat less is known about the wider factors that influence the conduct of

mental capacity assessments. Mental capacity assessments occur in a social context and as such may be influenced by the surroundings in which they occur. This paper reports on a qualitative study which sought to explore the factors that influence mental capacity assessments in home healthcare settings.

## **Methodology**

The study objectives were to identify the facilitators and inhibitors to the assessment process as perceived and experienced by generalist nurses and allied healthcare professionals (AHPs). Semi-structured interviews were conducted with a purposive sample of community nurses, community physiotherapists, and community occupational therapists. Nurses and AHPs were eligible to take part in the study if they were working in senior clinical roles (defined as Level 6 or above on the Agenda for Change pay scale). Participants were drawn from hospital admission avoidance teams, district nursing teams and community therapy teams in one NHS Trust in London. The interviews were carried out by the lead author using a topic guide. The topic guide was designed to be used in a flexible manner, allowing some areas to be discussed in greater depth, depending on the relevance for the participant. The interview also included the use of a vignette, which was based on a scenario where a patient refused to consent to care and which asked participants how they would approach the assessment of capacity (See Box 3). The topic guide and vignette were piloted with one nurse, one occupational therapist and one physiotherapist. Data collection was carried

out between August and September 2015. The interviews were audio recorded and transcribed verbatim.

Thematic analysis of the data was undertaken following the six-phase guide described by Braun and Clarke (2006). This allowed access to the thick description of the data set and uncovered insights into the experiences and perspectives of participants. The emergent themes, which are explored in the findings, were discussed and reviewed by the co-author.

The study was reviewed and approved by the School of Health Sciences Research Ethics Committee at City, University of London (MRes/14-15/28). Informed consent, which included permission to use the information collected, along with anonymous quotes, in research reports and publications was obtained from participants prior to the interview.

## **Findings**

A sample of fourteen nurses and AHPs were interviewed; including five community nurses (CN), three occupational therapists (OT) and six physiotherapists (PT). On average, participants had been working within the trust for 3.1 years and had been qualified for 8.6 years. Six participants were working at Level 6 of the Agenda for Change pay scale and eight at Level 7. No further demographic data are provided to prevent participants from being identifiable.

All fourteen participants reported that they had at some point in their careers assessed a person's capacity to make decisions; however, few reported carrying out these assessments on more than two occasions. The

circumstances giving rise to these assessments were varied but largely reflected the respective professional background of each participant and the principle that the person most closely involved in the decision being made should carry out the assessment. For example, nurses recounted occasions when they had completed an assessment with someone who had refused to consent to either a prescribed medicine, the administration of subcutaneous fluids, or transfer to hospital when clinically unwell. In contrast, occupational therapists recounted occasions with someone who had refused to consent to the provision of aids to daily living, and physiotherapists with someone who had cancelled their care package. At least one participant from each professional group recalled occasions when they had completed an assessment with someone who had refused to move into supported housing or a care home.

Thematic analysis identified five key themes describing the facilitators and inhibitors to the conduct and process of mental capacity assessments: patient factors, family influences, staff factors, team factors, and environment factors. Various subthemes also emerged (See Box 4).

***Patient factors*** were those patient specific factors that influenced the conduct and process of the mental capacity assessment. The first of these factors was the nature of the person's medical condition, which in most cases referred to the presence of dementia and was seen as a both a facilitator and inhibitor. For example, the presence of a dementia diagnosis made the first stage of the assessment relatively straightforward since participants could

confirm an impairment in the functioning of the person's mind. However, a number of factors related to the dementia diagnosis impacted on the relative ease with which the second stage was completed. These factors included dementia severity:

*It's easier to do a capacity assessment when someone clearly doesn't have an impairment of their mind or brain or when they're severely cognitively impaired and unable to communicate things back to you (PT3)*

They also included issues related to maintaining attention and concentration. For example, participants recounted the difficulties some patients experienced attending to the assessment activity:

*They can be challenging when it's really hard to focus the patient on the actual process (PT1)*

Attention deficits in people with dementia are well documented (Amar and Wilcock, 1996). These patients would need additional support to ensure they had a fair chance of their voice being heard and demonstrating capacity. Participants indicated that additional support most commonly involved the provision of extra time or delaying the assessment to an occasion when the patient might be more willing or better able to engage. This type of support is in line with recommendations contained within the Code of Good Practice, which provides guidance to anyone working with adults who may lack capacity (Department of Constitutional Affairs (DCA), 2007).

