

Doctor's Perceptions of the Systemic Influences on Advance Care Plan Application: A Thematic Analysis

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Context: Healthcare consumers are encouraged to develop an Advance Care Plan (ACP) to help to ensure their preferences are known and respected. However, the role of governing systems in the application of ACPs must be understood if patients' voices (expressed within this medium) are to be heard.

Objective: To explore systemic barriers influencing Queensland public hospital doctors' application of the Advance Care Plans of hospitalized people with a neurodegenerative disorder.

Methods: Using a constructivist grounded theory approach, 16 semi structured interviews were conducted with public hospital doctors. Data were inductively analysed using open and focused coding.

Results: Analysis revealed two main themes: Practicing Medicine within a Legal Construct, and Delegitimizing ACP. Participants found the application of ACP in Queensland unduly complex, and they were inadequately prepared by education or training. Doctors maintained a dominant role in temporal medical decision-making and cited hospital practice culture for delegitimizing patient-owned ACPs.

Conclusion: The public healthcare system in Queensland exerts considerable influence over the degree to which ACPs influence decision-making. Despite the premise that ACPs give patients a powerful voice, hospital doctors often do not understand the underpinning law on which they depend when citing their responsibility for good medical practice. Systemic influences have contributed to a practice culture that has delegitimized the patient's voice when expressed through an ACP.

Keywords: advance directive, hospital doctors, living will, legislation, substitute decision making

Introduction

Formal advance care planning has grown out of medical, ethical, and legal debates associated with patient autonomy. The concept of a Living Will was first described in a 1969 publication by human rights lawyer, Luis Kutner who conceptualised the Living Will as a contract promising legal protection to both patient and healthcare provider.^{1,2} Advance care planning legislative frameworks and formal advance care plan (ACP) templates have been progressively utilized in countries such as Canada, the United States of America, New Zealand, the United Kingdom, Germany³ and Australia,⁴ where autonomy is accepted as a cultural norm. ACPs are defined as patient owned, written statements, articulating future healthcare wishes or directions applicable only during incapacity to consent. Thus, competent adults who wish to retain a voice in decision-making during incapacity can establish an ACP reflecting their fundamental right to prevent unwanted or unduly burdensome medical treatments upon them.

In Queensland, Australia, the law which governs a competent adult's right to complete a statutory ACP, namely an Advance Health Directive (AHD), is the Power of Attorney Act 1998 (Qld) and Guardianship and Administration Act 2000 (Qld). For an AHD to take effect, the principal must have lost capacity to make the current healthcare decision. Doctors are not obliged to apply directions which they have reasonable grounds to consider are inconsistent with good medical practice or are unclear, or when the doctor reasonably believes that circumstances have changed and application to care would be inappropriate. If an AHD refuses life sustaining treatment, certain illness criteria must be met. (Please

see Operation of Advance Health Directive. Power of Attorney Act 1998 (Qld), s36in [Appendix 1](#)) Alternatively, competent adults may utilize a values based, non-statutory form (Statement of Choices) to guide decision makers.

The above legislation, as it applies to withholding or withdrawing life sustaining treatment, is complex.⁵⁻⁸ Queensland doctors have significant difficulty applying the legislation^{6,9,10} and research suggests they tend to maintain a medical approach to decision-making, regardless of the law.¹¹ Some scholars have posited that ACPs which limit treatment upon the patient, philosophically conflict with doctors' treatment focus, thus doctors may resist ACP application.^{12,13} Further, access to ACPs requires cooperation from patients (the principal) as document owners or their representatives. However, representatives can feel conflicted about decision-making processes, leading to barriers applying the ACP.¹⁴⁻¹⁹ Any philosophical or practical conflict between patient autonomy and medical culture or systemic weaknesses may leave patients at risk of voicelessness despite their ACP.

