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Intensive Care Consultants and their obligation from the Assisted Decision Making (Capacity) Act 2015

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Abstract

Aims

The purpose of this paper was to explore the level of knowledge and preparedness that Intensive Care Consultants have of their obligations under the Assisted Decision Making (Capacity) Act 2015 as it pertained to patients requiring decisions to be made on their behalf within the Intensive Care Environment.

Methods

The 2015 Act was reviewed and a questionnaire was developed assessing key provisions of the Act necessary for lawful decision making. The questions were formatted with binary responses to confirm that respondents were operating within the meaning of the law; subject to the legal principle of *ignorantia legis neminem excusat*. This questionnaire was circulated amongst Intensive Care Consultants working in Model 4 Hospitals approved for Joint Facility of Intensive Care training. A third-party online survey platform was used to anonymously collect and process responses from those who consented to participate. Qualitative analysis of the responses was performed.

Results

22/63 (35%) ICU physicians completed the questionnaire. 19/22 (86%) were aware of the introduction of the 2015 Act. 14/22 (64%) were able to identify a "relevant person" under the meaning of the Act. 9/22 (41%) had received training in relation to the act. 7/22 (32%) of respondents were aware of the scope of decisions covered by the Act. 6/22 (27%) were aware of the legal obligations placed upon them by the Act. When challenged, 0/6 (0%) of those were able to successfully identify all statutory criteria for decision making capacity. 5/22 (26%) of respondents stated they had changed their approach to patient decision making since the introduction of the Act.

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Discussion
Deficits in preparedness, knowledge of and familiarity with the Act were evident amongst all respondents. The legislation does not allow for physician interpretation and requires full compliance at all times. Training was either not provided to or not sought out by the majority of respondents. Of those who reported that they were aware of their obligation no one was able to fully demonstrate the minimum expected statutory criteria for decision making capacity. Failure to comply with the legislation leaves practitioners subject to liability. More worryingly physicians have reported little change in their approach to decision making. More training in the area is likely needed.

Introduction

Critically ill patients who lack capacity to make decisions for themselves offer challenges to the physicians working in the Intensive Care Unit (ICU)[1]. The extent of this issue is difficult to define. Patients admitted to the ICU may have pre-existing decision-making issues, or develop new issues because of their critical illness. Issues with decision-making may be temporary or permanent, and temporary issues may be fluctuant. Acute neurological conditions, such as traumatic brain injury, stroke and anoxic brain injury, are typically associated with loss of decision-making capacity, though any condition leading to ICU admission may result in such a change. The very fact of being a patient in an ICU under the effects of sedation is likely to alter one's decision-making abilities.

The Assisted Decision Making (Capacity) Act 2015 came into effect on the 26th April 2023[2]. The purpose of the Act is "to provide for the reform of the law relating to persons who require or may require assistance in exercising their decision-making capacity…". The Act has outlined, inter alia, a series of obligations to consider when making decisions in respect of a "relevant person" under the Act. A "relevant person" is defined as a person whose capacity is in question or a person who lacks capacity. It is therefore certain that ICU physicians care for "relevant persons" and make decisions on their behalf.

Making decisions for patients who lack capacity is a complicated, nuanced and solemn obligation which predates the introduction of the 2015 Act, and there is potential variation in such decision-making practice amongst ICU physicians[3]. Case law suggests no unifying approach existed prior to the creation of the 2015 Act. Indeed, most rulings were heavily based on the unique facts that were brought before the Court. This lack of a concrete framework may have introduced a wide variation in clinical practice prior to the introduction of the Act. ICU physicians have historically used a combination of clinical context, previously stated wishes, and perception of family and/or friends to make decisions "in the patient's

best interest" for those who lack capacity. It is unknown whether the introduction of the 2015 Act has changed ICU physicians' approach to patients who either lack, or may lack, decision making capacity.

The purpose of this study was to identify how physicians recognise a "relevant person" under the Act, how they approached making decisions for those patients prior to and since the introduction of the Act, how physicians avoid the common pitfalls of decision making and to what extent they were and are prepared for the introduction of the 2015 Act.