Factors impacting on the second stage of the assessment also included behaviours associated with the dementia diagnosis. For example, masking of cognitive impairment and/or aggression. Whilst aggressive behaviour is not unique to people with dementia, people living with dementia do at times behave aggressively (Alzheimer's Society, 2016). The extent to which aggression prevented the completion of assessments was unclear:

*[It] was very difficult because this man was verbally abusive, very aggressive. We would come in the door and he would scream and shout... I think we were making him more upset and agitated... today I still wonder, does this man actually have capacity to make decisions for himself? (OT6)*

In contrast to dementia, some medical conditions presented problems for the first stage of the capacity assessment, making it difficult to determine whether or not to proceed to the second stage. For example, whilst low oxygen saturations affects cognitive processing in normal young adults (Pighin et al, 2012), the extent to which similar levels represent an impairment, or disturbance, in the functioning of a person's mind or brain was not straightforward depending on the person's condition:

*We look after a lot [of patients] with Chronic Obstructive Pulmonary Disease. They're quite used to running on low oxygen saturations and they will present very well in themselves, despite having ... the kind of saturations that would be consistent with hypoxia (CN10).*

The second patient factor was the language needs of patients who had limited English proficiency. It is estimated that 22% of people living in London have English as a second language (Migrant Observatory, 2013). Even if a person previously communicated in English, they may have lost some verbal skills because of dementia or after a stroke (Christle et al, 2013; Musser, 2015). Participants found communicating with people who do not share the same first language challenging. This concurs with research which has highlighted concerns about the quality of nursing assessments when patients had limited English proficiency (McCarthy et al, 2013). When language needs were identified, participants commonly drew on family members as interpreters. However, this approach was often ineffective:

*Initially it was the family who would answer what they thought we wanted to know because [I felt] they were not giving exactly the information she was saying. They were giving their interpretation of what he was saying (OT6).*

An alternative approach was the use of professional language interpreting services, including face to face interpreting and telephone interpreting. This approach reflects recommendations contained within the Code of Good Practice, which states that it is often more appropriate to use a professional interpreter rather than family members (DCA, 2007). Despite being difficult to arrange, especially at short notice, participants considered face to face interpreting preferable to telephone interpreting.

**Family influence** related to the capacity of family members to effect the conduct and outcome of an assessment. In relation to the former, family members were often seen as a facilitator, someone who could help explain things in a way the person could understand. At other times, their input was seen as a threat to the conduct of an objective assessment:

*Families are more empowered out in the community, more than in hospital where it's quite an intimidating [and] sterile setting. [In the community] they will often pitch in and if you're trying to gage someone's interpretation of something they will sometimes sit there and answer for them ... It's kind of difficult to broach and say 'I actually need to hear that from your mother ... to actually hear what they understand of the situation' (CN10)*

The Code of Good Practice (DCA, 2007) is clear that family members may be able to provide valuable background information but their personal views and wishes about what they would want for the person must not influence the assessment. Participants felt that interruptions by family members were sometimes unintentional, where family members were unclear about the purpose or process of the assessment. At other times, they deemed interruptions to be intentional and used to deny the person being assessed the opportunity to demonstrate capacity. Various reasons for this behaviour were put forward including stress associated with the caring role:

*You do have that pressure, especially when it comes to patients with dementia and that stress you can see [in] relatives or carers... But we are*

*there for the patient, we have to act as their advocate. So if it's determined that they have capacity, we have to advocate for that patient and their choices. They are never fun those situations (PT1)*

On other occasions, reasons included self-interest but were more often thought to be benign:

*The main difficulty was the family's understanding of the patient's right to make her own decisions, even if it was a decision they didn't agree with. In their opinion, their mum needed to go somewhere supportive; she wasn't safe at home... and didn't understand the risks ... In a very caring way, they wanted to make what was the best decision for her. I think it's difficult with families because so many emotions are involved (PT7)*

Participants endeavored to keep patients at the centre of the assessment and some sought to interview patients and family members separately. It was not until after the determination of capacity, when best interest decisions were being made that there was a strong consensus that family members should be encouraged to be more actively involved.