Regardless of contentions that ACPs help to ensure patients' preferences are known and respected,²⁰ state public hospital doctors are encouraged rather than mandated to incorporate existing ACPs.²¹⁻²³ In 2009, in response to criticism from a State Coroner, Queensland's public health system manager developed an Acute Resuscitation Plan (ARP) and described this tool as an important part of ACP processes for inpatients.²³ Essentially, by completing ARPs, the health system partially meets its ACP obligations by providing a process through which doctors discuss with patients (or representatives) a proposed medical response to organ failure. In 2015, a web-based ACP application known as an Advance Care Planning Tracker was implemented to assist advance care planning processes by providing public hospital clinicians with read and write access to ACP records. Further, read-only access is available to General Practitioners and Queensland Ambulance Service to assist communications between stakeholders. Importantly, the application was intended to improve concordance between actual healthcare and patients' stated preferences. However, where an ARP is completed in consultation with a representative without reference to the patient's existing ACP, the voice of the now incapacitated patient is potentially lost.

The role of governing systems in the application of ACP must be understood if patients' voices (lawfully expressed within this medium) are to be heard. The two ACP documents meeting the criteria for this research were the Queensland AHD (Version 4) and the Statement of Choices (Version 5.1). In line with study aims, AHD and Statement of Choices are specified only where relevant to distinguish legislated applicability. This paper reports state public hospital doctors' perceptions of the systemic barriers influencing their application of ACPs to treatment decisions for incapacitated persons with a neurodegenerative disorder.

Methods

The findings presented in this paper constitute part of constructivist grounded theory research exploring enablers and barriers to hospital doctors' application of ACPs of incapacitated patients with neurodegenerative disorder (see separately published results).^{19,24} Consistent with the constructivist grounded theory methodology, this research commenced with broad aims rather than specific objectives. This paper provides a thematic analysis explaining how system factors potentially influence doctors' application of ACPs to public hospital healthcare decision-making.

Study Design

An inductive thematic analysis informed by the constructivist grounded theory approach of Charmaz²⁵ was chosen for its capacity to help develop a new understanding of the underlying phenomena associated with this study. Grounded theory is recognized as providing tools that allow the development of explanations about largely unknown phenomena.^{26,27} Constructivist grounded theory²⁵ methods were used to inductively describe the perspectives of doctors who are responsible for decision-making on behalf of patients with a neurodegenerative disorder who are deemed incompetent and have an ACP in place. The theory developed as a result of this study has been published elsewhere.²⁸

Ethical Approvals

Multisite approvals were granted by Townsville Hospital and Health Service Human Research Ethics Committee (54,125) and James Cook University (H7930). Participant access to professional support, if distress occurred, was

incorporated into approvals. Participants were informed about the purpose of the study, which was conducted in accordance with the Declaration of Helsinki.

Participants and Recruitment

Participants were public hospital doctors who had direct experience of medical decision-making for incapacitated patients with a neurodegenerative disorder and an ACP. Participants received written and oral study information and consented to interviews being digitally recorded, analysed, transcribed, anonymized, and excerpts published. Recruitment occurred via health service newsletters, snowball referrals and emails disseminated by heads of departments. Purposive sampling was undertaken from units most associated with end of life including palliative care, emergency, geriatrics, intensive care, and medical oncology.⁶ In line with theoretical sampling techniques, some specialties (such as neurology, general medicine, psychiatry, respiratory and renal) were specifically invited to participate during the later stages of data analysis.

Data Collection and Analysis

The authors developed a semi-structured interview guide based on professional experience and research, to flexibly explore systemic factors contributing both barriers and enablers to the application of the ACPs (see [Figure 1](#)). The guide containing open questions was piloted across health services and then amended iteratively as theoretical concepts emerged from the data. Modifications to guides ensured that each subsequent interview explored emerging areas. Interviews were conducted between November 2019 and November 2020 across two major hospitals and health service districts by both authors. Face to face or via telephone or “MS TEAMS” online software was used, and interviews ranged from 20 to 70 minutes (mean of 51.8 minutes).

