Chapter 1

NEGOTIATING CAPACITY AND CONSENT IN SUBSTANCE MISUSE

Kritika Samsi
Social Care Workforce Research Unit, King's College London, UK

Introduction

Mental capacity is an individual's ability to make autonomous decisions for themselves, the significance of which has increased with greater recognition of the involvement of the individual as a 'self-governing welfare subject' [1] with greater emphasis on personal choice and self-determination of his or her own health and social care decisions [2].

The complexity of problems associated with substance use in older people means that there are particular risks around capacity or 'competency', through impairment in cognition, judgement and function [3]. There could be co-morbid mental health problems that may further contribute to their impairment [4]. Decision making capacity is vital not only for individuals to be able to express their preferences for long-term care but also in the case of immediate in-patient care, when practitioners may face complex decision making issues. Some of these issues include: (i) timing of capacity assessment; (ii) conflict between presence of capacity, alongside evidence of self-neglect and need for medical care; and (iii) the role of the practitioner in encouraging the older person to give up addictions that are harmful to them [3].

Substance abuse and capacity

There had been diagnostic limitations in the Diagnostic and Statistical Manual of Mental Disorders iv (DSM-iv) in how substance abuse and dependence were classified, resulting in what some believed were deceptively low rates of identification of older individuals with substance abuse and dependencies [5]. Some of the criteria used – such as giving up activities and the inability to fulfil major role obligation at work – were also criticized for being irrelevant to an older population [5].

The physiological impact of acute alcohol intoxication is more severe in the elderly, with an increase in the risk of delirium [5]. In the brain, alongside an acute confusional state, cerebral atrophy can result in global cognitive impairment [5].

Substance Use and Older People, First Edition.
Edited by Ilana B. Crome, Li-Tzy Wu, Rahul (Tony) Rao and Peter Crome.

Mental capacity, judgment and ability to consent can also be affected. Most types of dementia are more prevalent in older people with alcoholism [6].

Impaired decision making capacity characterizes substance misuse. The diagnostic criteria according to the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5) acknowledge this, as substance dependence is described as persistent use despite knowing the negative physical and psychological effects of the substance [7]. The self-destructive choices and decisions made by substance abusers have been termed 'myopia', which are deficits in emotional signalling that produce poor short-term decisions for immediate gains despite potential for higher losses in the future [8].

Mental capacity legislation

Several western countries have existing legislation that addresses and protects autonomy, capacity, dignity and decision making for vulnerable people. None of this legislation codifies 'age' as a specific vulnerability in itself, and safeguarding incapacity or deteriorating capacity more wholistically is prioritized instead. By handing over decision making powers to a trusted relative or nominated consultee, an individual can choose who makes decisions on their behalf and, thereby, assert their choices and preferences through them.

The Guardianship and Administration Act was introduced in 1993 in South Australia and in 2000 in Queensland, two of Australia's largest states. The Substitute Decisions Act and the Health Care Consent Act were introduced in Ontario, Canada, in 1992 and 1996, respectively. Most of these Acts incorporate the same principles, with variations in the way capacity assessments are carried out, and how care priorities are determined. Presuming an individual has capacity, unless proven otherwise, is the guiding principle in all of these Acts.

Scotland, England and Wales introduced legislation around capacity more recently. Scotland introduced the Adults with Incapacity Act in 2000, and the Mental Capacity Act 2005 was introduced in 2007 in England and Wales; both are applicable to those over the age of 16 years.

Using the Mental Capacity Act 2005 as a case example in England and Wales, the rest of this chapter illustrates some of the principles embedded in current legislation in the area of capacity and consent, focusing specifically on its applicability to those with a history of substance abuse.

Mental Capacity Act 2005

The Mental Capacity Act 2005 (MCA), implemented in England and Wales in 2007, introduced a variety of provisions to safeguard and enhance the rights of vulnerable people with compromised capacity [9]. Prior to the Act, it was sometimes challenging to ascertain 'mental capacity' to make decisions and different approaches were described under mental capacity legislation and mental health legislation [1].

