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Palliative care healthcare professionals' perspective on the Assisted Decision-Making (Capacity) Act 2015 in Ireland

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ABSTRACT

Objectives People receiving end-of-life care often require assistance with decision-making. We aimed to ascertain from the perspective of palliative care healthcare professionals in Ireland, the impact of the Assisted Decision-Making (Capacity) Act 2015 (as amended) in Ireland on their practice for end-of-life care decision-making with patients and family caregivers.

Methods A qualitative study comprising focus groups was conducted with 22 healthcare professionals from different healthcare professions. Participants were recruited from a large regional specialist palliative care service in Ireland comprising two hospice sites. Data were analysed using thematic analysis.

Results Participants reported uncertainty about the Assisted Decision-Making (Capacity) Act 2015 (as amended) and emphasised a need for more public education to avoid misinterpretation of the Act. Participants felt that patients who need assistance with decision-making should be autonomous in decision-making but expressed concerns when patients made decisions about care that participants considered unwise. Participants considered that the Act would be beneficial in situations to support early communication between patients and their family caregivers about patient preferences for care.

Conclusions Larger scale multicentre examination of the Assisted Decision-Making (Capacity) Act among specialist palliative care providers in Ireland is needed to better understand its utility for practice.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ People receiving end-of-life care often require assistance with decision-making.

WHAT THIS STUDY ADDS

⇒ Healthcare professionals in palliative care can proceed with advance care planning despite uncertainty about legislation that is relevant to decision-making in practice.

⇒ Some healthcare professionals who provide specialist palliative care in Ireland may not necessarily refer to supported decision-making legislation for their practice.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Healthcare professionals' understanding of patient autonomy when patient decision-making capacity is impaired warrants further investigation in palliative care.

INTRODUCTION

In healthcare, decision-making capacity is understood as a person's ability to make decisions about their care. People receiving palliative care including end-of-life care often require assistance with decision-making, particularly if their decision-making capacity is impaired.[1 2] Decision-making capacity legislation can be lacking across jurisdictions.[3 4] The Assisted Decision-Making (Capacity) Act (ADMCA)[5] was enacted in the Republic of Ireland in December 2015 amended in 2022, and fully commenced in April 2023. Under the new law, capacity refers to the person's ability to make a specific decision at a specific time. Capacity is presumed unless proven otherwise.

The legislation comprises a framework of supported decision-making.[5] Where a person needs assistance with making decisions, decision-making supporters in the form of a decision-making assistant or a codecision-maker can be appointed by the person (through a written and signed decision support agreement, as appropriate) to assist them to make decisions of their own choice. In circumstances where a person is unable to make a specific decision even with appropriate supports, a

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decision-making representative can be appointed by the courts to make decisions on behalf of the person. The 2015 Act also provides a legislative basis for advance healthcare directives under which a person can appoint a designated healthcare representative who will have the power to advise on and interpret a person's will and preferences regarding treatment. Family members may occupy any of the above roles, but otherwise do not have decision-making authority in respect of the patient. We sought to examine from the viewpoint of healthcare professionals in palliative care, the impact of the above legislation on their practice for end-of-life care decision-making with patients and their family caregivers.

METHODS

We used a qualitative study design incorporating thematic analysis[6] in conducting the study. We recruited 22 healthcare professionals from a large regional specialist palliative care service in Ireland, which covers a catchment of approximately 700 000 people. The regional service comprises two hospice sites and provides inpatient, outpatient, day and home-based care. Sampling was purposive to capture participants of different healthcare professions and variation in clinical expertise and professional and/or clinical grade. Eligibility criteria included having at least 1-year experience working in specialist palliative care with direct engagement with patients and family caregivers. Table 1 outlines further detail on participants.

Table 1 Summary of participants

Men	1
Women	21
	(n=22)
Discipline	
Medicine	
Consultant medical doctor	1
Non-consultant medical doctor	3
Allied health professional	
Occupational therapist	1
Physiotherapist	2
Medical social worker	1
Nursing	
Staff nurse	1
Clinical nurse specialist	10
Clinical nurse manager	3
Specialist palliative care setting	
Inpatient hospice	6
Community-based care	12
Outpatients and day services	4
Years working in specialist palliative care	
1–5 years	6
5–10 years	5
> 10 years	11

Data collection comprised a total of five focus groups[7] with doctors, nurses and allied health professionals conducted by the first author between August 2023 and April 2024. A schedule containing a set of open-ended questions on the topic of investigation was developed by the first and last author (please see online supplemental material for focus group questions). Four of the focus groups were conducted in-person and the fifth via Zoom. Focus groups ranged in duration between 46 min and 78 min with an average duration of 65 min. Field notes were compiled to record key observations and aided contextualisation of the data. Member checking was performed by clarifying and confirming participants' accounts during and at the end of each focus group. All focus groups were audio-recorded and transcribed verbatim. Braun and Clarke's framework for analysing qualitative data[6] was used to analyse the data. Cross-checking of the data between two authors (HJF and GF) allowed for refinement of coding and the subsequent themes that derived from the data.[8] Data saturation was reached after analysing data from 22 participants (ie, when the fifth focus group did not result in any new significant findings).