Interviews were transcribed verbatim by either the first author (DC) or a professional transcription service. Early interviews were independently coded line by line by both authors (DC, RR), after which coding was discussed with a wider research team including a health professional and a legal expert (DH, MS). The first author then coded all transcripts using a combination of open and in vivo codes, using QSR NVivo 12 software to assist with data management. Data and codes were constantly compared,²⁵ and codes were discussed during regular research team meetings using a consensus approach to resolve occasional discrepancies, then revised to increase confidence in analysis. Codes were progressively collapsed into categories representing recurring themes. Reflexive memos were recorded to investigate and elucidate categories and diagrams were developed by the team to record emerging relationships between themes

Interview prompt guide

Can you tell me about your experience with patients who have neurodegenerative disorder and an ACP?

How are Advance Care Plans included in decision-making?

At what point do you look for the ACP?

When does an ACP help you? Has an ACP ever made things harder for you?

How confident are you that patients understood the decisions they made in their ACP?

Have any ACP treatment decisions ever troubled you?

What is the role of family when AHD addresses the matter?

How is the decision-maker or consent to healthcare ascertained?

Do other disciplines influence ACP application?

What are your thoughts about differences between AHD and Statement of Choices?

Would you have one yourself? Do you have one?

What do you tell people that they can expect from an ACP?

Figure 1 Example interview guide questions.

and an overarching conceptual framework. An independent medical consultant reviewed the research team's conclusions and provided supportive feedback. Data collection and analysis occurred concurrently until no new data were forthcoming, and the research team were satisfied that data saturation had occurred.

Results

Participants

Fifteen senior doctors (consultants) and one junior doctor (registrar) representing a broad range of specialties, all with experience in the role of ACPs in decision-making for incapacitated patients with a neurodegenerative disorder in public hospitals within the study region, participated in this research (see Table 1).

During data analysis, two main and interrelated themes that play a restrictive role in the application of ACP were constructed. The first theme, Practicing Medicine within a Legal Construct, designates the overarching background to the non-application of ACP in decision-making for incapacitated people during hospitalization. Undergraduate and post-graduate doctors receive limited or no education about the application of ACP. The second theme, Delegitimizing ACP, was associated with workplace culture, deferring to ARPs, and accessing ACP. Table 2 diagrammatically represents the systemic influences effecting the application of ACP in public hospital practice.

Set in the context of legislation, consumers are told that an ACP will give them a voice and help their families at times of future medical decision-making. However, as incapacitated inpatients the patient's voice is diffused by the shared temporal decision-making model present within public hospital practice.

Theme One: Practicing Medicine Within a Legal Construct

Participants overwhelmingly interpreted Queensland legislation as unduly complex. Many described tensions between the separate frameworks of law and medicine and were not confident about their understanding of the law. They managed competing responsibilities by prioritising their interpretation of ethical practice.

Table 1 Participant Characteristics

Doctors	n
Cardiology	1
Emergency Department	2
General Medicine	3
Geriatrics	5
Intensive Care	1
Neurology	1
Oncology (medical)	1
Palliative Care	1
Psychiatry	1
Seniority	
Registrar	1
Senior Medical Officer	15
Gender	
Female	6
Male	10
Age range	
30–39	6
40–49	4
>50	6
Years experience	
5–10	3
11–20	7
> 20	6

Table 2 Example Coding Process

Initial Coding	Focused Codes	Themes and Subthemes
“So much grey” Practicing medicine not law Being protected by law	“So much grey” Marrying law and medicine Practicing good medicine	Law: practicing medicine within a legal construct
Ineffective EOL and ACP education. Ad hoc learning Education is voluntary	Insufficient education	(Subtheme) Education
Giving GPs responsibility GPs ill-equipped ACPs lacking transparency “Efficiency efficiency efficiency”	Disconnecting hospital from primary care Distrusting ACP Deferring to ARP Resources constraining practice	Delegitimizing ACP
Working to diagnose and treat Going into medicine to help Being siloed	GPs' responsibility Socialized to treat	(Subtheme) Workplace culture
Resuscitation plan the priority	Deferring to ARPs	Deferring to ARPs
Including ACP is voluntary. Relying on being given access Unfamiliar with ACP Tracke.	Access optional. Ill-equipped to access ACP	(Subtheme) Accessing ACPs