A central principle of the MCA is the presumption that all adults have the capacity to make decisions for themselves, unless proven otherwise. Provisions for surrogate

decision making should only be resorted to after it has been proved that an individual lacks capacity. The other four central principles of the Act include:

- A person must be given all practicable help before anyone treats them as not being able to make their own decisions.
- A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- Anything done or any 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.
- Anything done or decided for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

Capacity assessment

There are a number of capacity and decision making assessment tools currently available [4]. In the MCA, a four-stage assessment of decision making ability is required to prove that an individual is unable to make a specific decision at that specific time. These include asking the following four questions:

1. Does the person have a general understanding of what decision they need to make and why they need to make it?
2. Does the person have a general understanding of the likely consequences of making, or not making, this decision?
3. Is the person able to understand, retain, use and weigh up the information relevant to this decision?
4. Can the person communicate their decision (by talking, using sign language or any other means)? Would the services of a professional (such as a speech and language therapist) be helpful?

Inherent to this assessment is the recognition that capacity is not an absolute state but varies over time and with the decision that is required to be made. For substance misusers, this becomes an even more crucial issue, as their states of incapacity may fluctuate according to the level of intoxication or delirium. Capacity should, therefore, be seen as decision specific, rather than all encompassing. If a person is deemed to be 'lacking capacity', it means that they lack capacity to make a particular decision or take a particular action for themselves at the time the decision or action needs to be taken. The MCA applies to anyone who has 'an impairment of or disturbance in the functioning of the mind or brain' and was warmly welcomed for not using the phrase 'mental disorder', which may not be appropriate to a person with substance abuse problems. Similarly, an 'incapable' adult is defined in the Scottish and the Canadian legislation as someone unable to act, make, communicate, understand or retain the memory of decisions.

Legal frameworks such as the MCA 2005, codifying complex phenomena that can threaten the autonomy of vulnerable individuals, have wide applicability: from types of decisions, such as day-to-day support [10], advance decision making about

personal health and welfare [11], end of life care [12]; to different settings [13], such as medical encounters [14] and long-term care facilities [15]; and to a wide range of professionals [16–19].

Capacity and unwise decisions

A central feature of the Mental Capacity Act is the acknowledgement that individuals who have the capacity to make their own decisions are in a position to make what may be deemed 'unwise' decisions. In many cases, this applies to risk taking, such as gambling, forming relationships and choosing a certain type of lifestyle. In the case of substance misuse, individuals may choose to continue to use a substance in spite of being aware of its harmful effects. If that individual is deemed as having the capacity to make a decision for themselves – that is if that individual is shown as being able to weigh up the consequences of their decision and still choose to use a particular substance – the MCA safeguards that individual's decision making capacity by suggesting that decisions otherwise deemed 'unwise' are legally acceptable.

Consent, barriers to decision making and substituted decision making

If capacity is an individual's ability to make decisions, 'consent' can be seen as granting permission or agreeing to the decisions themselves. In relation to consenting, the relevance of the MCA covers three relevant areas: substituted decision making powers, best interest principles and independent decision makers.

The MCA facilitates substituted decision making through the uptake of Advance Care Planning (ACP) in three forms:

1. Statements of wishes and preferences for future care that an individual would want, that was made before they lost capacity. These can include requests for specific medical treatments, such as artificial nutrition and hydration. Although these written statements are not binding, a practitioner must consider them before making a proxy decision on an individual's behalf, and any reason they are choosing to go against the written statement of wishes should be clearly recorded.
2. Advance decisions to refuse certain treatment where an individual stipulates that they do not want a particular intervention, such as artificial nutrition or hydration, or withdrawal of life support system. These are more binding on practitioners. (Box 1.1 shows provisions outlined in the MCA).
3. Granting a trusted friend or relative Lasting Power of Attorney (LPA) to cover health and welfare decisions. Granting LPA is a powerful principle since the MCA was introduced, as it enables individuals to have their wishes and preferences included at a time when they may be unable to contribute themselves.

Box 1.1 Provisions for Advance decisions outlined in the MCA

24.1 'Advance decision' means a decision made by a person ('P'), after he has reached 18 and when he has capacity to do so, that if:

(a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and
(b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.

Box 1.2 Provisions for Lasting Power of Attorney outlined in the MCA

9.1 A lasting power of attorney is a power of attorney under which the donor ('P') confers on the donee (or donees) authority to make decisions about all or any of the following:

(a) P's personal welfare or specified matters concerning P's personal welfare, and
(b) P's property and affairs or specified matters concerning P's property and affairs, and which includes authority to make such decisions in circumstances where P no longer has capacity.

A health and welfare LPA can run in conjunction with a financial LPA, which sets out a decision maker for property and financial affairs. Surrogate decision makers may also be granted the power to make decisions about life-sustaining treatment. (Provisions relating to an LPA outlined in the MCA are outlined in Box 1.2.)

