Mental capacity, declining insulin injections and multidisciplinary team working

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Introduction

Diabetes mellitus (DM) is a common condition in older adults: 23.8% of those aged over 75 are recorded as having diabetes,[1] and 9.2% of insulin-treated people with diabetes are severely frail.[2] This value is, however, likely to be an underestimation of the true prevalence owing to the impact of common co-morbidities such as anaemia on haemoglobin A1c (HbA_{1c}) values,[3] and the impracticality of measuring it in severely frail, housebound people. Cognitive fluctuations can have a challenging impact on decision-making capacity.[4] In the care of frail people with diabetes it is not uncommon, in our experience, to encounter people who make decisions which have serious adverse consequences for their health. In such cases it is important to have a clear understanding of both the legal framework on which decisions regarding capacity must be made, and of the concepts of macro- and micro-decisions and fluctuating capacity.[5]

To illustrate the dilemmas this can cause in diabetes management, we present a case involving a frail person with insulin-treated diabetes who has cognitive impairment and fluctuating capacity. We describe recent developments in case law that should determine how to approach best-interest decision-making in such circumstances.

Case report

A 77-year-old female with type 2 diabetes (T2DM), diagnosed in 2008, was commenced on Toujeo insulin in December 2018 in view of osmotic symptoms and significantly elevated HbA_{1c} (112 mmol/mol) on oral glucose-lowering therapy. She frequently declined oral medication and the taking of capillary blood glucose (CBG) readings. Community nurses (CNs) were instructed to administer her insulin but she often denied them access to her property, and her family took over this responsibility. In the same month she was diagnosed with Alzheimer's disease. Four months later she moved into residential care. A Deprivation of Liberty Safeguarding (DoLS) was put in place in March 2020.[6] Article 5 of the Human Rights Act (1998) states that '*everyone has the right to liberty and security of person. No one shall be deprived of his or her liberty [unless] in accordance with a procedure prescribed in law*'.[7] The Deprivation of Liberty Safeguards (DoLS) is the procedure prescribed in law when it is necessary to deprive a person who lacks the capacity to consent to their care and treatment of their liberty in order to keep them safe from harm. The legal framework for DoLS is found in an amendment of the Mental Capacity Act (MCA) 2005 which came into force in 2009.

Once she was in residential care the CNs resumed insulin administration, with the patient's consent. From July 2020 onwards she was deemed by the CNs to lack capacity to decide about treatment with insulin and so was treated in her best interests.[8] She was initially adherent but she became increasingly physically aggressive towards the CNs, who were consequently unable to administer insulin 20% of the time. They sought advice from the Diabetes Specialist Nurses (DSNs) who advised that, although the patient had a DoLS in place, which suggested she lacked the capacity to consent to care and treatment generally, a capacity assessment be undertaken specifically around treatment with insulin. This is in keeping with the legislation which states that capacity is time- and decision-specific, as described in Section 2 paragraph 1 of the MCA 2005.[9] This states: '*a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.*' Section 4.4 of the MCA Code of Practice adds: '*an assessment of a person's capacity must be based on their ability to make a specific decision at the time it needs to be made, and not their ability to make decisions in general*'.[9] DoLS capacity assessments are frequently undertaken by social workers when a person resides in a residential setting so the specific issue regarding insulin may not have been addressed in the initial DoLS paperwork.

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Table 1. Behavioural approaches to help improve adherence to insulin

- Prepare the insulin outside the room to minimise distress
- Only one staff member in the room when insulin is administered to reduce overstimulation
- Explain your actions when administering insulin
- Quickly administer insulin as it is more likely to be successful
- Carers to support CNs with insulin administration if they are struggling
- In a mental health emergency, contact the Crisis Intervention Team for Older People

Therapeutic intervention

In August 2020 the DSNs referred the patient to the Diabetes Frailty Multidisciplinary Team (MDT), a group comprising a consultant diabetologist, advanced nurse practitioners (ANP) in frailty, DSNs and community nursing matrons. They aim, through monthly discussions and subsequent interventions, to facilitate an integrated and individualised approach to the management of diabetes in frailty. The outcome of this person's MDT discussion was to refer her for a comprehensive geriatric assessment (CGA); a holistic, multidisciplinary, diagnostic and treatment process that identifies the medical, psychosocial and functional needs of frail older adults in order to develop a coordinated and integrated treatment plan.[10] The overall aim was to achieve the maximum benefit of the prescribed therapy and to administer insulin with the minimum distress to the patient, CNs and carers. The MDT liaised with a frailty ANP with a specialist interest in mental health. His assessment was that, despite explaining the necessity for her diabetes to be treated with insulin in simple language, the person lacked capacity to make this decision. He identified the behavioural and psychological symptoms of dementia impacting on adherence. He documented approaches in the electronic patient record (EPR) that would increase the likelihood of successful insulin administration (see Table 1). Her family were consulted and in agreement with the plan.