These are legal constructs, they're not medical constructs, so we're trying to apply medicine to what is a legal construct. D3

You read it [law] but you're not a lawyer and things are explained to you, but they may not be correct and sometimes the lawyers don't understand it either... Every time I ring the coroner I get a different version from each and they think they're right but there is another coroner who thinks they're wrong... With this withdrawing of care, that's a very complicated area and there's odd things in that legislation which have been exempted and others haven't because of various interest groups... [there are] all sorts of odd exceptions like blood transfusion... because there is a religious interest group. Why would you represent one religious interest group over another?... It's just so difficult, there are so many different scenarios... someone can have a blocked trachy. We unblock it and they just need 24 hours on a ventilator... and then they're back to where they were for another year or two... you think, 'we're going to let them die for their Advance Health Directive when they didn't envisage that they could have had this obstruction of their trachy?'. You don't want to let them die for that... it comes down to, I'm afraid, a certain doctor knows best paternalistic attitude and where sometimes it can be appropriate... The law is a mishmash...because of all the different scenarios... which have never been envisaged by the people that did it... D5

Although doctors admitted to being confused by Queensland law, they expected that law courts would be on their side if legal action was taken against them. Most expressed confidence that as leaders of healthcare decisions, they would be provided with legal protection.

I haven't gone and read the laws myself but... whenever the courts have been asked to adjudicate about withdrawal of treatment or refusal to provide treatment the courts in Australia have always taken the side of the doctor. I find that reassuring. D11

I haven't specifically looked into Queensland Law because I haven't had to... It's like a national umbrella for healthcare workers and doctors that medical judgement is very important. We're protected in that we can make the decision to withdraw care on a patient against their will and against the family's will if we feel like it is futile, or we're inflicting pain and torture on a person for no benefit. D15

Participants associated their limited understanding of the law with the complexity of the legislation, citing a need for law reform.

(The hospital) has some good policies to read but at the end of the day the law's too grey and far too ambivalent... For the difficult situations, I've talked a bit with legal but it's problematic... They really do need something that is more clear cut. D3

Improve the legislation because it's incomprehensible... What might be clear cut to a solicitor is not clear cut to other people because they haven't had the education. That's the problem with the law, "ignorance of the law is no excuse" is a catch phrase which comes out all the time from the coroner... There's this disconnect between reality and ignorance of the law, which is just plain stupid. The laws should be reviewed and maybe made simpler. D5

Educating Doctors About ACP Legislation

Overall, doctors reported being inadequately prepared to understand Queensland's Power of Attorney Act 1998 (Qld) and Guardianship and Administration Act 2000 (Qld).

[Legal education is] very limited. [In] medical school... they do a reasonable bit these days, but you've also got to do 50 million other things... the problem is, for instance, your specialty exams are nationwide, and laws are state based... it makes it very difficult to create a framework for assessment. D4

When I was going through medical school... we had no [legal education], nothing, zero. It was never even discussed...and we still have problems now because... legislations are very different in Queensland... you'll get a doctor who'll come in and will fall foul of the Coroner's Act all the time because we have doctors from overseas who don't imagine that it would be so silly, but it is... [orientation] doesn't include those things. You can only include so much, and they just don't realize that the law is different here...there should be a complete subject of law [in medical school]. D5

Post graduation, professional development relevant to the application of ACP, is a voluntary undertaking. Doctors often influenced by workplace culture and clinical scenarios, independently develop their understanding of the law.

