

Psychiatric Issues in Palliative Care: Assessing Mental Capacity

Itoro Udo¹, Zeid Mohammed² and Amanda Gash²

¹Darlington Memorial Hospital, Darlington, UK. ²University Hospital of North Tees, Stockton-on-Tees, UK.

ABSTRACT: Issues surrounding capacity to consent to or refuse treatment are increasingly receiving clinical and legal attention. Through the use of 3 case vignettes that involve different aspects of mental health care in palliative care settings, mental capacity issues are discussed. The vignettes tackle capacity in a patient with newly developed mental illness consequent to physical illness, capacity in a patient with mental illness but without delirium and capacity in a patient with known impairment of the mind. These discussions give credence to best practice position where physicians act in the best interests of their patients at all times. It is important to emphasize that capacity decisions have to be made on a case by case basis, within the remit of legal protection. This is a fundamental requirement of the Mental Capacity Act 2005, England & Wales (MCA). The latter is used as the legal basis for these discussions. The psychiatric liaison service is a useful resource to provide consultation, advice and or joint assessment to clinicians encountering complex dilemmas involving decision-making capacity.

KEYWORDS: Mental Health Care, Psychiatric Issues, Palliative Care, End of Life, Mental Capacity, Mental Competency, Consent to Treatment, Consent to Refuse Treatment, Mental Capacity Act, Patient Centered Approaches

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CORRESPONDENCE: dr_itoro@yahoo.com

Introduction

Understanding a patient's illness as well as a patient's experience in relation to the illness requires a complex set of communication skills.¹ It is also an integral part of patient-centered approaches to healthcare delivery.² Patient centeredness is crucial because through it clinicians can promote a collaborative partnership with patients during decision making.³ By adopting a patient-centered approach, better outcomes, increased satisfaction and a better quality of life may be achieved.^{1,3,4} However, at times, this partnership may be impossible to establish, especially in circumstances where a patient's mental capacity, that is, the person's ability to make specific decisions for his or her self, is affected.⁶

People are constantly called upon to make decisions about issues ranging from simple daily things like what to eat or wear and where to go to other more complex decisions like whether to take life preserving medication.⁷ Some necessary decisions may have more far-reaching consequences than others. The consequences of these decisions may involve loss of health and life, poverty, abuse, and so on.

At the inception of the Mental Capacity Act, England & Wales,⁵ in October 2007, it was estimated that there were about 2 million people who lacked the ability to make some decisions and may need to be assessed to determine appropriate course of action.⁶ The Act provides guidance about how these issues should be approached and managed.

Loss of capacity is very common in palliative care patients. It could be postulated that almost all patients lose their capacity at some point in the dying process, for some patients only for a few hours and others for many days, weeks or months.⁸ The Care Quality Commission (the organisation in England charged with ensuring that health facilities provide high-quality services)⁷ has "found a lack of understanding of the wider mental capacity act" among healthcare professionals in England and Wales.⁸ Through our role in delivering mental health service in acute care settings, we observe that this is likely to be the reality in those settings. As the achievement of good mental health is increasingly regarded as integral to good palliative care⁹ and is based on discussions with clinicians in this specialty, we have identified a training need



in the often complex issue of capacity assessments within palliative care settings; hence, we have created this resource. The discussions presented in relation to the case vignettes below represent a liaison psychiatry perspective on these palliative care scenarios.⁹ This is important, because failure to accord due regard to the Act and its implications⁹ may result in claims of medical neglect, abuse or assault.¹⁰

Issues related to capacity are likely to take an upward trajectory over the coming years, as clinicians^{11,12} and the wider society¹³ begin to consider more vigorously the issues of euthanasia and physical illness. In addition, as our medical knowledge of illnesses expand, individuals may begin to more widely plan for such a time when they may lack the ability to decide on what treatment or care they may receive. The principles of the Mental Capacity Act, 2005, though limited to England & Wales, may be considered a standard for good defensible practice in other jurisdictions where no statutory capacity legislation exists.

Whose Responsibility is it to Assess Capacity?

As a department, liaison psychiatry is often called upon to assess capacity in various circumstances. However, the statutory responsibility rests with all health care professionals within the broader multidisciplinary team proposing a treatment or intervention to assess the patient's ability to properly consent to receive or refuse a treatment.¹⁴ A healthcare assistant may assess a patient's capacity to refuse a wash; a nurse may assess the capacity of a patient to decline a particular dose of medication offered; social workers and allied health professionals may provide input into capacity assessments around discharge planning; a doctor may have more wide ranging responsibilities regarding treatment and management decisions.¹⁰ The role of a liaison psychiatry team may then be to advice and guide in complex cases, especially when mental illness is suspected.