Despite these recommended strategies, insulin doses were still frequently being declined by the person. This led to multiple discussions between health and social care professionals, but a unified and consistent approach was not taken in the absence of a nominated key decision-maker. Seeking resolution, a Best Interest Meeting (BIM) was held in November 2020, three months after initial referral to the MDT.[8] This involved the responsible professionals, care home staff and the person's family. During the meeting, her carers described the challenges faced with the person's diabetes management. She was able to decide, for example, what she wanted to eat but did not understand the impact her diet had on her diabetes management nor the reasons for insulin administration. Following the BIM an action plan was created (see Table 2).

Table 2. Best Interest Meeting action plan

- A care plan, including a recovery plan to follow when the patient was unwell, was created stating:
  - A healthy, varied diet should be offered without overly restricting foods she enjoys.
  - If the CBG is high, encourage her to drink plenty of water
  - If insulin is declined and she is well there is no need to inform the GP
  - If insulin is declined and she is unwell the CNs should immediately inform the GP (a ketone meter was provided to use in such circumstances)
- DoLS documentation was updated to include the diabetes care plan
- Behavioural strategies for successful insulin administration were reiterated
- Alternatives for obtaining regular CBG readings were considered, including using a free style libre device and comfort lancets
- Toujeo was changed to Tresiba to provide longer cover.

Follow-up and outcome

The MDT were contacted a year later with concerns from the carers that the person was "variable in mood" and that it "can take all day to coax her to have medication". However, only 10% of insulin doses were now declined at this time. The MDT identified that the original care plan should be made more visible in her records and an alert on her EPR was added. Since the creation and implementation of the care plan, and increasing its visibility, the person's adherence to insulin has greatly improved. In the last six months, only one dose of insulin was initially declined but was later successfully administered. Consequently, the DSNs and the Diabetes Frailty MDT have not had to be involved in her care and, since there has not been a re-referral to the team, we can assume that she is not experiencing any adverse symptoms and that her diabetes management is adequate. Her BMI reduced from 25.8 kg/m^2 in June 2020 to 23.1 kg/m^2 in November 2023 and her HbA_{1c} improved from 112 (2018) to 69 mmol/mol in April 2023.

Discussion

Application of the Mental Capacity Act (MCA) 2005 was of paramount importance in this case.[8,9] Key principles of the Act are that capacity should be assumed and that, before deeming capacity is lacking, all practical steps should be taken to optimise a person's decision-making ability.[9] A person is deemed to lack capacity if they are unable to either understand, retain or use relevant information to weigh up a decision or to communicate their decision.[9] Within the management of diabetes, patients may make decisions that health professionals consider risky or eccentric, particularly if they choose not to follow professional advice, but this does not necessarily mean they lack capacity to do so. In practice, it can be hard to separate an incapacious decision from an unwise one.11 Fluctuating capacity refers to a changeability in decision-making capacity which can vary over time or in specific situations, for example, during an acute illness.[12] There may be times when the person has capacity and is able to participate in shared decision-making but at other times this ability may be lost, highlighting the complexities in having a binary approach to capacity assessment.[12] Where capacity is fluctuating, it is important therefore to gather information and opinions from

Table 3. Relevant MCA Sections[9] and their application to this case

MCA (2005) section	What the MCA (2005) says	How this relates to the case
2 (1)	For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain	Alzheimer's disease is the cause of the disturbance of the mind or brain in this person's case
1 (4)	A person is not to be treated as unable to make a decision merely because he makes an unwise decision	'It is not uncommon to encounter people who are making decisions which have serious adverse consequences for their health'. Declining insulin could be perceived as an unwise decision
Mental Capacity Amendment Act 2019	D (decision maker) may deprive P (person) of their liberty if, by doing so, D is carrying out arrangements authorised under Schedule AA1 (arrangements enabling the care and treatment of persons who lack capacity)	Deprivation of Liberty Safeguards
3 (1)	Inability to make decisions	Provides the framework for a capacity assessment
3 (2)	A person is not to be regarded as unable to understand the information relevant to a decision if he is able to understand an explanation of it given to him in a way that is appropriate to his circumstances (using simple language, visual aids or any other means)	'Explaining the necessity for her diabetes to be treated with insulin in simple language'. Providing information in the most appropriate way for the person is example of supported decision making by the MDT
4 (6)	The person's past and present wishes and feelings	The person knew 'what she wanted to eat but did not understand the impact her diet had on her diabetes management'. Her usual dietary preferences were considered
4 (7)	Best Interests, anyone engaged in caring for the person or interested in his welfare	'Care home staff and the person's family' were included in the BIM
1 (6)	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	Toujeo was changed to Tresiba to provide longer cover. Fewer injections required thus making this the least restrictive option

multiple sources and address each individual decision independently.[5]

