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Mental Capacity and Consent

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Most courses in medical ethics begin not with the contested battlefields of the beginning, end and moral status of human life, but rather with the far more mundane issues of capacity and consent. These related concepts are crucial to the whole practice of medicine – for a healthcare practitioner even to take a medical history from a patient (let alone administer medication or perform surgery), it is vital that the patient gives their consent. For them to be able to do this, the patient must be deemed to have the mental capacity to make such a decision.

Healthcare workers generally begin any consultation by assuming that the patient they are treating has the mental capacity to make decisions about their care – the ability to consent to, or refuse, different types of treatment. The subject is usually considered at points where patients or their families may disagree with professionals over their care, or where patients may appear to lack decision making abilities (for example if they are unconscious or confused), in which case professionals may formally assess the patient's capacity to refuse medical advice.

In a previous *CMF File*, it was argued that patient autonomy is perhaps the most important guiding principle of current secular medical ethics.[1] In that paper it was argued that whilst the Bible recognises the ability and right of the individual to make choices, the Western ideal of autonomy (based on unrestricted individualism) falls far short of the biblical ideal of freedom in Christ – in which the individual is set free to obey the law of God, and to serve God and others in love. If Christians are concerned about limitations on individual choice, what should they think when an individual makes a decision that seems unusual, foolish or irrational? Do we as caregivers have the authority (or even the duty) to go against a patient's wishes in favour of what we think is in their 'best interests'?

Key principles of mental capacity in UK law

The Mental Capacity Act[2] provides the framework for governing consent and capacity, and professional guidance from the General Medical Council helps doctors with the practicalities of implementing the law. The following steps are taken whenever any decision is made in the treatment of a patient:

- **All adult patients are assumed to have capacity to consent to (and refuse) treatment unless proved otherwise.**
- Caregivers should maximise a patient's ability to make decisions, by (for instance) discussing decisions at the patient's 'best time of day' or by supplying them with relevant information in a format that is easy to understand.
- Capacity is decision specific and time specific: a patient may have capacity to decline lunch, but not to decline life-saving treatment; they may lose or regain capacity to make decisions as their clinical condition changes.
- A patient's capacity to make a decision is formally assessed by determining if they can **understand, retain, use and weigh up the information needed to make that decision, and communicate their wishes**. If they can achieve this, the patient's decision must be respected by the team treating them (although patients do not have the right to demand treatment that is not deemed to be indicated by their doctors).
- If a patient is deemed to lack capacity to make a decision, healthcare providers must act in the patient's 'best interests', following the least restrictive course of action and respecting the patient's previously-held wishes.
- In order to ensure that the patient's best interests and previously-expressed preferences are properly respected, an Independent Mental Capacity Advocate or IMCA (often a specially-trained social worker) may be appointed in cases where caregivers wish to act against a patient's wishes. In particularly difficult cases, the Court of Protection can give a final decision.[3]

The changing landscape around mental capacity

Big changes in the way medicine has been practised in the past few decades have affected the way mental capacity is viewed now. Patient choice is increasingly viewed as a guiding principle of medical ethics, as it has been recognised that patients are equal partners in the treatment of their illnesses alongside the healthcare workers who treat them. Conversely, as the phrase 'best care' has been used increasingly in guidelines and policies, institutions feel a growing burden to ensure that all relevant interventions are provided for patients, especially for those who need to be treated in their 'best interests'. As medicine has become more regulated and scrutinised, capacity assessments – that may in the past have been assumed or 'fudged' – are now documented and examined, resulting in a greater diligence to ensure legal processes are followed correctly.

In recent years, a number of test cases and high profile stories have thrust the assessment of mental capacity under closer scrutiny. This has revealed two main concerns: that a patient may be wrongly deemed to lack mental capacity (and have their freedom curtailed inappropriately) or that they may be wrongly deemed to have capacity when they lack it (and so would not be appropriately protected from the consequences of misguided actions).