General Principles

The Mental Capacity Act 2005,⁵ England & Wales is embodied by 5 operating principles that are stated in Table 1. Clinicians are expected to give due regard to these principles in clinical matters pertaining to clinical procedures or treatment.

Based on the Act,⁵ a person is unable to make a decision if they cannot

1. Generally understand information about the decision to be made
2. Retain that information in their mind
3. Use or weigh that information long enough to make a decision
4. Communicate their decision (by talking, using sign language or any other means).

The presence of any of the above implies lack of ability to make a decision. The assessment of capacity is then expected to go through 2 stages¹⁴:

Table 1. Principles of the Mental Capacity Act 2003, England & Wales.¹⁴

Principle 1: "A person must be assumed to have capacity unless it is established that he lacks capacity".
Principle 2: "A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success".
Principle 3: "A person is not to be treated as unable to make a decision merely because he makes an unwise decision".
Principle 4: "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 best interests." ¹¹
Principle 5: "Before an 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".

Stage 1: Consideration is given to whether there is an impairment of the mind or brain such as to affect the way the brain or mind works. It does not matter whether this impairment is temporary or permanent.

Stage 2: If impairment is present, a determination is made of whether it is affecting the ability of the individual to make a specific decision at a particular time.

A person is also considered to lack capacity if they have an impairment such as a disability, condition or trauma that affects the way their mind or brain works AND if the presence of this impairment or disturbance affects their ability to make a decision at the point a specific decision needs to be made; i.e., inability to understand, retain, "weigh up" or communicate.¹⁴ Presence or lack of capacity can vary over time, even over the course of a day.

How Does the Mental Capacity Act Relate to the Mental Health Act, England & Wales?

It is important to note that in certain situations the Mental Health Act 2007 (England & Wales)¹⁵ may override the mental capacity act, such as if there are reasonable suspicions that the decision taken by the patient is influenced by a mental health disorder.¹⁴ The mental health act may also override advanced directives.¹⁴ Advance directives are documents that explain what specific medical treatments in particular circumstances a person would not want in the future, in event they lose capacity as defined by the MCA 2005.¹⁶⁻¹⁸ It does not necessarily have to be written; an exception is if it relates to life-sustaining treatment.^{16,17} In the latter, it should have the signatures of 2 witnesses and should have been made when the individual was fully capable of doing so and not under duress.^{16,17} In England and Wales, they are legally binding documents.¹⁶ They may also be called Advance Decision to Refuse Treatment (ADRT). If healthcare professionals have doubts about the validity of advance directives, they can apply to a Court of Protection to make a decision.^{17,19} A term "advance statement" is now increasingly being used. This is an expression of the individual's desires and may refer to their



values, desires and beliefs. It is not legally binding but may act as a guide to a doctor who has to make a decision in the interests of a patient who lacks capacity.^{12,14,17,19}

In practice, for example, a patient with schizophrenia may, in their advance directive, specify that they do not want to be given the medication Olanzapine in event of a mental health crisis. Where the directive is valid, healthcare professionals are bound to respect this wish. However, if there is reason to believe that non-receipt of this medication may not have been the genuine wish of the patient, the professional/multidisciplinary team may apply to the court of protection to declare the directive invalid. If, for clinical reasons, the person's treatment is placed under the Mental Health Act, then this also invalidates the advance directive. It is good practice for clinicians to continue to give due, reasonable regard to the contents of the directive in order to improve patient experience. With advance directives, patients may not demand particular treatments. As in the scenario above, the person cannot in their directive demand to be given the medication Aripiprazole in a crisis.¹³

What about Independent Mental Capacity Advocates (IMCAs) and Courts of Protection?

An independent mental capacity advocate (IMCA) is an advocate who functions independently of local authority or courts and may be consulted as a safeguard on issues concerning a person who lacks capacity.²⁰ They are provided by independent advocacy services/organisations. They may make an application to a court of protection on behalf of persons lacking capacity if necessary.

IMCAs are not consulted if^{14,20}:

- a person who now lacks capacity had nominated someone to be consulted specifically on the same issue
- a person has an attorney who is authorised specifically to make decisions on the same issue; or
- a deputy has been appointed by the court to make decisions on the same issue.