I think we educate each other in certain aspects of law...but there's variations in practice. One doctor won't do exactly the same as the next doctor, which is very challenging. D8

If I were a chest physician I wouldn't be worrying about this. But my trade involves dealing with this all the time, so I have to make some special effort to go through the documents and the legislation to try and understand the working practice, and also speaking to my colleagues to try and get an understanding of how they function. That is unfortunately part of my tools of the trade, so I have to do it myself. D6

Theme Two: Delegitimizing ACP

Although doctors asserted that ACPs give patients a voice which is best supported by GPs, hospital doctors distrusted GPs' knowledge. However, most participants argued that hospital-based doctors are not resourced to support ACP development, leading to a pervasive distrust in ACP processes.

The extent of understanding of the disease when they make the advance care directive is often inadequate, I think... there are specialist occasions where the specialist should be involved (but is not). D6

You need the relevant specialist to communicate adequately with that doctor to give an idea about what to expect, and prognosis, which we sometimes do well and sometimes don't... [Only] if I'm prompted by a GP to give an idea of prognosis, I will reluctantly do so. D9

Some doctors associated under-resourcing with their inability to spend sufficient time with patients, and one directly associated this factor with doctors making fear-based decisions.

For most of the doctors, a lot of their decisions are made on anxiety. They feel the wrong decision may be made. They don't have enough time, they don't have enough resources. They don't feel they have the clinical experience or skills to do these things. Most of their decisions are made on the basis of "what if I do the wrong thing?". D16

The greatest barrier that we're coming across in contemporary medicine is the constant drive to create efficiencies... the constant drive to move along (every) five minutes, you know, efficiency, efficiency, efficiency... that is where we are creating issues for ourselves in other areas such as this [ACP]. D13

Workplace Culture

One important factor was the influence of workplace culture in the application of ACP, with most doctors socialized towards treatment and deferral to ARP. Participants reported prioritising the diagnosis and active treatment of patients in their care wherein they focused on a medical model which did not incorporate timely consideration of ACP.

Even when we talk about metastatic colon cancers, I don't think we ever talk about end of life. We just talk about treatment, no one talks about end of life, so when do they die, when do you stop? We don't cover that in the training...doctors are treatment focused because that's how they are trained. D14

Supposedly they (patients) are there to be helped, they go to the hospital to be helped. They're in the hospital and they've come because they're unwell, I'm there to help them. I don't think the system in itself, or culturally, we'd be predisposed to go and look for an Advance Care Plan. D10

Doctors also recognized and acknowledged the variability of organisations, training, and subspecialties in influencing doctors' socialization towards, or away from ACP application.

[The application of an ACP] Depends on the team dynamics, the culture, the emphasis of the organisation and culture within the organisation, and it depends on the individual. As in any system, it is highly team and person dependent... there's a lot of training dependency as well... there's quite a difference and a dichotomy in terms of, for instance, hematology... they often do far more heroic things. Quite often oncology's very different... there's a lot more therapy, so once again, it [application of ACP] tends to be at a later phase... It's often modelled by the culture of the seniors. If you're on an orthopedic team, it won't be given the same priority as if you're on a general medicine [ward] D4

Deferring to Acute Resuscitation Plans (ARPs)

Doctors overwhelmingly conceptualised the ARP as the type of ACP most relevant to hospital care. Directions provided within an AHD were considered potentially useful when completing an ARP. However, ARP as succinct plans take precedence over other ACPs during hospitalization.

Health Directives or Statement of Choices are not always available to us and I think people [doctors] sometimes just don't even think about [them]... because we work in a hospital, if you don't have a hospital plan then you mustn't have a plan... it's usually the resuscitation plan from the hospital to be honest, that I find most helpful because it's a single page... I know exactly what I need to do. D12

The priority has always been knowing what the patient's resuscitation status is... the rest can be sorted out the next day or later in the admission... once we've seen an ARP documented for us it will be like, "OK, well, ARP is in place. I think that's good enough". D7

Doctors' deference to ARPs appears to have been systematically embedded into workplace culture, and some doctors misinterpreted completion as policy.