Example 1:
Sheila is an 86-year-old woman with dementia who is admitted to hospital after suffering a fall at home. Because of her frailty and poor eyesight, she is deemed to be at high risk of further falls. After a multi-disciplinary team assessment, it is recommended that she be discharged into a residential home. Sheila is adamantly opposed to this, responding 'I just want to go home' whenever she is asked about discharge planning, but not engaging in discussion about the risks of doing so. A formal mental capacity assessment is carried out by the clinical team and the hospital's mental capacity nurse specialist; both deem that Sheila lacks capacity to make this decision because it is felt that she is unable to understand and retain the information given to her about her risk of falls at home. Under DoLS legislation she is admitted to a residential home against her wishes.

There has been an increase in the number of formally-conducted capacity assessments carried out in healthcare settings, many under the auspices of the Deprivation of Liberty Safeguards (DoLS). These were added in 2009 to the Mental Capacity Act (2005) in order to provide legal protection for organisations in England and Wales (such as hospitals or social services departments) that might deprive individuals of basic human rights – for instance, a hospital that will not allow a confused patient to leave the ward. The legislation ensures that there is appropriate legislative oversight of such deprivations, by formalising the way mental capacity is assessed, and by allowing for challenges to deprivation of liberty orders. Since a legal case in 2014 [4] set out an 'acid test' for when the DoLS legislation needs to be used, it has been estimated that as many as 176,000 patients in hospitals and social care institutions in England and Wales may need to have their care formalised under the DoLS framework [5] (although a more recent ruling suggests that routine use of DoLS legislation for temporarily incapacitated patients is not required). [6] The DoLS legislation has been criticised as being overly bureaucratic by a Select Committee of the House of Lords, who described the legislation as 'not fit for purpose', and also expressed the concern that unscrupulous agencies could use DoLS legislation to impose unnecessary controls on patients in their care. [7] A recent 'File on Four' documentary noted how local authorities were using mental capacity legislation to rule that individuals in their care who suffered from learning disabilities may not have the mental capacity to consent to having sex, and thus could be observed day and night to prevent them from having (potentially abusive) sex. [8]

Why might DoLS legislation be troubling to Christians? In some ways this legislation is to be welcomed: it seeks to regulate the extent to which the lives of individuals who lack mental capacity may be controlled by hospitals and care agencies, and opens up such decisions to public scrutiny. That said, a binary-outcome test is applied to patients, which means they are deemed either to possess or lack mental capacity. For those who lack capacity, all responsibility for their care decisions then falls to the institution looking after them. In an era of increasingly defensive decision making in medicine and social care (where 'best practice' is increasingly set out in guidelines) there is the risk that burdensome treatments or living conditions are imposed on patients, who may object to such actions but not be able to express their objections in a coherent enough manner to be deemed to have capacity.

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Conversely, concerns have also been expressed that mental capacity may be wrongly attributed to patients who actually lack capacity to make major decisions. In 2007 Kerrie Wooltorton, a 26-year- old woman with a long history of an 'untreatable' unstable personality disorder and repeated suicide attempts, was admitted to Norwich and Norfolk University Hospital after drinking anti-freeze in a further suicide attempt. On this occasion she declined emergency treatment. She was deemed to have capacity to refuse treatment and died four days later. At the inquest into her death in 2009, the coroner deemed that doctors had acted lawfully by respecting her decision to refuse treatment.

Example 2:
Ronald is a 77-year-old man receiving intravenous antibiotics as a hospital inpatient for community acquired pneumonia. Whilst an inpatient, he develops urinary retention with evidence of acute kidney injury. He refuses urethral catheterisation, and states clearly that he wishes to be left alone. He understands that this will lead to him dying from renal failure. The physicians treating him feel that he has capacity to make this decision on the basis that he can understand, retain and use the information given to him to make a decision, and can communicate this decision to the doctors and nurses looking after him. However, there is conflict between professionals when a second opinion is sought from the elderly care physicians, who feel that Ronald is delirious secondary to sepsis, uraemia and pain, and that despite him meeting the basic criteria for mental capacity, he does not have sufficient capacity to refuse life-saving treatment. The case is referred to the hospital's ethics committee.