Methods

A cross-sectional survey design was developed from the 2015 Act. This study was conducted across intensive care units in the Republic of Ireland between October 2024 and December 2024. Eligibility to participate in the survey included consultant intensive care physicians working in Model 4 hospitals approved for Joint Faculty of Intensive Care Medicine of Ireland training. Data from the Irish national ICU audit 2023 suggests that 62.7% (n=9,373) of all ICU patients admissions occurred in Model 4 hospitals which were approved JFICMI training centres[4]. The JFICMI Model of Care for Adult Critical Care 2015, indicates it is desirable for Model 3 and 4 hospitals to provide critical care by " a specialist who is a Fellow of the Joint Faculty of Intensive Care Medicine of Ireland, or who is trained to a level that allows accreditation by the JFICMI"[5]. Thus those Consultants from Model 4 hospitals working in JFICMI approved training centres were chosen to be respondents to the survey. The study excluded centres which primarily specialised in providing paediatric intensive care (subject decision-making to the Guardianship of Infant Act, 1964 and its amendments) and those centres not approved for specialist training in intensive care medicine.

A third-party online survey software was used to circulate and collect responses to the survey. Demographic information was collected to assess whether a respondent had managed patients who lacked capacity prior to and after the introduction of the 2015 Act in April 2023. This consisted of seven 'Yes' or 'No' answer questions. Those respondents who answered "Yes" to those questions and were deemed eligible to proceed to the remaining questions.

Included with the circulated link with the survey was a brief explanation of the survey, the purpose of data collection and use thereof. Potential respondents were informed that any data collected would be fully anonymised. Potential participants were informed that they reserved the right not to complete the survey at any time during, and that there would be no consequences in doing so.

A questionnaire was developed by a qualified Barrister and Intensive Care trainee (JB) and Intensive Care medicine Consultant (SK) with reference to key provisions of the Assisted Decision Making (Capacity) Act 2015. The relevance of each provision for the practising

physician was compared with the guidance outlined in the Health Service Executive's National Consent Policy[6] and the Decision Support Service Code of Practice for Healthcare Professionals[7]. Those provisions and their interpretation in the provided guidance documents were used to create the questionnaire. The questionnaire assessed: (i) eligibility to partake in the questionnaire, (ii) knowledge of the 2015 Act and (iii) training received in relation to the 2015 Act.

Knowledge of the 2015 Act was assessed using a series of fourteen questions consisting of ten binary answer questions and four multiple choice questions. The binary answer questions assessed respondents' direct knowledge of provisions outlined by the 2015 Act. The multiple-choice questions contained options which used direct language taken from the main body and appendices of the 2015 Act.

The final four questions assessed the respondents' access to training and support, personal changes made to practice, and satisfaction with preparation since the introduction of the 2015 Act. Changes to clinical practice were provided as multi choice options using the wording available in the 2015 Act. All respondents were offered an opportunity to comment or provide insight into any of the questions asked via a free text box included at the end of the survey.

Questionnaires were circulated to intensive care consultants working in centres approved for Joint Faculty of Intensive Care Medicine of Ireland (JFICMI). Responses were collected anonymously with a third-party cloud-based survey software. The collected data was reviewed and analysed.

Results

The questionnaire was circulated to 63 Consultant Intensivists working across five JFICMI approved training centres. 35% of those contacted (n=22) completed the survey. All the respondents stated that they are or have been responsible for patients in the critical care environment who were unable to make decisions for themselves. 18/22 (82%) respondents stated that they made decisions on behalf of patients who could not make decisions for themselves on a daily basis. 18/22 (82%) respondents stated that they routinely invited friends and family of those patients to help make a decision prior to the introduction of the 2015 Act. 21/22 (96%) respondents stated that they routinely made decisions without the input of those stakeholders. 7/22 (32%) respondents stated that they had been criticised for decisions made on behalf of patients who were unable to make decisions for themselves, however no respondent recorded that they had ever faced legal consequences for a decision made in respect of those patients.