Where a person has no family or friends to represent them, but does have an attorney or deputy who has been appointed specially to deal with property and affairs, then an IMCA must be instructed.

Where serious medical treatment is being administered under the Mental Health Act then there are safeguards already in the Act.

Staff working in a hospital: doctors, nurses or social workers have the power to instruct an IMCA under the MCA. The only circumstances in which the obligation under the Act to instruct an IMCA need not be followed is when an urgent decision is needed; for example, to save a person's life.²⁰ However, if additional serious treatment follows the emergency situation, there will then be a need to consult an IMCA.²⁰

Courts of Protection are specialist courts that make decisions on behalf of people who are unable to make decisions

about their health, finance or welfare.²¹ It may also appoint deputies to act on its behalf. Deputies are appointed to look after the affairs of someone who is unable to. They are usually close friends or relatives of the person. They could be professionals such as an accountant or solicitor.²² They are expected to act in the person's best interest and to only make decisions about areas they are asked to. The court may also make decisions relating to lasting powers of attorney. A power of attorney is a document that allows an individual (the attorney) to make decisions on behalf of someone else in certain circumstances. It can allow for decisions to be made relating as to the existence, validity or applicability of an advance directive to refuse treatment. It may make determinations about best interests where there is dispute between concerned parties.¹⁴ For cases involving medical treatment, the treating hospital can make an application to this court through its solicitor. These courts can be assessed in emergencies.²³

In order to further elucidate on issues involving capacity in palliative care, the following case vignettes, one real and two fictional, are presented to illustrate the dilemmas that clinicians may experience and how these may be managed.

Case Vignette 1

A man in his late forties, suffering from advanced multiple sclerosis, was referred to liaison psychiatry by his neurology team, following a refusal to accept a Percutaneous Endoscopic Gastrostomy tube (PEG) inserted for his feeding.¹⁶ At the time, the patient did have a nasogastric tube for feeding, which he did not object to or resist. His admission to the neurology ward was mainly to rehydrate him, and improve his nutritional status during an episode of multiple sclerosis flare up. The intended outcome was to discharge him home with a palliative care package. When the patient was seen, he was lying in bed and sleepy. He did not object to the assessment, though his speech was difficult to understand; he generally expressed himself using "yes" or "no" replies, and single words. When asked if he was aware that PEG is considered as an option for his feeding, he replied in the affirmative. He used the term "sad", when asked how he would feel if this is done against his wish. He clearly said "no", when he was asked if he wanted this procedure at all.¹⁷

He was reviewed again within a few days. This was to allow time to assess whether he had retained previously discussed information and when he would hopefully be fully awake. On this second assessment, due to its complex nature, he was seen by 2 psychiatrists.

The patient could not remember the previous assessment; he was confused and could not explain the purpose of a PEG tube. It was concluded that there was reasonable ground to believe the patient lacked capacity.

Discussion. Capacity assessments, in general, can be carried out by any fully registered doctor or senior nurse,¹⁴ but in this case, a difference of opinion between the treating team, who felt that the patient was capable of refusing the



procedure, and the patient's caring parents, who believed that their son lacked capacity to refuse this particular treatment, precipitated the involvement of liaison psychiatry. His parents' understanding was that PEG could prolong their son's life. This was at odds to the opinion of the multidisciplinary team caring for their son.

We first established that there was disorder or impairment of the mind. Here, the advanced multiple sclerosis itself can be an indicator of issues, especially given that the concept of a disorder of the mind is broadly defined and that no diagnosis is needed. Thus, the fluctuating confusion caused by his condition may be argued to indicate, represent or raise reasonable suspicion of the existence of a disorder of the mind.

Having established the possibility of a presence of a disorder of the mind¹⁹ on the first assessment, the second assessment enabled us to establish clearly his inability to understand, retain, weigh and communicate the information given to him earlier, as regards the proposed intervention. The interval to the second assessment also allowed the team to go through old treatment notes that elucidated his previous consistent objection to PEG insertion on occasions when his capacity was not in doubt. The Act recognizes that individuals, in general, have the right to take unreasonable decisions.¹⁴ If he had problems with communication, the time to a subsequent assessment would also have afforded opportunity to maximize his communication with involvement of speech and language therapy, communication aids, and so on.