The coroner's decision signalled a change in approach to suicidality. Patients are commonly detained under various sections of the Mental Health Act [9] for assessment or treatment if they are presenting to hospital with a suicide attempt and felt to be at risk of significant harm, particularly if they might have an underlying mental disorder. Although the Mental Health Act does not allow for treatment of physical health problems, patients detained under the act would usually be deemed to lack capacity to decline life-saving medical care and be treated in their best interests. In the case of Kerrie Wooltorton, she was deemed not to have a mental illness impairing her capacity to make decisions and so was allowed to die. Was this a good decision – sadly accepting and respecting a clearly-made decision by an autonomous individual? Or was Kerrie Wooltorton let down by a system that failed to protect her from a bad decision, driven by a personality disorder that clouded her thinking?

The decision is complex and subtle. Most of us change our minds at different points in our lives. We may all be able to look back

at times when we made decisions we now regret – perhaps carried along by powerful emotions or influenced disproportionately by pressing circumstances. Various factors which are common in patients receiving medical care have been shown to impair decision making in scientific studies – for instance pain, [10] use of opiate medications, [11] sleep deprivation [12] or the many factors that may lead to delirium, especially in elderly patients. [13] Given evidence that shows illness and medications can impair cognitive performance, is the relatively low bar of being able to 'understand, retain, use or weigh up the information needed to make that decision, or communicate their wishes', really enough to allow a patient to make decisions that may cost them their life, if there is reason to suppose that their cognition is impaired?

Mental capacity in the Bible

To explore issues of mental capacity within a Christian framework, let us consider two linked questions and ask what the Bible has to say about them. First, a question concerning the notion of mental capacity itself: 'are individuals always able to judge what is best for themselves, or do they sometimes get this wrong?' And second, a question relevant for caregivers: 'is it ever right to overrule an individual's choices if we think they are harmful?'

Concerning the first question, is there evidence within the Bible that individuals may make bad choices for themselves? Certainly – and a large part of the Bible's varied literature is devoted to wisdom, which may be thought of as 'the ability to make right decisions', or as one dictionary has defined it the 'ability to judge correctly and to follow the best course of action'. [14] Folly (the opposite of wisdom) is often associated with sin, godlessness and destruction, [15] but the Bible also speaks in far less pejorative terms of those who are simple and naïve. [16] The Bible is full of hope for those who lack wisdom. Children need to be instructed in wisdom and the word of God in order to make wise choices later in life. [17] Those who lack wisdom can get it by being in right relationship with God (part of which is fearing him), [18] asking him [19] and studying his word. [20] When someone accepts the gospel, spiritual light replaces blindness [21] and wisdom displaces folly. [22] From this brief overview, therefore, we can say that the Bible very strongly advocates a right way and a wrong way to live. Whilst situations may be complex – and indeed, in some situations there may be a range of right choices that can legitimately be made – nevertheless, people are able to choose what is right by basing their decisions on God's word, and seeking to serve him in what they do. Sin undermines our capacity to choose rightly, but nevertheless Paul saw his role as an evangelist as a work of reasoning and persuading, trying to convince people to trust in God. [23]

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Does the Bible say anything directly about dementia and cognitive impairment – probably the leading reasons why mental capacity is assessed in the modern world? There is little direct reference to it; however, Ecclesiastes 12:1-8 paints a picture of a person growing old and experiencing loss of pleasure, weariness, failing sight and hearing, and the dying process. Perhaps poignantly, the advice with which the passage starts is towards cognitive activity: 'remember your Creator in the days of your youth'. [24]

Concerning the second question, is it ever right to act in a person's best interests, but against their expressed wishes? The biblical picture is complex and takes us into the depths of the theological tension between human choice and divine sovereignty. In one sense the answer has to be a resounding 'yes', as the Bible describes the salvation of every human being as an act against the wishes of that individual: 'when we were God's enemies, we were reconciled to him through the death of his Son'. [25] Yet the complexity of God's work in a person's heart, leading them to put their trust in God and giving them faith to make a choice to serve him, [26] implies that God is a great respecter of human decision making – the biblical basis of the concept of free-will.