Table 3 summarises the relevant sections of the MCA 2005 legislation in the order they appear in the case study.[9]

In a recent Court of Protection Case RB Greenwich v CDM [2018] EWCOP [15,13] a complex case about the management of diabetes in the presence of emotionally unstable personality disorder, the Judge states at paragraph 48(a) -

> *'On the assessment of capacity to make decisions about diabetes management, in all its health consequences, the matter is a global decision, arising from the interdependence of diet; testing her blood glucose and ketone levels; administration of insulin; and admission to hospital when necessary in the light of blood glucose levels'.*

This acknowledges that each individual decision-making process required for diabetes care, the 'micro-decisions' such as performing CBG measurements or modifying diet appropriately, must be taken in the 'macro' context of overall diabetes management. Usually, individual decisions are assessed independently but, in this case, the micro-decisions are deemed to be so intimately related that they all need to be considered together as a single macro-decision of diabetes management.[5]

The Judge goes on to say at paragraph 47[13] -

> *'I do not think it is necessary or helpful to draw inferences or parallels on examples of other conditions or other classes of individuals, since the interrelationship between the micro- and macro-decisions still needs to be decided, having regard to a particular individual in particular circumstances, and having regard to their particular condition. No two people self-evidently are ever the same, their condition the same condition, or the circumstances the same. The elements in relation to CDM's own particular conditions are unique to her. CDM has diabetes which is not unique to her, being shared with many other millions of people in the United Kingdom, but as an individual the factors are unique'.*

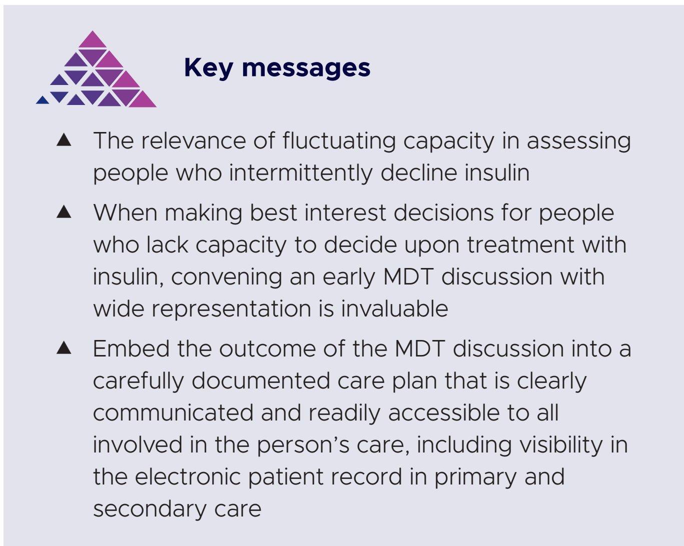
Although this judgement gives a framework for managing diabetes in cases where adults lack capacity to make decisions for themselves, the Judge is clear that each individual case needs to be taken on its own individual set of circumstances. Our patient had capacity to decide what she wanted to eat, for example, but she did not understand the impact of this on diabetes control nor the role of insulin and was therefore deemed to lack capacity in relation to her diabetes management.

Decisions made on behalf of people who lack capacity must be in their best interests.[8] The multi-professional BIM, involving the person's family, addressed the macro-decision of her

diabetes management in her best interests. MDT working is fundamental in the care of frail adults,[10] and optimisation of MDT working is a part of the NHS workforce plan.[14] The BIM discussed strategies for treatment of the person's diabetes with insulin and an individualised care plan was created. Care plans must be personalised to the person's unique needs and accessible to all involved care providers.[15] As the clinical situation changes, the goals of care and treatment strategies should be reviewed and therefore this person remains open to re-referral to the Diabetes Frailty MDT for advice as required.

Learning points

The Diabetes Frailty MDT was central to the diabetes care of this person. On reflection, communication could have been improved and the involvement of multiple health and social care professionals unified. There is now a defined pathway for managing people predicted to have fluctuating capacity in relation to insulin administration and who may refuse doses intermittently (see Figure 1). There is an emphasis upon earlier involvement of the MDT, taking a more proactive approach, convening an early BIM and ensuring visibility of the care plan on the EPR. The Diabetes Frailty MDT is evolving and continues to learn from cases such as these about how to improve the service further.



Key messages

- The relevance of fluctuating capacity in assessing people who intermittently decline insulin
- When making best interest decisions for people who lack capacity to decide upon treatment with insulin, convening an early MDT discussion with wide representation is invaluable
- Embed the outcome of the MDT discussion into a carefully documented care plan that is clearly communicated and readily accessible to all involved in the person's care, including visibility in the electronic patient record in primary and secondary care

Figure 1. Diabetes Frailty MDT fluctuating capacity pathway

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