We have to do an ARP within 24 hours of admission, so it's taken away the whole discussion of the Advance Health Directive. So that's taken priority, usually registrars do that because they know it's "you need to do this, you need to do this" because it's part of protocol. D10

An Acute Resuscitation Plan is not legally binding in any way. We defer to it, but it's actually not a legal document... It's the policy that it's done for every patient. D3

Despite the binding nature of AHDs, doctors often consulted with and obtained consent from substitute decision makers when generating an ARP. Accordingly, decisions documented within both an AHD and ARP may be inconsistent.

Quite often patients have got ARPs done during this admission and in fact, they've got an Advance Health Directive that was done, maybe, a year ago and they're not the same. The ARP is often done by a statutory health attorney and in fact, this person did an AHD, and that's not what's been used to inform the ARP. D2

Doctors were confident that ARPs address the needs of clinicians who respond to patient deterioration. By generating an ARP, doctors retain a degree of control over shared decision-making despite the presence of a binding AHD.

That [AHD] can be done well or it can be done badly and there's no way for me to know which way it's done. But that's why I do, whenever possible, create an Acute Resuscitation Plan... The Acute Resuscitation Plan is really the only way that you can message to other health workers what the intentions of treatment are and if you don't have that filled out then the patient is considered to be absolutely full medical resuscitation efforts. And so, whatever's written in that Health Directive gets translated in a way that allows some contemporizing of it. D11

Despite the predominance of ARPs in hospital practice, some doctors expressed concern about the poor quality of junior doctor training, leading to poor quality ARPs described as inappropriate to the circumstances.

Our juniors are told that they have to do the ARPs, but no one ever teaches them how to do it. And they're not in a position really to understand that balance between burdensome treatment and benefit... there's a lot of ARPs that are created that are completely useless, that should never have been written because they're not taking into account any of the complexities of the patient's illness or the possible resuscitative techniques that might have to be applied to them. D11

Accessibility of ACP

A persistent constraint reported by most doctors was timely access to ACP. In situations where doctors do seek access to their patient's community generated ACP, doctors are dependent on the ACP being provided to them.

Sometimes the actual Advance Health Directive takes longer for people to chase up...it's rarely sent to hospital with them. The old system in other states of having the yellow envelope on the fridge doesn't always happen here. D3

I think that the advance care planning documentation is poorly filed. It's not in a consistent place in terms of our records, particularly our electronic records. We've got the Tracker which is fabulous, but very often it's not there or you'll just see that someone's written "Advance Health Directive exists", but no one has sighted it. D2

Discussion

This research has elucidated systemic contributors to the non-application of the ACPs of patients with a neurodegenerative disorder during hospitalization in state public hospitals. Two major themes and four subthemes were constructed from the data. The first major theme, "practicing medicine within a legal construct" and its subtheme, "educating doctors about ACP legislation" describe the legal context of the non-application of ACP in this study. The second major theme, "delegitimizing ACP" and subthemes "workplace culture", "deferring to ARPs" and "accessing ACP" describe hospital-specific factors that affect doctors' behaviour. Public hospital doctors make healthcare decisions about incapacitated patients within the context of complex legislation and medical organizational practices. Despite legislation designed to give patients a voice during incapacity, public hospital doctors maintain dominance over treatment decisions, often without reading the voice of the person who is central to the decision. This paper discusses the implications of these findings and makes recommendations intended to help redress the doctor-patient power imbalance.

