Absence of monitoring in withdrawal of clinically-assisted nutrition and hydration (CANH) and other treatments: a cause for concern?

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ABSTRACT

Since 2018, there has been no requirement to bring decisions about the withdrawal of clinically-assisted nutrition and hydration (CANH) in patients with persistent disorders of consciousness before the courts, providing that the requirements of the Mental Capacity Act 2005 (MCA) are fulfilled. Subsequent British Medical Association and Royal College of Physicians guidance on CANH withdrawal recommended standards of record keeping and internal and external audit to ensure local decision making was compliant with the MCA to safeguard patients. The scope of the guidance also included patients with stroke and neurodegenerative disorders.

Freedom of Information requests made 2 years after the introduction of this guidance have shown that none of the NHS trusts or clinical commissioning groups who responded were undertaking any systematic monitoring of these decisions. Neither is the Care Quality Commission reviewing these decisions, as there is 'no statutory requirement' to do so. It appears there is a lack of organised scrutiny of these highly complex life-ending treatment decisions. This omission must surely be a cause for concern.

KEYWORDS: treatment withdrawal, CANH, persistent disorders of consciousness

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Introduction

Decisions about limitation or withdrawal of life-sustaining treatments in patients who lack capacity in England and Wales are the responsibility of the treating doctor. The withdrawal of clinically-assisted nutrition and hydration (CANH) in patients in a vegetative state, however, was treated differently until recently.

In 1993 it was established in case law that CANH is 'treatment' and not just 'routine care', and that it could be withdrawn on the basis that a treatment with no therapeutic benefit was 'futile'.[1] It was recommended, however, that until a body of expertise and practice had been built up, decisions about withdrawal of CANH (specifically from patients in a vegetative state (VS)) should be brought before the court to obtain declaratory relief that the proposed action was legal on the grounds of futility. VS is just one of three recognised persisting disorders of consciousness (PDOC) which include coma and minimally conscious state (MCS).

The case of *W v M* (2011) established that it was reasonable to extend the grounds for declaratory relief regarding withdrawal of CANH to cases of patients in MCS.[2] This meant all PDOC states were subject to the same decision-making process even though determining outcomes in MCS is more challenging.

In 2018, the Supreme Court ruled that there was no legal requirement for cases where CANH withdrawal was under consideration to be brought to the court provided there was agreement upon what was in the patient's best interests and that the provisions of the Mental Capacity Act 2005 were followed and the relevant guidance observed.[3]

The British Medical Association (BMA) and Royal College of Physicians (RCP) later in 2018 drew up guidance for best interests decision making, proportionate external review and documentation regarding the process for withholding or withdrawing CANH in patients with PDOC.[4] Importantly, this guidance covers not only patients with newly acquired brain injury but also patients with neurodegenerative disorders and stroke in whom CANH was not thought to be in their best interests.

In March 2020, the RCP issued the national clinical guidelines *Prolonged disorders of consciousness following sudden onset brain injury.*[5] This expands on the levels of external scrutiny required to oversee decisions regarding withdrawal of not only CANH but also other treatments that it may be appropriate to limit.

The 2018 BMA/RCP guidance stipulates that, where decisions are made to withdraw CANH, then the following standards of audit and record keeping should apply:

> *A detailed record should be kept of the decision-making process and the decision reached, in a format that can be easily extracted from the rest of the medical record.*

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For patients in VS or MCS following a sudden-onset brain injury, use of the model proforma developed as part of this guidance is recommended. This can be accessed at www.bma.org.uk/CANH.

Decisions about CANH should be subject to internal review and audit, including through established procedures for reviewing deaths. They should also form part of the external review undertaken by the Care Quality Commission and Healthcare Inspectorate Wales.

Where relevant national data collection and audit exist, health professionals should contribute to them.[4]

These recommendations are endorsed in the RCP 2020 PDOC national clinical guidelines including the requirement that review of CANH withdrawal decisions should form part of any Care Quality Commission (CQC) inspection.

Since 2018 CANH withdrawal decisions in patients with acquired brain injury, neurodegenerative disease and stroke have therefore been the responsibility of clinicians at local level but internal review and audit has been required with external scrutiny from the CQC. We were concerned to know if this system is effective and therefore made Freedom of Information (FOI) requests to healthcare providers to clarify what systems are in place.

Methods

Between January and March 2020, FOI requests were made to acute hospital trusts, specialist hospital trusts and clinical commissioning groups (CCGs) in England asking for information on the following.

- In your trust/CCG, is there any formal register kept of deaths occurring as a result of withdrawal of CANH that occur under the provisions of the Mental Capacity Act 2005 and BMA/RCP guidelines 2018?
- If such a register is kept, can you advise if there is any independent internal or external audit made of such deaths and the degree to which there is compliance with the BMA/RCP guidelines, 2018, when such deaths occur?
- Where deaths due to withdrawal of CANH are recorded and an audit is made of these, can you give an indication of the number such deaths in 2018 and in 2019, and the percentage of cases where the BMA/RCP guideline checklist has been used and fully completed?