**Staff factors** related to the motivation and ability of staff members to competently undertake mental capacity assessments. As medico-legal judgements, participants were keenly aware that decisions about capacity have a significant impact on individuals and families:

*I was very aware that we would have their future in the balance, it's quite a responsibility (CN4)*

These perceptions meant participants were anxious to perform well. To exercise competence, two interdependent factors emerged from the data, self-awareness and experience. In relation to self-awareness, experience fostered increased feelings of confidence. Some participants had relatively high levels of relevant experience having previously worked in mental health settings or discharge planning, and considered themselves competent and their judgement trustworthy. However, others were less self-assured and complained that relevant experiences were difficult to find:

*You learn through experience, you learn [when you do something] everyday but if you do it once in a while, that's difficult... It's just lack of practice and we don't use it day to day (PT5)*

Given participants were attuned to the impact of assessment findings on individuals and families, it was clearly important that they were aware of personal biases and mindful not to let factors such as their own values, beliefs and preferences or the quality of any pre-existing relationship with the patient hinder objectivity during the assessment process:

*When I did it with a patient, I did it after months of knowing her and I think it did have an impact on the assessment... I mean it might have affected it in a good way because she could completely be herself but it might have*

*influenced her in a bad way because we couldn't look at it 100% objectively...  
I don't know if you want them done by someone who doesn't know the patient  
(PT2)*

The community practitioner-patient relationship lends itself to establishing long term and more interpersonally connected relationships (Miller, 2008). Some practitioners were clear that a pre-existing relationship with the person was beneficial as familiarity generated trust. Whilst there was no consensus of opinion on this matter, research has found that patients identify familiarity and trust as important elements in the conduct of mental capacity assessments (Myron et al, 2008).

**Team factors** were those factors that affected team effectiveness, particularly the ability of the team to work together to optimise shared practitioner-patient decision making. The first of these factors was role perception. Most participants felt the conduct of capacity assessments was everyone's responsibility and that it was appropriate for them as individual nurses or AHPs to be undertaking these assessments when they were the person most closely involved in the decision being made:

*Yes, so around the care that I provide. I would never obviously consent to an operation but I wouldn't accept a doctor to do one about rehabilitation (PT3)*

Some recognised this was not necessarily the norm amongst colleagues and recalled occasions when colleagues had sought to consign the assessment of

mental capacity to a medical doctor, psychiatrist or social worker:

*I think people often think, let's get the geriatric psychiatrist to do the capacity assessment. When actually it doesn't need to be a psychiatrist to do a capacity assessment and then they say well let's get the social worker in to do it and well actually it doesn't need to be them either (PT7)*

This concurs with research conducted with Admiral Nurses (specialist nurses working in dementia care) which highlighted ambiguity about whose role it is to complete mental capacity assessments (Manthorpe et al, 2014).

Participants felt colleagues were inclined towards medical doctors, psychiatrists and social workers due to their experience assessing people for detention and care under the Mental Health Act 1983. Indeed these disciplines were often held in high esteem and turned to for help, advice and information:

*We have a daily MDT that has doctors. I would discuss that with them and draw on their experience to see where to go next (CN13)*

Pooling of resources, including the diverse knowledge, experience and skills of other professionals, has been identified as a key mechanism in inter-professional teams (Sims et al 2015). Whilst discussion in one-to-one or group meetings was the most common form of inter-professional learning, some participants sought opportunities to shadow or conduct joint assessments with other professionals:

*And then if anything were to happen sometimes you feel that 'oh my goodness', because it's quite a big decision and that's why I think it's best ... in the first instance, you might bring another professional to take the heat of your back (PT9)*

Inter-professional learning opportunities were especially important because access to training varied between participants; some had attended specific MCA training, whilst others had not and instead learnt the two stage test as part of dementia awareness training. There was consensus amongst participants that further training would be helpful, particularly training that adopted a strong practical element. This reflects research that sought to identify the training and guidance needs of community nurses in relation to the MCA, which found that 78% wanted more guidance on the conduct and process of the assessment (Alonzi et al, 2009). Whilst participants were often co-located with practitioners from other disciplines, as lone workers an important barrier to inter-professional learning was the lack of physical proximity to other workers in peoples' homes:

*In the acute it tends to be slightly easier doing capacity assessments than in the community; I think having the MDT there as back can be a lot easier. [In the community] you might have a physio colleague that goes out to see them [with you] and you can always talk to their GP but it's just not as close working (OT8)*

Physical distance from coworkers was particularly troublesome in emergency situations:

*It's a very different environment than a hospital where you've got twelve people that might be able to give their opinion. When you're out in the community you have to make that decision there and then. Although you've got support people back at base you don't have someone there with you ... Especially if the patient is unwell, if they are septic, you have to make a decision if they are refusing hospital whether they have the capacity (CN10)*

**Environment factors** related to the physical surroundings in which the assessment of capacity took place. On the whole, providing family input was appropriately managed and practitioners did not need immediate assistance from colleagues, participants felt the home environment was conducive to the conduct and process of the assessment:

*If you took her into a clinic or a hospital where she would be out of her own environment, she would appear more confused [than] in her own home... Plus the decision we were making [was] about whether she could be in her own home, so it makes sense to make that decision in the context of what you're discussing (PT7)*

Research has shown that the surroundings of people with dementia affect how they perform their daily activities and how they behave (Cioffe, 2007).