Practicing Medicine Within a Legal Construct

In all situations, the law underpins an individual's power and the application of ACP to healthcare decision-making, yet this study revealed significant tensions between Queensland's legislation and state public hospital doctors' application of ACPs to decision-making. Most doctors were either ambivalent or resentful towards the law which has imposed powerful limitations on medical practice and provided consumers with opportunities to exercise agency by recording binding (yet potentially naïve) directions. Participants concurred with the argument by Willmott et al,¹⁰ that the law governing the

withholding or withdrawing of life sustaining treatment in Queensland is counterintuitive and often inconsistent with good medical practice. Consistent with other research,^{7,8,29–32} participants believed they held responsibility for making medical decisions, and they prioritized ethical and clinical factors above legal obligations. Doctors' belief that good medical practice fulfils their medicolegal responsibilities thus weakened their motivation to understand the legislation. This result supports and extends the conclusions of Moore et al,²⁹ White et al,⁸ and Wong et al²⁷ and indicates the potential benefit of improved education and training to enable doctors to be more confident in the application of the law governing ACPs.

To deliver healthcare within a legal framework that they do not understand, doctors have prioritized good medical practice in a process that often usurps ACPs. Good medical practice is consistently endorsed within clinical guidelines,²¹ the Australian Medical Board's Code of Conduct for Doctors in Australia,³³ legislation (Powers of Attorney Act 1998 (Qld) and Guardianship and Administration Act 2000 (Qld)) and research.⁸ Importantly, under the legislation, doctors are excused from applying a Queensland AHD if they reasonably believe the directions are inconsistent with good medical practice. As a result, patients who provide directions within an AHD might find that doctors make temporal decisions based on good medical practice unless the patient's family, nurses or allied health clinicians advocate for ACP application.¹⁹ Doctors' privileged authority to discern good medical practice has thus enabled an asymmetrical power dynamic that enables the patient's voice to be excluded.

Interestingly, doctors recognized that legislation provides them with a protective decision-making framework. This concept was employed to their advantage when they assumed that in the event of conflict with a patient or family, the judicial system would uphold the right of doctors to discern and deliver good medical care even when counter to the ACP. Participants' confidence appears well placed, with Willmott et al, providing evidence that the Australian Supreme Court "has usually deferred to medical opinion when assessing best interests".³⁴ These findings extend the conclusions of Willmott et al³⁵ and Moore et al²⁹ by revealing that doctors within the study region use their interpretation of the law to justify setting aside ACPs. When a legal framework intended to safeguard the rights of all parties is not understood, medical care may contradict the rights of patients and support the assertions of legal academics White and Willmott et al,^{5,11} that legislation should be reformed, and the education of doctors improved.

Educating Doctors About ACP Legislation

State-based laws and nonspecific education programs leave doctors at risk of legislative knowledge gaps. A key contributor to doctors' limited knowledge of Queensland's legislation resides in both undergraduate and postgraduate education structures. Legal education was described by most participants as generic or not delivered at all, which accords with the findings of others.^{9,36} This leaves doctors (and therefore patients) vulnerable to peculiarities within a nationally fragmented legal system and accords with the submissions of Parker³⁷ and Willmott et al,⁷ that medical law education and training of doctors in Australia is uneven. Despite the passage of two decades since the inception of the governing legislation and recognition by the public hospital system that end of life decision-making is complex,²¹ medico-legal education is not a part of mandatory training for any discipline within the public hospital system. Therefore, training to ensure patients' rights are understood is yet to be addressed by peak bodies and this study suggests the need to reform medical curricula and postgraduate education. In the absence of such reform, it is the responsibility of the public hospital system to ensure doctors understand the legislation and their responsibilities concerning patients' choices. This would require suitable mandatory workplace education for all clinical staff.

Delegitimizing ACP

The extent to which hospital doctors have delegitimized patient-owned ACPs calls into question the relevance of ACPs for inpatients. Despite hospitalization risking a high treatment burden³⁸ that patients sought to avoid,^{39,40} doctors in this study divested themselves of ACP application responsibilities by suggesting that ACPs are most relevant to implementation in community settings. Doctors also cited hospital resource limitations as an antagonist to ACP processes and applications. These findings support the proposal by Scott et al⁴¹ that GPs are best placed to engage patients in ACP. However, the current study expands scholarship by revealing that participants consider GPs to be under resourced and often lack knowledge of prognoses, yet hospital doctors refrain from supporting GPs and patients in ACP processes.