Having an advanced directive to refuse this treatment could have helped this patient, his parents and the medical team in this dilemma. If the patient had stated that he did not wish to be fed if his multiple sclerosis illness advanced, that would be an unspecific request and the directive would be invalid. If he specifically stated that he would not want a PEG tube, then this would be valid and his wish would have to be respected. If there are queries about possible mental ill health influencing the advance directive, the patient could be detained under the mental health act. Under those circumstances, the advanced directive becomes non-applicable and standard medical treatment ensues.¹⁴ However, it is good practice to try to accommodate respective patients' wishes as much as is practicable; however, generally in progressive neurological conditions such as motor neuron disease, multiple sclerosis, and dementia, where loss of capacity is a likely outcome and parenteral feeding is likely to be an option, there is an important role for discussing the possibility of advance care planning early whilst the patient has capacity to make these decisions.^{17,18}

Case Vignette 2

A 46-year-old man, Mr. XY was referred to liaison psychiatry from an inpatient palliative care unit where he was on the Liverpool Care Pathway as a dying patient with chronic liver disease.²⁴ He had just been transferred there from a tertiary gastroenterology unit. It was the view of the transferring unit

that he had just a few days to live. The reason for the referral was that Mr. XY was found to be secretly ingesting alcohol whilst in the toilet. The unit was unable to determine how he came to possess alcohol on the unit. It was suspected that it could have been brought in to him by visiting family members at his request. The dilemma was whether he had the capacity to decide to continue to consume alcohol, given the effect of continued alcohol consumption on his health.

On assessment of his mental health, he was a chronically ill man who described 30-year history of severe alcohol dependence. He had experienced past episodes of delirium tremens and had experienced numerous withdrawals. His longest period of abstinence was for a period of 6 months, 5 years ago. He did not describe any mood symptoms and had no persisting perceptual or cognitive disturbance. He was in painful distress from abdominal pain associated with his illness and reported not gaining any meaningful relief from opioid analgesics and felt that the alcohol gave him relief from his pain.

On assessment of capacity, he could clearly understand the effect of his continued drinking on his physical health. He stated that his drinking was the cause of his liver problems and accepted responsibility for his health. He was able to weigh up and report back that with continued alcohol consumption, his demise was likely to be hastened. He also stated that without alcohol, his physical and mental distress was going to be exacerbated. In his own view, his demise was imminent and whether he drank or not, it was not going to change the end point and he had chosen to make himself comfortable in his own way. He showed capacity to make a medically unwise decision.

Discussion. It was the view of the liaison psychiatrist that though the patient had severe chronic alcohol dependence, a disorder of the mind, he was choosing to cope with his distress through a means that was familiar to him and which he could control. He was found to have capacity to make the decision to continue drinking. This may have been viewed by medical professionals as an unwise decision, but this is well within the orbit of the Act that persons are entitled to make unwise decisions (See Principle 3).¹⁴ Based on the outcome of this assessment, further discussions were held between the patient and his clinicians; he did not want to continue staying in the inpatient unit. Based on medical professional duty of care, he was offered suitable alternatives to the inpatient unit such as a nursing home where he could be allowed to consume alcohol freely, which he accepted. The palliative care team had not realised that there were some nursing homes that would allow free consumption of alcohol. This option was preferred to discharge home as his family did not think they could manage him at home.

Case Vignette 3

A 67-year-old woman with mild learning disabilities was admitted to an inpatient palliative care unit. She was admitted with advanced ovarian carcinoma and end-stage renal disease.

Prior to her admission she had been in the care of an oncology team where she received several courses of chemotherapy in addition to radiotherapy. By the time she arrived in palliative care, she had begun to grow tired of treatments and did not want to continue receiving life-prolonging treatments. Surprisingly, the patient's definition of life prolongation treatments included not just antineoplastic agents, but also opioid medications. The palliative care team were concerned that the patient's learning disabilities impacted on her capacity to make this decision to refuse treatment and hence referred her to liaison psychiatry to assist in assessing her capacity to withdraw from treatments.

The patient was known to learning disabilities services. Review of notes available to mental health services showed that the patient had a long past history of self-injurious behaviours that included swallowing and insertion of various objects into body parts especially when distressed. She had received mental healthcare in various residential and nursing settings during which time she was often treated in Accident & Emergency departments for self-harm. She had frequently rejected pain medications on these occasions. This was also documented in her past treatment and care plans. Thus, it appeared that either the patient had a high threshold for tolerating pain, or may have been using physical pain as a means of soothing her emotional pain.