RESULTS

Four key findings (themes) were identified from the data and are presented here. The data extracts are tagged with a unique identifier with 'P#', indicating participant number and their corresponding focus group.

Uncertainty about ADMCA

Participants felt that they did not have full knowledge of the ADMCA and some had questioned whether the legislation had been commenced:

> I think we need to know a bit more about the changes in the Act (P8, focus group 2)
> I don't think that [Act] comes in for us until December [2023] is it? (P5, focus group 1)

Participants expressed concern that palliative healthcare professionals in Ireland could be initially hesitant to advise patients and family caregivers about assisted decision-making because of their own uncertainty about the Act:

> I wonder now that it [assisted decision-making] has become more formalised, will there be a hesitation amongst staff, who are aware that something has changed but not quite sure what that means (P14, focus group 3).

Participants suggested that there was a lack of public awareness of the Act, which included patients and family caregivers. They emphasised a need for more public education to avoid misinterpretation of the Act and unnecessary decisional conflict in practice:

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> Sometimes they [public] are not fully informed on what the Act is … They don't actually have the proper education. That's when it can backfire because [even] I won't know enough about the Act (P21, focus group 5)

Perceived impact of ADMCA on practice

When asked about the impact of the ADMCA on their practice, most participants reported that they did not foresee significant change to their practice. A reason for this was that participants felt they already placed patients at the centre of the decision-making process:

> We have always put the patient at the centre anyhow, and I think the act is very much that the patient is the centre … That is also part of our values (P4, focus group 1).

Some participants reported that they had not needed to refer to the Act because they had not encountered significant problems in supported decision-making when patients needed assistance to make decisions about end-of-life care:

> I think I haven't really had to address it [refer to Act] because any of the decision-making I have been involved in, it hasn't become particularly contentious if you like (P12, focus group 3).

Others suggested that regardless of legislation for assisted decision-making, it is not always possible to fully mediate between patient preferences and the actions of an individual who is already intrinsically involved in decision-making about patient care. Participants felt that with or without assisted decision-making legislation, psychological and emotional factors at play in palliative care can unexpectedly negate previously stated preferences for care. For example, a participant recounted:

> There was one particular lady and there were so many conversations about her decisions … she did not want to be resuscitated, this was the big thing she didn't want… When she died at home … the children got such a shock … that he [husband] started giving her CPR [cardiopulmonary resuscitation] because he didn't want his children to think that he didn't try (P10, focus group 2)

The ADMCA ensures the rights of patients to make decisions about their care that they feel is best for them. However, participants expressed concerns for patients when they thought that decisions made by the patient (with or without family caregivers) were ill-advised and contrary to their clinical advice. In these situations, participants hoped for patients and family to follow their advice:

> It is about what the patient and family want … but I suppose we are their [patients] advocates and best practice is that we fully inform them. If they don't want to listen to us that's one thing. But unless they're making very educated guesses, they are only going to suffer then. Like when is the point where we have to be more assertive? (P19, focus group 5)

Perceived benefits of ADMCA for practice

While participants did not envisage significant change in their practice since the introduction of the Act, they perceived benefits to the Act. First, participants were pleased that patients who had difficulty making decisions were now no longer subjected to Ward of Court proceedings (ie, when the High Court in Ireland decided a person was unable to make any decisions about their affairs) but instead were supported by people who patients themselves preferred to assist them with decision-making:

> Before when someone did have difficulty in cognition, the only avenue to us at that point was ward of court … But I mean that was very archaic (P15, focus group 4).

Second, participants felt that the Act could ultimately serve to ensure earlier discussion between patients and family caregivers about the patient's preferences given the necessity for family caregivers to be clear about patients' preferences if appointed as a decision-making supporter:

> To help the person as well who has been asked to be for instance their co-decision maker or [decision-making] assistant, to help support them as well and give them an idea about what they [patient] want to do (P18, focus group 4).

Perceived limitations of ADMCA for practice

Participants perceived two main limitations of the Act. First, participants felt that decision support agreements with family caregiver(s) could (inadvertently) make it difficult for some patients and family caregivers to manage their own expectations of and preferences for care. For example, a participant explained:

> If somebody [patient] was saying they want to pursue active treatment, and full resuscitation is documented but actually the person … was beginning to die in the bed, possibly families would be more attached to wanting to pursue this active treatment even though that moment in time is gone (P20, focus group 5)

Second, participants suggested that the Act could potentially impede their ability to support the patient's wider family unit if the responsibility to assist the patient in making decisions about their care was delegated by the patient to only a single family member:

> If somebody has been nominated [to assist patient with decision-making], I wonder will there be a little bit of confusion? … Do they then feel they have to make every single decision. That's a lot of pressure on one person in the family when in

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> reality it might still be possible to have the family come along together as a unit (P13, focus group 3).