In God's dealings with people he always confronts them with a choice: will they serve God or reject him? [27]

However, we are not God and do not share his divine power and authority. And yet elsewhere in the Bible we sometimes see a similar principle at work, where individuals are commended for acting responsibly in the best interests of others for their good – sometimes with, and sometimes without, their consent. 'Love each other deeply, because love covers over a multitude of sins' [28] are Peter's instructions to the Christians he addresses. Forgiveness and grace can be offered to others regardless of whether they request it, and may be the first step in turning the other party back from sin or judgement: 'whoever turns a sinner from the error of their way will save them from death and [again!] cover over a multitude of sins' [29]; 'blessed are the peacemakers'. [30] In 1 Samuel 25 we meet 'intelligent and beautiful' Abigail who is married to 'surly and mean' [31] Nabal, whose name means 'fool'. [32] Nabal sets out to insult David (Israel's future King), but Abigail acts – without her husband's consent – to play down the insult, make reparations and prevent conflict. She is commended for her actions and bloodshed is averted. [33]

What does this mean for 21st century doctors confronted with complex decisions regarding capacity, which affects frail and vulnerable patients? First, it means that we can be confident in asserting that there are good and bad choices in life and that, in a world filled with relativism, we can be confident in encouraging decisions that are wise, rather than foolish. Second, it means that –whilst also recognising their God-given autonomy and ability to choose for themselves – there can be a role for us to intervene lovingly in the best interests of our patients.

Reflections on the current UK law governing mental capacity

The current provisions in the UK to govern mental capacity assessment are to be commended in their efforts to strike a delicate balance between respect for individual choice on the one hand and recognising the validity of professional opinions on the other. It is positive that such efforts are made to avoid abuses. The current system of assessments, although bureaucratic and cumbersome, protects patient choice and offers them the right to appeal against decisions, whilst also ensuring that the most vulnerable do not miss out on beneficial interventions because they lack capacity to

consent. In its overall form, UK law reflects biblical principles of preserving individual choice whilst also allowing well-intentioned care to 'cover over a multitude of evils'.

However, as has been noted above, concerns persist about the potential for the current framework wrongly to attribute or wrongly fail to attribute capacity to patients. Sometimes this may be due to the failure of individuals properly to assess capacity, perhaps fearing criticism or litigation; or by them making unfair assumptions about a patient's abilities. The system needs to be robust enough to ensure patients are protected from individual errors and to correct institutional biases that allow other priorities to outweigh a patient's autonomy and best interests.

Another danger of the current framework is that, whilst it correctly recognises that capacity is decision specific and can vary over time, it imposes a binary division between having and not having capacity for any particular decision and fails to recognise the nuances involved. For example, a patient who is unwell, sleep deprived or suffering significant pain may pass a 'capacity assessment' (by being able to understand, recall and repeat information relevant to a decision they have to make) but may be in a mental state far from their 'normal'. Conversely, a patient with significant cognitive impairment may fail a strict capacity assessment, but still express strong preferences towards certain courses of action. Disentangling these difficult situations of conflict is hard work and must be done on a case-by-case basis.

Conclusion

Current mental capacity legislation in the UK strikes a helpful balance between preserving biblically-mandated human autonomy and the rightfully well-intentioned efforts of healthcare providers to act in patients' 'best interests'. What is crucial is to ensure that concerns other than for the patient do not creep in, such as a desire to avoid conflict, or to avoid potential criticism or litigation. Christian doctors, indeed all doctors, have a responsibility to speak up for those whose wishes are drowned out by institutional priorities, but also to be bold in treating vulnerable people who may lack capacity to act in their own best interests. In a world wary of medical paternalism, where perhaps the pendulum of opinion has swung against expert medical opinion, Christian doctors should be advocates for vulnerable people and seek to preserve life and limb as, in almost all cases, an appropriate goal of medical care.

The current law carries the scope to act in love, both to respect and to overrule a patient's wishes. Doctors should pray for wisdom (and common sense) in knowing the course of action required in any given situation.

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