On assessment, the patient explained that she had not found past treatments to be helpful, and in particular, she did not like some of the side effects of opioid medications. She felt she was not in as much pain as to consider opioid medications essential. She felt she would rather cope with her pain in non-medical ways. She was willing to try aromatherapy and reiki. She understood the general purpose of her treatment, which was to make her comfortable. She understood the consequences of not taking medications, which was that her demise would be hastened. She also recalled her lived experience of taking medications. Based on all the available information, she reached a decision that she did not want the purposed treatments.

Discussion. Clinicians were worried about being seen to be negligent in providing clinical care to persons with learning disabilities or being accused of assault. Though she had learning disabilities of a mild degree, based on Principle 1 of the Act,¹⁴ we had to presume that this patient had capacity and assume the task of disproving it. Based on the criteria of understanding, retention, weighing and communication of information, she was capable of making a valid decision about accepting further treatments. This decision was consistent with similar decisions she had made in the past. The role of the psychiatrist here included ensuring that information was presented in a manner and level simple enough to clearly determine that she understood the consequences of her decisions. Though learning disabilities are considered impairments of the mind, they are stable conditions for which individuals may be supported to make a decision, depending on the nature

of the decision. Where necessary, pictures and equipment may need to be used in the explanation. A slower rate and flow of speech was used with appropriate hand movements. In this particular case, this patient already had an Independent Mental Capacity Advocate (IMCA)^{14,20} who had been appointed for previous issues because she had no family involved in her care. Her IMCA was consulted; the latter agreed with the patient's decision, which gave the clinical team confidence to continue her treatment within her wishes. If her IMCA had disagreed with the clinical decision, then matters would have been posed to a Court of Protection¹⁴ for a decision on the matter.

Summary

The above 3 case vignettes illustrate various possible dilemmas in the assessments of capacity in palliative care: capacity in newly developed mental illness consequent to physical illness; in a patient with mental illness but without delirium; in a patient with known impairment of the mind. Decisions have to be made on a case-by-case basis.

Though the responsibility for capacity assessment rests with the clinician proposing to treat, there is clearly a role for liaison psychiatry in assisting and/or advising on complex circumstances where suspected or known mental disorders may be impacting on clinical care/decisions. The intended outcome should always be that specific clinical decisions are made in the best interests of the patient in question. It is important to note that this refers to specific clinical decisions at specific times.

Clinicians may not always implement the mental capacity act correctly in decision-making where patients lack capacity, perhaps due to a lack of knowledge or experience or of confidence. The evaluation by Kornfield et al of mental capacity assessments within American general hospitals showed that 64% of requests for capacity assessments were due to patients threatening to leave against medical advice and/or refusal of treatments or procedures. They suggested that consultation-liaison psychiatrists may use these requests as teaching opportunities to other physicians.²⁵ These 2 types of circumstances occur in palliative care settings as well. It is important for palliative care staff to consider the situation more closely when faced with clinical circumstances in which patients withdraw from treatments, or procedures in cases where those patients actually have the capacity to make those decisions.³⁰

Some situations are genuinely complex and even 2 psychiatrists may not agree. This theme of possible difference in opinions has been observed between psychiatrists and bioethicists in the USA.²⁶ In the study by Fassassi et al disagreements among professionals on the outcome of capacity assessments were partly due to the fluctuating nature of capacity.²⁷ The default position is that individuals are able to make decisions and it is up to the assessor to disprove this by conducting an assessment of capacity.



Further Reading

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Author Contributions

Conceived and designed the experiments: IU, ZM, AG. Analyzed the data: IU, ZM, AG. Wrote the first draft of the manuscript: IU, ZM, AG. Contributed to the writing of the manuscript: IU, ZM, AG. Agree with manuscript results and conclusions: IU, ZM, AG. Jointly developed the structure and arguments for the paper: IU, ZM, AG. Made critical revisions and approved final version: IU, ZM, AG. All authors reviewed and approved of the final manuscript.

DISCLOSURES AND ETHICS

As a requirement of publication the authors have provided signed confirmation of their compliance with ethical and legal obligations including but not limited to compliance with ICMJE authorship and competing interests guidelines, that the article is neither under consideration for publication nor published elsewhere, of their compliance with legal and ethical guidelines concerning human and animal research participants (if applicable), and that permission has been obtained for reproduction of any copyrighted material. This article was subject to blind, independent, expert peer review. The reviewers reported no competing interests. Provenance: the authors were invited to submit this paper.

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