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Moving From 'Best Interests' to 'Will and Preference': A Study of Doctors' Level of Knowledge Relating to the Assisted Decision-Making (Capacity) Act 2015

C. Curtis[1], O. Fatoki[2], E. McGuire[3], A. Cullen[1]

1. Mayo Mental Health Services.
2. NUI Galway Deanery, Galway, Ireland.
3. Sligo Mental Health Services, Ireland.

Abstract

Aims

Irish decision-making capacity legislation is due to fundamentally change from 2022, with the commencement of the Assisted Decision-Making (Capacity) Act 2015, removing 'best interests' decision-making and replacing it with a 'will and preference' basis. This study aimed to investigate awareness amongst doctors regarding this Act, and specific knowledge relating to capacity assessment and advanced healthcare directives.

Methods

The study utilised a cross-sectional anonymised self-report questionnaire within a second tier hospital located in a rural part of Ireland.

Results

Only 2% of doctors had received any formal training on the Act, 25% were unsure of their role and 45% were unsure of a patient's role in decision-making. 37% believed that best interests was retained in decision-making. 50% were unaware of their obligations in assessing capacity, 23% were unable to assess capacity correctly and 47% were unsure of any consultative obligations in decision-making. 90% were unaware of what constituted a valid Advanced Healthcare Directive.

Conclusion

Further training is urgently required if the Act is to be successfully implemented in 2022.

Introduction

Health and welfare decision-making relating to people who lack capacity in Ireland remains a complex issue, largely due to the existing legislative framework. Section 4 of the Mental Health Act 2001 permits 'best interests' substitute decision-making by clinicians for patients detained under this Act.[1] People without a legally defined mental disorder but who are deemed to be a 'person of unsound mind who is incapable of managing their affairs' may be taken into Wardship under the provisions of the Lunacy Regulation (Ireland) Act of 1871.[2] Both statutes are constructed around best interests decision-making, and do not require a formal consideration of the person's own will and preferences in a decision-specific manner. For the majority of people who lack capacity for healthcare decisions who are not subject to these statutes, clinicians retain a duty of care to make best interest decisions for them,[3] albeit in the absence of defined legal safeguards.

The historical predominance of best interests decision-making in Ireland is due to end with the introduction of The Assisted Decision-Making (Capacity) Act 2015 (ADMCA),[4] which enshrines guiding principles entirely based on will, preference, beliefs and values of the patient as required by the United Nations Convention of the Rights of Persons with Disability.[5]

This study aimed to gain a clearer understanding of the knowledge and attitudes of doctors working in an Irish hospital, regarding the ADMCA.

Methods

The study utilised a cross-sectional anonymised self-report questionnaire within a second tier hospital located in a rural part of Ireland, across departments of General Surgery, Orthopaedic Surgery, General Medicine, Elderly Medicine, Emergency Medicine, Obstetrics/Gynaecology, and Psychiatry. The names of all doctors employed in these departments were obtained from hospital management, and an information sheet and questionnaire was posted to each doctor by internal hospital post. The questionnaire contained a combination of demographic items, Likert scale items, and qualitative items focused on the level of awareness of the ADMCA, the level of understanding regarding patient will and preference, the degree of acceptance by individual doctors to undertake capacity assessments, the ability to assess capacity, the relationship between unwise decision-making and capacity assessment, and the level of knowledge relating to Advance Healthcare Directives.

Doctors were invited to complete the questionnaire voluntarily, and return by post to the lead author in a pre-addressed envelope. Consent was implied by the return of the questionnaires to the author. Ethical approval was granted by the Hospital Research Ethics Committee prior to commencement of the study.

Data was stored securely in hard copy in a locked filing cabinet in the lead author's office, and electronic results were saved to an encrypted computer. Results were analysed using a combination of descriptive statistics using SPSS, and thematic analysis of qualitative elements. Individual doctors were not identifiable at any stage during the analysis of results.

Results

A total of 140 questionnaires were posted to hospital doctors, and 62 were completed and returned, representing a completion rate of 44%. The occupational grades of participants are displayed in *Table 1*.

Table 1: *Grade of participants.*

Grade	Number (Proportion %)
Intern	4 (7)
Junior Doctor on Training Scheme	33 (53)
Non-Training Junior Doctor	13 (21)
Consultant	12 (19)

Knowledge relating to the general provisions of the ADMCA

54 doctors (87%) identified being aware of the ADMCA, but only 1 doctor (2%) had received any formal training regarding the ADMCA. 16 doctors (26%) reported no understanding of the ADMCA, 5 doctors (8%) reported a full level of understanding of the ADMCA, and the remainder of the sample reported insufficient understanding to competently apply the ADMCA in practice.