A total of 342 hospital trusts and CCGs in England were approached which represents 95% of providers.

With respect to external scrutiny, an FOI request to the CQC was made asking the following questions.

- Does the CQC check whether trusts, practices or other organisations inspected keep any formal register of deaths occurring as a result of withdrawal of CANH that occur under the provisions of the Mental Capacity Act 2005 and BMA/RCP / General Medical Council (GMC) guidelines, 2018?
- If such a register is kept, can you advise if the CQC performs any audit of such deaths and the degree to which there is compliance with the BMA/RCP/GMC guidelines, 2018, when such deaths occur?
- Where a CQC inspection finds that deaths due to withdrawal of CANH are recorded and an audit is made of these, are there any data on the number of cases and the percentage of cases where the CQC inspectorate finds that the BMA/RCP/GMC guideline checklist has been used and fully completed?

Table 1. Details of Freedom of Information requests to NHS trusts and clinical commissioning groups January–March 2020

	Acute hospital trusts	Specialist hospital trusts	CCGs
Number of trusts/ CCGs January 2020, n	133	17	211
Number of trusts/ CCGs polled, n	128	17	197
Number of responses, n	103	16	182
Response rate, %	80.5	94.1	92.4

CCGs = clinical commissioning groups.

Results

The overall response rate to the FOI enquiry to providers was 88.8% (Table 1). All respondents advised that they had no register of CANH withdrawal cases and, therefore, in not one organisation was there internal or external audit recorded. None of the respondents had any data on numbers of cases where CANH withdrawal had occurred.

The response from the CQC stated that they did not have any requirement to hold a register of deaths associated with withdrawal of CANH and did not specifically seek data about such deaths:

In accordance with section 1(1) of FOIA we are able to confirm that CQC does not hold recorded information in relation to this matter.

No register of deaths occurring as a result of withdrawal of Clinically Artificial [sic] Nutrition and Hydration (CANH) is required to be kept by organizations registered with CQC.

CQC sets statutory requirements on the notification of deaths in any setting. However, we do not currently have a specific statutory requirement that a formal register of deaths be kept where it is known that these occur as a result of the withdrawal of Clinically-assisted nutrition and hydration (CANH).

Despite their general powers to look into deaths as part of an inspection, they acknowledged that data about such events are not routinely collected.

It appears, therefore, that at the present time there is no systematic collection of data regarding deaths following withdrawal of CANH and the CQC is not actively monitoring such events.

Discussion

The publication of detailed guidance about CANH and other treatment withdrawal decisions is welcome. The removal of the requirement to involve the court in these decisions is also potentially positive for families and clinicians. There are, however,

significant risks with this process that can only be mitigated by appropriate external scrutiny. These might include the following.

- Unrecognised lack of expertise or unconscious ignorance in clinicians in determining prognosis may result in the improper withdrawal of CANH (or other treatments). The act of treatment withdrawal becomes a 'self-fulfilling prophecy'.
- Clinical decision-making can be influenced by individual philosophy and institutional culture. Treatment withdrawal decisions can vary widely between institutions independently of clinical factors and between regions.[6–8] A culture of nihilism also becomes a 'self-fulfilling prophecy'.
- Conflicts of interest can influence the contribution of parties involved in the best interests discussion. The available guidance cannot prevent or detect this. External review is needed to ensure best interests have been determined appropriately.
- The reliability of third-party information to determine a patient's wishes is controversial.[9,10] There are currently no safeguards to review this information nor to ensure people with important views are not overlooked or deliberately excluded.

The extent to which these risks exist and truly affect patient outcomes is not known. There is a need for further prospective studies to generate better data about the withdrawal of CANH and other life sustaining treatments. Such studies would need to look not only at compliance with existing guidance but also at the prevalence of conscious or unconscious bias, the risk of conflict of interest, the validity of third-party information and, importantly, the effect of these decisions on patients' families and the clinicians who are involved.

Monitoring of these decisions could be improved by requiring all deaths associated with withdrawal of life sustaining treatment to be formally notified and subject to review. The medical examiner system, recently started in the UK, could fulfil this role to some extent but might still be flawed by personal and institutional bias and the lack of data without further studies. A further level of external scrutiny is likely to be needed to reassure society that these decisions are safe and humane.

Our findings indicate that that there is presently a lack of organised scrutiny of decisions to withdraw CANH, despite national guidance requiring this from 2018 onwards. This, combined with the lack of any requirement to record or monitor decisions to withdraw other life sustaining treatments and our lack of knowledge about factors that may adversely affect these decisions, must surely be a cause for concern. ■

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