There are some pre-conditions that govern the behaviour of an LPA, such as any substitute decision must be made in the individual's best interest [20]. Moreover, there are a number of decisions that are outside the remit of substitute decision making, where it is deemed impossible to be able to gauge another's likelihood of consent (section 27 of the MCA). For instance, nothing in the Act permits a substituted decision to be made regarding any of the following:

- consenting to marriage or a civil partnership;
- consenting to have sexual relations;
- consenting to a decree of divorce on the basis of two years' separation;
- consenting to the dissolution of a civil partnership;
- consenting to a child being placed for adoption or the making of an adoption order;
- discharging parental responsibility for a child in matters not relating to the child's property; or
- giving consent under the Human Fertilisation and Embryology Act 1990.

Box 1.3 Best interest checklist in the MCA

- Can the decision be delayed to when the individual may have capacity?
- No decision should be based on the person's appearance, age, medical condition, or behaviour.
- All relevant information should be considered, and every attempt to involve the person in the decision should be made.
- Any written or verbal statement expressing the individual's wishes, values, choices, preferences, beliefs and feelings should be considered.
- Views of family members, partners or other supporters who may know the person better should be incorporated.
- If the decision is about treatment, the decision maker should not be motivated by a desire to bring about their death, nor by assumptions of their quality of life.

Best interest decisions

An individual's best interest is always protected under capacity legislation. The MCA 2005 deems that all surrogate decisions should be in an individual's best interest. However, research has indicated prevalent discrepancies about how this may be rolled out in practice [21], especially in relation to challenges with resolving conflicts [22]. Best interest decision making includes a checklist, which takes into account key indicators of an individual's well-being. In complex cases, such as working with older people with substance misuse problems, assessing impaired capacity may not be straightforward and there may be additional criteria to take into account. Hazelton *et al*. [3] suggest delaying significant decisions for as long as possible, or at least until acute effects have passed, as well as differentiating between alcohol-related cognitive deficits and addiction-related denial. Using the least restrictive option is also always recommended. (Box 1.3 shows a best interest checklist outlined in the MCA.)

Independent decision makers

Family networks of older people with a history of substance misuse may be absent, chaotic and challenging to engage. A relationship between the older person and their family relative may not be based on trust or prior knowledge of preferences of the individual.

Legislation has provided for these cases through the establishment of new roles; for example, in England and Wales, that of an Independent Mental Capacity Advocate (IMCA), or someone who can step in to the role of substitute decision maker, to make major decisions regarding treatment or accommodation for a person with impaired capacity [23]. Definition of roles and remits in all of the legislation largely overlap, with their main remit being to consider the best interests of the vulnerable person in order to make the decision that contributes most to their well-being (Box 1.4).

Box 1.4 Stipulations covering an Independent Mental Capacity Advocate

36.2 The regulations may, in particular, make provision requiring an advocate to take such steps as may be prescribed for the purpose of:

(a) providing support to the person whom he has been instructed to represent ('P') so that P may participate as fully as possible in any relevant decision;
(b) obtaining and evaluating relevant information;
(c) ascertaining what P's wishes and feelings would be likely to be, and the beliefs and values that would be likely to influence P, if he had capacity;
(d) ascertaining what alternative courses of action are available in relation to P;
(e) obtaining a further medical opinion where treatment is proposed and the advocate thinks that one should be obtained.

Conclusion

The relevance of capacity and consent to older people with a history of substance misuse is significant, given that capacity to consent for this vulnerable group may be impaired, may fluctuate and many of them may have absent or chaotic social networks. This then leaves professionals working with this group with greater responsibilities to assess capacity, safeguard the interests of this group, uphold the dignity and enhance the autonomy of their patients. While there is availability of and access to training in these legal matters in some countries, and much of current legislation has been welcomed as being easy-to-read and apply, there needs to be greater emphasis on the availability of these resources in order that all professionals prioritize this in their daily work. Ultimately, creating a safer environment where patients are self-determining individuals making their own choices about their well-being is the goal of any health and social care system.