37 doctors (60% of participants) believed that doctors would have a sole right to decide treatment for a patient who lacked capacity, 9 doctors (15%) believed this was not the case, and 16 doctors (25%) stating that they did not know.

28 doctors (45%) were unsure as to the rights of patients to decide their own treatment, with 21 doctors (34%) believing that patients would have the right to decide, and 13 doctors (21%) believing patients had no decision-making power.

Participants were also asked to clarify what they perceived to be the balance between best interests and patient will/preference in the Act. The results are displayed in *Table 2*.

Table 2: Perceived balance between best-interests and patient will/preference in the Act.

Perceived balance between best-interests and will/preference in the Act	Number of doctors agreeing with each statement (Proportion %)
Best-interests are not mentioned at all	2 (3)
Best-interests are mentioned but will/preference take priority	12 (19)
Best-interests and will/preference are equally weighted in the Act	23 (37)
Best-interests take priority over will/preference	19 (31)
Best-interests are the sole consideration	2 (3)
Unsure of the balance	4 (7)

Knowledge relating to the assessment of a patient's capacity to make decisions

29 doctors (47%) acknowledged their obligation to assess capacity, 2 doctors (3%) believed they has no such obligation, and 31 doctors (50%) were unsure if the obligation existed. 18 doctors (29%) identified a complete absence of knowledge in capacity assessment, whereas 10 doctors (16%) reported sufficient competence to assess capacity. The remainder of the sample reported possessing 'some knowledge' but of an insufficient level to accurately assess capacity.

14 doctors (23%) were unable to correctly name any element of capacity assessment, and only 16 doctors (26%) correctly identified all key elements.

Participants were also asked to identify whether their capacity assessment would be impacted upon by a patient choosing to make an unwise decision, as outlined in *Table 3.*

***Table 3:** Impact of patient making an unwise decision after a doctor's initial capacity assessment.*

Impact of patient making an unwise decision after the doctor's initial capacity assessment	Number of doctors agreeing with the statement (Proportion %)
Unwise decision makes doctor uncomfortable but doesn't affect doctor's capacity assessment	8 (13)
Unwise decision makes doctor consider reassessing capacity	13 (21)
Unwise decision would definitely result in doctor reassessing capacity	37 (60)
Unwise decision would lead doctor to automatically reverse capacity assessment in favour of incapacity	2 (3)
Doctor unsure of impact	2 (3)

Knowledge relating to the role of consultation to support capacity assessment

29 doctors (47%) were unsure of their consultative obligations, 24 (39%) believed they did have a duty to consult, and 9 (14%) did not believe they had such a duty.

Doctors who positively identified the need to consult expressed a preference to consult with a medical colleague (19 doctors, 80% of the consultative group) or a patient's family member (15 doctors, 62% of group). Other identified consultees included the patient's GP (8 doctors, 33% of group), next of kin (5 doctors, 21% of group) and a mental health team (3 doctors, 13% of group).

Knowledge relating to a patient's Advance Healthcare Directive

56 doctors (90%) reported being unaware of what constituted a valid Advance Healthcare Directive.

Qualitative feedback from doctors regarding the Assisted Decision-Making (Capacity Act 2015)

6 doctors (10%) identified the ADMCA as 'positive', and 9 (15%) believed that 'doctors need more training'. Additional comments included concerns about 'conflict between the ADMCA and the Mental Health Act', and 'vested interests in decision-making and potential coercion by the Decision-Making Representative'. Other concerns included 'increased workload especially for psychiatrists', 'potential ethical conflicts in unwise decisions', 'lack of clarity about the duty of care for doctors in best interest decision-making', 'resource implications', 'giving too much power to non-experts in decision-making' and 'going too far to protect patients from doctors'. The concept of Advance Healthcare Directives received positive commentary, 'providing clarity'.

Discussion

This study aimed to investigate the level of knowledge relating to the ADMCA amongst a sample of Irish hospital doctors. Whilst the response rate was sub-optimal at 44%, the respondent sample of 62 doctors yielded information over a breadth of topics relating to knowledge of the Act, and qualitative data regarding the Act.