Of those surveyed, 19/22 (86%) were aware of the introduction of the 2015 Act. Only 9/22 (41%) had received any training relating to the Act, while 8/22 (37%) had received legal advice

relating to the Act's introduction. 14/22 (64%) respondents stated that they would be able to identify a "relevant person" under the meaning of the 2015 Act. Only 7/22 (32%) respondents stated that they were aware of the scope of decisions covered by the Act. While 15/22 (68%) of those surveyed were confident that they could declare that a patient did not have capacity, only 6/22 (27%) were aware of the legal expectations placed upon them by the 2015 Act.

Those 6 participants who stated they were aware of the legal expectations placed upon them by the 2015 Act were then presented with a selection of options of inclusion or exclusion criteria for decision-making capacity. None of those surveyed selected all the correct options as defined by the Act. 2/6 (33%) respondents failed to identify that overriding a directive that appeared "unwise" was not an obligation of the physician under the Act. 4/6 (67%) respondents identified a history of dementia or other cognitive decline as a reason to doubt the decisions made by a patient. 2/6 (33%) of respondents stated that an inability to speak English and Irish would prompt them to doubt the decision-making capacity of a patient.

12/22 (57%) respondents had encountered a patient with an Advanced Directive and 7/22 (33%) respondents had encountered an appointed decision maker. 9/22 (42%) respondents were aware that a registry of decision support arrangements were provisioned for within the 2015 Act. 9/22 (43%) respondents were aware of the obligation of the physician to involve the friends and family of a person lacking capacity to support decision making.

5/22 (23%) respondents stated that they had changed their approach to patient decision making since the introduction of the 2015 Act. Of those, 4/5 (80%) stated that they now more routinely perform capacity assessments and 3/5 (60%) more routinely involved the family and friends of those who require a decision to be made for them. For those who stated that their approach remained unchanged; 6/22 (27%) stated that they had read the Act and were comfortable with their current approach, while 3/22 (14%) had been legally advised that no change was necessary.

Discussion

All the respondents had been responsible for the care of patients who required a decision to be made on their behalf. Most respondents routinely made decisions for patients without involving their friends or family prior to the introduction of the Act. Criticism and moreover legal consequences for those decisions appear to have been rare events prior to the introduction of the 2015 Act.

Most respondents were aware of the introduction of the 2015 Act. Despite this, training and legal advice received relating to the Act was rare. The nature and extent of any training or advice received was not within the scope of questionnaire, however even rudimentary training or legal advice was not received by the majority of respondents. Despite this more

than half or respondents felt that they could correctly identify a "relevant person" within the meaning of the 2015 Act. Fewer respondents were aware of the decisions that were within the scope of the Act. Far fewer were aware of the legal expectation placed upon oneself by the 2015 Act. The disparity in these responses is unclear. It may be the case that physicians are comfortable and able to identify those patients who lack capacity but are unsure of their legal responsibilities where a person lacks capacity or what decisions that person may be restricted in making. Despite this uncertainty most respondents were aware that "unwise" decisions were not grounds to doubt a person's capacity. Further respondents were split over the new provision that creates an obligation on the physician to involve friends and family in decision making processes. The heterogeneity in physician approach may be influenced by numerous factors however it is clear that physicians are uncertain on a universally correct approach.

More than half of physicians surveyed had encountered an Advanced Directive, and less than half had encountered an appointed decision maker. The 2015 Act created an obligation on physicians to check the registry of decision support arrangements, which less than half of respondents were aware of. This obligation is not yet active as the registry has not been created by the Decision Support Service as of time of survey. It will be important for physicians to be aware of this obligation when the registry goes live.

Only those respondents who had selected that they were aware of their legal expectation under the 2015 Act were asked the multiple-choice questions relating to assessing a patient's capacity. None of these respondents was able to correctly identify which conditions applied to a hypothetical patient who lacked capacity. This was investigated via a multiple-choice question which contained options based on the guiding principles from section 8 of the 2015 Act. Options were provided which were contrary to these guiding principles; if any of those options selected the respondent was considered to be in breach of the Act. A history of dementia or other cognitive decline was selected as the most common incorrect response. Some symptoms of dementia or cognitive impairment may prompt an assessment of capacity in clinical context; however mere presence of the diagnosis should not in itself be grounds to doubt a patient's decision-making capacity. As per the 2015 Act, there is a presumption of capacity which favours all patients. Other respondents selected a "poor psycho-social background" and an "inability to understand English or Irish" as reasons to doubt a patient's decision-making capacity. These results would suggest that even those who feel more confident in their responsibilities under the Act can still be misinformed regarding assessing decision-making capacity.