The Code of Good Practice (DCA, 2007) refers to the importance of creating

the best environment for assessing capacity and some participants evidently felt that the home environment was a reassuring influence and one where shared decision making was optimised.

### **Limitations**

Some limitations of the study are acknowledged; for example, due to the sample size it was not possible to compare and contrast the facilitators and inhibitors identified by the different disciplines. However, the sampling target was met and there was no evidence to suppose there would be any great differences. At the same time, it is acknowledged that the sample only included AHPs from an occupational therapy or physiotherapy background and did not include podiatrists or speech and language therapists.

### **Conclusion**

A sample of generalist community nurses and AHPs reported the factors that facilitate and inhibit the conduct and process of mental capacity assessments in home healthcare settings. Some of these factors – such as patient condition factors - appear germane to both hospital and home healthcare settings. However, others appear unique to - or manifest very differently in - home healthcare settings. For example, the influence of family members was understood by participants to be more intense away from the hospital ward. Similarly, the long term practitioner-patient relationship in community settings was reported to be a potential threat to objectivity.

The findings from this study provide evidence to suggest the social context in

which mental capacity assessments occur make the conduct and process of these assessments an inherently complex endeavor in home healthcare settings. Nevertheless, key facilitators were identified that included inter-professional learning in the form of face to face meetings, shadowing and joint visits.

This study provides educators and managers with an opportunity to develop mechanisms to support practitioners manage the challenges and tensions encountered when completing mental capacity assessments with adults in home healthcare settings, particularly mechanisms that utilise the knowledge and skills of experienced colleagues within the inter-professional team.

### **Box 1: Five Principles of Mental Capacity Act**

- We must begin by assuming that people have capacity “A person must be assumed to have capacity unless it is established that he/she lacks capacity.”
- People must be helped to make decisions “A person is not to be treated as unable to make a decision unless all practicable steps to help him/her to do so have been taken without success.”
- Unwise decisions do not necessarily mean lack of capacity “A person is not to be treated as unable to make a decision merely because he/she makes an unwise decision.”
- Decisions must be taken in the person’s best interests “An act done, or decision made under this Act for or on behalf of a person who lacks capacity must be done, or made, in his/her best interests.”
- Decisions must be as least restrictive of freedom as possible “Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person’s rights and freedom of action.”

## **Box 2: Two Stage Test of Capacity**

Stage 1 (Diagnostic Test): Is there an impairment of, or disturbance in, the functioning of the person's mind or brain? If so:

Stage 2 (Functional Test): Is that impairment or disturbance sufficient that the person lacks the capacity to make a particular decision? A person lacks capacity to make a particular decision if they cannot either:

- Understand information relevant to the decision, or
- Remember the information long enough to make a decision, or
- Use or weight up that information as part of the process of making the decision, or
- Communicate their decision – by talking, using sign language etc.

### **Box 3: Vignette**

Mrs Jones is an 85 year old woman with dementia who was admitted to hospital with a fractured right neck of femur. She had hip replacement surgery and was discharged home two weeks ago with a four times a day care package from social services. She has a daughter who visits alternate days. The district nursing team has been visiting her daily for the administration of low molecular weight heparin injections and allied health care professionals are visiting to progress her mobility back to her baseline function with the use of a home exercise programme.

A micro living environment has been created. Mrs Jones has her bed and a commode in the front room. She has also had a key safe and intercom fitted and has a pendant alarm, which she wears around her neck. She has been provided with a Zimmer frame and has been advised not to mobilise outside of the front room without supervision.

Despite this advice, Mrs Jones has continued to mobilise outside her micro living environment and has fallen on three occasions since her discharge home. Whilst she has not sustained any further injury, on the last occasion she did not activate her pendant alarm and was found on the floor by her home carer who estimated she had been there for over an hour.

Mrs Jones' daughter has contacted you to say that she is worried that her mother's next fall '*will be her last*' and she wants her to go into a care home. You have spoken to Mrs Jones and offered to arrange a temporary stay in

an inpatient rehabilitation unit until she reaches her full rehab potential but she has declined saying she does not want to leave her home.

<b>Box 4: Key Themes</b>	
<b>First Order</b>	<b>Second Order</b>
Patient Factors	Patient's medical condition
	Language needs
Family Influence	Stress associated with caring role
	Self-interest
	Benevolence
Staff Factors	Self-awareness
	Experience
Team Factors	Role perception
	Inter-professional learning
	Physical distance from colleagues
Environment Factors	

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