References

1. Newman, J. (2007) The double dynamics of activation. *International Journal of Sociology and Social Policy*, **27**, 364–375.
2. Okai, D., Owen, G., McGuire, H., *et al*. (2007) Mental capacity in psychiatric patients: systematic review. *British Journal of Psychiatry*, **191**(4), 291–297.
3. Hazelton, L., Sterns, G.L. and Chisholm, T. (2003) Decision-making capacity and alcohol abuse: clinical and ethical considerations in personal care choices. *General Hospital Psychiatry*, **25**(2), 130–135.
4. Jeste, D.V. and Saks, E. (2006) Decisional capacity in mental illness and substance use disorders: empirical database and policy implications. *Behavioural Science and Law*, **24**, 607–628.
5. Menninger, J.A. (2001) Assessment and treatment of alcoholism and substance-related disorders in the elderly. *Bulletin of the Menninger Clinic*, **66**(2), 166–183.
6. Thomas, V.S. and Rockwood, K.J. (2001) Alcohol abuse, cognitive impairment, and mortality among older people. *Journal of the American Geriatrics Society*, **49**(4), 415–420.

7. American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders*, 5th edn. American Psychiatric Publishing, Arlington, VA.
8. Bechara, A., Dolan, S. and Hindes, A. (2002) Decision-making and addiction (Part II): myopia for the future or hypersensitivity to reward? *Neuropsychologia*, **40**, 1690–1705.
9. Office of Public Sector Information (2005) The Mental Capacity Act 2005. http://www.legislation.gov.uk/ukpga/2005/9/contents (last accessed 27 March 2014).
10. Stanley, N. and Manthorpe, J. (2008) Small acts of care: exploring the potential impact of the Mental Capacity Act 2005 on day-to-day support. *Social Policy and Society*, **8**(1), 37–48.
11. Dunn, M.C., Clare, I.C.H. and Holland, A.J. (2010) Living a life like ours: support workers' accounts of substitute decision-making in residential care homes for adults with intellectual disabilities. *Journal of Intellectual Disability Research*, **54**(2), 144–160.
12. Schiff, R., Sacares, P., Snook, J., *et al*. (2006) Living wills and the Mental Capacity Act: a postal questionnaire survey of UK geriatricians. *Age and Ageing*, **35**(2), 116–121.
13. Weiner, M.F., Davis, B., Martin-Cook, K., *et al*. (2007) A direct functional measure to help ascertain optimal level of residential care. *American Journal of Alzheimer's Disease and Other Dementias*, **22**(5), 355–359.
14. Shah, A., Banner, N., Heginbotham, C. and Fulford, B. (2009) The application of the Mental Capacity Act 2005 among geriatric psychiatry patients: a pilot study. *International Psychogeriatrics*, **21**(5), 922.
15. Manthorpe, J., Samsi, K., Heath, H. and Charles, N. (2011) 'Early days': knowledge and use of the Mental Capacity Act 2005 by care home managers and staff. *Dementia*, **10**(3), 283–298.
16. Johnstone, C. and Liddle, J. (2007) The Mental Capacity Act 2005: a new framework for healthcare decision making. *Journal of Medical Ethics*, **33**, 94–97.
17. Lyons, C., Brotherton, A., Stanley, N., *et al*. (2007) The Mental Capacity Act 2005: implications for dietetic practice. *Journal of Human Nutrition and Dietetics*, **20**(4), 302–310.
18. Tullet, J. (2008) Legal and Ethical Frameworks for Mental Health Nursing. In: *Older People and Mental Health Nursing: A Handbook of Care* (eds R. Neno, B. Aveyard and H. Heath), Blackwell Publishing Ltd, Oxford, UK. doi: 10.1002/9780470692240.ch6.
19. Manthorpe, J. and Samsi, K. (2009) Implementing the Mental Capacity Act 2005: challenges for Commissioners. *Journal of Integrated Care*, **17**(3), 39–47.
20. Brown, R. and Barber, P. (2008) *The Social Worker's Guide to the Mental Capacity Act 2005*. Learning Matters, Exeter.
21. Myron, R., Gillespie, S., Swift, P. and Williamson, T. (2007) Whose Decision? Preparation for and Implementation of the Mental Capacity Act in statutory and non-statutory services in England and Wales. The Mental Health Foundation, London.
22. Joyce, T. (2010) *Best Interests Guidance on Determining theBest Interests of Adults who Lack the Capacity to Make a Decision (or Decisions) for Themselves [England and Wales]*. The British Psychological Society, Leicester.
23. Ministry of Justice (2007) Mental Capacity Act 2005 Code of Practice. TSO (The Stationery Office), Norwich. http://webarchive.nationalarchives.gov.uk/+/http://www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf (last accessed 27 March 2014).