It is of some concern that whilst the majority of respondents were aware of the Act, very few had received any formal training relating to the Act, and only a minimum of doctors reported possessing sufficient understanding to be able to implement what the Act may require of them. The Codes of Practice for the Act have yet to be fully finalised despite the Act being scheduled to commence in mid-2022.[6] The HSE online information portal also lists the training that has been provided relating to the Act, including an 'explainer video', two webinars, and a briefing, but many respondents in this sample appear not to have availed of this training, nor have they engaged in any additional self-directed learning about the Act. There is no reference on the portal to the implementation of mandatory education and training for frontline professionals, despite the requirement for these professionals to implement the Act when fully commenced in 2022.[7]

Despite Ireland being on the cusp of legislative change to remove best interests decision-making for those who lack capacity, the results of this study suggest that doctors remain unsure about the decision-making process for patients who lack capacity, with only a third of doctors believing that patients in this situation were supported by the Act to make a decision for themselves. The lack of knowledge in this area, one of the founding principles of the Act, clearly illustrates the need for further training. The responses also revealed inconsistency in doctors' opinions regarding the principles underlying decision-making in the Act, with clear evidence that best interests decision-making remains a central tenet for some doctors. This again highlights the knowledge gap in the founding principles of the Act, and is perhaps a reflection on medical paternalism that has permeated many areas of decision-making where patients may lack capacity.[8]

Regarding the process of capacity assessment, the results confirmed that only a minority of doctors reported a perceived competency in this area, reflected in the reduced proportion of doctors who correctly identified the core elements required for a capacity assessment defined in the Act. The results illustrate a significant lack of clarity for professionals in where their obligations will lie, in addition to difficulties in correctly identifying the elements of capacity assessment. This has previously been illustrated in the literature pertaining to capacity assessment, with an identified need for staff to receive ongoing support to undertake the complexity of assessments required to competently assess capacity.[9]

The issue of unwise decision-making is ethically challenging for doctors, as evidenced by the fact that 60% of doctors would reassess a patient's capacity if the patient was making a decision deemed to be unwise. There are several potential explanations for this. Beneficence and non-maleficence are key drivers underlying the ethics of care,[10, 11] and health professionals are understandably challenged when a patient expresses the intent to make a decision that is 'not in their best interests' and which could result in harm.[12] Whilst the principle of respect for autonomy prevails for patients with capacity, the situation is more complex for patients who lack capacity, and a reassessment of capacity may represent a means of preventing unwise decision-making whilst also reducing the risks of harm to the patient and breach of duty by the doctor.

Almost half of respondents were unsure as to whether they had a legal duty to consult in relation to identifying a patient's will and preference, and those doctors who believed they did have such a duty identified a wide range of potential consultees, the most frequent of which was a senior medical colleague/consultant, followed by family and GP. This finding suggests that 'consultation' is viewed as the need to consult with another medical professional, and that medicalisation of decision-making is viewed by doctors as necessary to determine the correct course of action, despite the deliberate change of emphasis of the Act to empower decision-making by non-medically qualified persons.

Of some concern is the fact that almost all respondents were unaware of validity criteria relating to Advance Healthcare Directives (AHD). This is a crucial issue for frontline clinicians due to the risk of criminal liability for providing treatment contrary to an AHD, or a finding of negligence for failing to treat in the erroneous belief that an AHD is valid. These difficulties were illustrated in practice by McGlade and colleagues, with some emergency department staff failing to recognise the validity of documentation and proceeding to deliver care they determined as clinically necessary for the patients.[13]

The most frequent qualitative opinions of participants relating to the Act was that of the need for further training, which should be addressed as a matter of priority by the employing health authority. The Act is scheduled to commence in mid-2022, but as yet the codes of practice remain at consultative level, raising concern that there will be insufficient time to deliver the amount of training required to upskill a large number of healthcare staff prior to commencement of the legislation.

The main limitation of the study was the response rate of 44%. Whilst this limits the generalisability of the findings, the apparent lack of engagement by respondents with any self-directed learning relating to the Act may be suggestive either of a lack of interest amongst doctors relating to medicolegal matters, or a perspective that the Act is of little relevance to their practice. If these are the reasons, it may indicate that implementation of the Act will be problematic amongst medical professionals. This study may be further limited by the sole inclusion of doctors in the study sample. The authors hope to undertake a subsequent larger study of multidisciplinary health professionals to determine the awareness of the ADMCA across the health service.

Declaration of Conflicts Interest:
None.

Corresponding Author:
Dr Camilla Curtis BSc MB MRCPsych MMedSc LLM PhD,
College of Medicine, Nursing and Health Sciences,
National University of Ireland Galway.
E-Mail: camilla.curtis@hse.ie

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