DISCUSSION

To our knowledge, this is the first study to report on palliative care healthcare professionals' perspective on the ADMCA in Ireland. The Act was fully commenced 4 months before the study started. However, by the completion of the study, some of the structures to support it were not in place and very few decision support agreements had been registered.[9] Although participants felt principles underpinning the Act were already central to their practice, they also reported that they were not fully knowledgeable of the legislation. Overall, participants expressed uncertainty about the ADMCA. Our findings pertaining to healthcare professionals' uncertainty about decision-making capacity legislation for practice resonates with studies in other countries.[10 11]

Early discussion about patients' preferences for end-of-life care was strongly advocated by participants; healthcare professionals' perspective in palliative care on the benefits of advance care planning has been documented elsewhere.[12 13] However, healthcare professionals' facilitation of advance care planning for patients in the context of the assisted decision-making legislation necessitates further attention. It is worth noting that advance healthcare directives in Ireland do not require capacity assessment or healthcare involvement; and although the legislation allows for a register of advance directives, it is not intended to set up such a register.

Consistent with other studies in palliative care,[14 15] we found that healthcare professionals wished for patients to adhere to what they considered best for the patient even though they valued patient autonomy. Participants praised the Act for ensuring that the patient's right of autonomy and self-determination is respected. However, they still expressed concern for when patients made decisions about their care that were deemed by participants to be unsafe or ill-advised. Healthcare professionals' understandings of patient autonomy when decision-making capacity is impaired warrant further investigation in palliative care.

CONCLUSION

This study reports from a purposive sample of healthcare professionals in one (although large) specialist regional palliative care service in Ireland, and so the generalisability of the findings to all healthcare professionals in specialist palliative care in Ireland is limited. Nonetheless, the findings are informative for those tasked with implementing policies arising from new legislation. Larger-scale multicentre examination of the ADMCA among specialist palliative care providers in Ireland is needed to understand its implications for practice.

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REFERENCES

1 Trevizan FB, Paiva CE, Julião M, *et al*. Comprehension and decision-making capacity questionnaire about palliative care and advance care planning: a delphi study. *J Palliat Care* 2023;38:41–51.
2 Kepple AL, Azzam PN, Gopalan P, *et al*. Decision-making capacity at the end of life. *Prog Palliat Care* 2015;23:133–6.
3 Browning M, Bigby C, Douglas J. Supported decision making: understanding how its conceptual link to legal capacity is influencing the development of practice. *Res Pract Intellect Dev Disabil* 2014;1:34–45.

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4 Davidson G, Kelly B, Macdonald G, *et al*. Supported decision making: a review of the international literature. *Int J Law Psychiatry* 2015;38:61–7.
5 Murphy VE, Gulati G, Whelan D, *et al*. The changing face of capacity legislation in Ireland: algorithms for clinicians. *Ir J Psychol Med* 2023;40:109–13.
6 Braun V, Clarke V. *Thematic analysis: a practical guide*. London: Sage Publications, 2022.
7 Tritter JQ, Landstad BJ. Focus groups. In: Pope C, Mays C, eds. *Qualitative research in health care*. 4th ed. Malden, MA: Wiley Blackwell, 2020: 57–66.
8 Barbour RS. Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *BMJ* 2001;322:1115–7.
9 Disability services, dail eireann debate Tuesday – 23 April 2024. Dublin House of the Oireachtas; 2024. Available: https://www.oireachtas.ie/en/debates/question/2024-04-23/559/ [accessed 24 Jun 2024]
10 Shepherd V, Griffith R, Sheehan M, *et al*. Healthcare professionals' understanding of the legislation governing research involving adults lacking mental capacity in England and Wales: a national survey. *J Med Ethics* 2018;44:632–7.
11 Hewitt J, Alsaba N, May K, *et al*. End-of-life decision-making in the emergency department and intensive care unit: health professionals' perspectives on and knowledge of the law in Queensland. *Emerg Med Australas* 2024;36:429–35.
12 Steiner JM, Oechslin EN, Veldtman G, *et al*. Advance care planning and palliative care in ACHD: the healthcare providers' perspective. *Cardiol Young* 2020;30:402–8.
13 Johnson CE, Singer R, Masso M, *et al*. Palliative care health professionals' experiences of caring for patients with advance care directives. *Aust Health Rev* 2015;39:154–9.
14 Johnson SB, Butow PN, Kerridge I, *et al*. Patient autonomy and advance care planning: a qualitative study of oncologist and palliative care physicians' perspectives. *Support Care Cancer* 2018;26:565–74.
15 Einstein DJ, Einstein KL, Mathew P. Dying for advice: code status discussions between resident physicians and patients with advanced cancer--a national survey. *J Palliat Med* 2015;18:535–41.

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