Despite the introduction of the Act necessitating change in widespread healthcare practice to meet the legal obligations, the physicians surveyed did not feel that a universal change to their clinical approach was required. For those who did change their practice there was a reported increase in the number of capacity assessments performed and the inclusion of

friends and family to support decisions for those who lack capacity. Most respondents who stated that their practice had remained unchanged had familiarised themselves with the Act or had received legal advice that no change to their practice was necessary. In either respect they were satisfied that they were practicing within accepted legal standards. This is consistent with the heterogenous approaches taken by physicians to identify a "relevant person" or perform their obligations under the Act.

As discussed in the methodology, participants were chosen from Model 4 hospitals working in JFICMI approved training centres due to the higher rate of ICU admissions in these centres. It must be acknowledged, however, that a significant number of patients requiring ADMA decisions are managed outside of these locations. At the time of circulation, nine centres had been approved by the JFICMI to provide training in intensive care medicine. Two of those centres primarily provide critical care to paediatric patients and thus are subject to the Guardianship of Infants Act, 1964 (as amended). There were no response from two of the adult centres; as such the data collected was limited to five centres. Overall response rate was poor, however results of the survey may provide some preliminary insights into the current clinical practice where patient capacity was absent.

This survey was further limited by the binary responses to most of the questions posed to respondents. This approach had been adopted to reflect the absolute position of many of the provisions of the Act. Either the respondent was compliant with the Act or they were practising in breach of the provisions outlined therein. While this approach granted insight into clinical practice in the strictest legal sense it does not explore other nuances of decision making such as treatment available, diagnostic information available or team dynamics. Where stated multiple choice questions used language which maintains the spirit of legal language of the Act combined with common errors described in the DSS guidance for physician documentation. This provided consistent language across options and made it difficult for respondents to select correct options based entirely on the phrases used. Nonetheless, the methodology employed of binary survey-style questions is limited as the relationship between decision-making capacity and the intensive care environment is complex. Further studies employing a more comprehensive qualitative approach could be insightful.

Patients with altered decision-making capacity are regularly encountered in the ICU environment. This patient cohort frequently requires decisions to be made on their behalf. Most ICU physicians have made and will continue to make decisions on behalf of this patient cohort. Prior to the introduction of the Act those decisions had been infrequently subject to criticism or legal scrutiny. Most physicians were aware of the introduction of the 2015 Act however training and legal advice has not been consistently received or sought by those physicians. ICU physicians are comfortable and sufficiently capable of identifying those people to whom the provisions of the Act apply, however there are unsure of their obligations under

the Act. Our study suggests that Intensive Care Consultants make assumptions regarding decision-making capacity which are not congruous with the guidance outlined in the Act. Advanced directives in ICU have been encountered by many physicians however the incidence of encounter with appointed decision makers is less frequent. Clinical practice has remained unchanged for most respondents despite new obligations under the Act. Lack of confidence as to physician obligations under the Act should have prompted a review of practice. Additional training and education should be made available to all Consultants working within the ICU environment.

In conclusion this study was limited by poor response rate, the binary nature of its design and its limit to only those consultants practising in JFICMI centres. Indeed a significant number of critically unwell patients are cared for outside of those centres. However, ignorance of the law is not a defence against its consequences and physicians must be aware of the effect of the 2015 Act. While limited, our study suggests that there may be some confusion over the effects of and obligations from the 2015 Act. Further research, such as a qualitative or mixed-methods study, drawing data from a larger sample size should be used to assess deeper knowledge and preparedness.

Declarations of Conflicts of Interest:
None declared.

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