These factors then jeopardize the quality of patient health literacy and may lessen the legitimacy of patients' written choices, suggesting the need for improved ACP facilitation processes. Treating doctors' doubt about ACP reliability has been well documented,^{29–31,42–44} however this study delivers new insights into the non-application of ACPs, despite legislation, within Queensland public hospitals.

Deferring to ARPs

Doctors' distrust of patient-owned ACPs has contributed to their ambivalence towards ACP application, at least within public hospitals where they are more likely to rely on ARPs. This suggests the potential benefit of multidisciplinary health professionals taking a collective approach to ACP revisions in a life-long process of comprehensive care. Instead, hospital doctors are enculturated to defer to in house ARPs, thus replacing the patient-owned ACP with a plan in which the (incapacitated) patient has no voice. The extent to which the hospital system has enabled deference to ARP as opposed to the statutory AHD is noteworthy. Given doctors' knowledge that AHDs are legally binding whilst ARPs are often poorly completed by junior doctors, this result was unexpected. This finding concurs with Bryant et al,⁴⁵ who found comparable concerns regarding resuscitation order processes in New South Wales (Australia). Despite participants' concerns, they considered ARPs were more likely than patient-owned ACPs to be relevant to the hospital environment. This study appears to be the first Queensland based research to demonstrate the dominant role of ARPs, which, in effect, compete with patient-owned ACPs rather than complement them. Accordingly, health service training in ARPs should be used to improve doctors' understanding of the important role of patient-owned ACPs and encourage multidisciplinary clinicians to assist patients and substitute decision makers to resolve contradictions between ACPs and ARPs.

Workplace Culture

This study revealed a treatment focused workplace culture of Queensland's public hospital doctors which associates death with failure and thus threatens doctors' willingness to apply a treatment limiting ACP. This finding contradicts the claims of Advance Care Planning Australia which asserts that ACP helps to ensure a person receives the care they actually want.²⁰ Predictably, the dominant practice culture of doctors reflected a longstanding death avoidant medical model: doctors assumed that patients attend hospitals for treatment and that doctors are trained and legally responsible for ethical decision-making in the best interests of patients. Consistent with the scholarship of Moore et al,²⁹ and Willmott et al,³⁰ doctors felt justified exercising medical control over decisions for incapacitated patients, thus moderating patients' power by discerning the applicability of ACPs (see also Craig et al).¹⁹ Somewhat problematically, ACPs were seen as an attempt by patients to naively limit treatment, which, if applied, may lead to an untimely death. The possibility of untimely patient death as a consequence of ACP was also reported by Katsetos and Mirarchi⁴⁶ and Willmott et al,³⁰ however others⁴⁷ have shown that there is no systematic increase in mortality associated with ACP. The present study extends the findings of Arruda 2020,⁴⁸ Johnson 2018⁴⁹ and Willmott 2013³⁰ by elucidating tension between the rights of people with a neurodegenerative disorder to document decisions in advance of incapacity, and the death delaying treatment focused medical bias of hospital doctors.

The death as a failure mindset of doctors⁵⁰ may well have been maintained by the healthcare sector's decades long "name blame shame" culture.⁵¹ Quality indicators selected for regular monitoring include in hospital mortality⁵² in part to signal suboptimal healthcare and provide a remedial response to it.^{51,52} Emphasis on mortality rates in public hospitals and reference to "favourable trends seen (overall) for all measures of mortality"⁵³ does little to normalize death as a natural outcome of old age or the end stage of chronic illness.⁵⁴ Consequently, persons with a neurodegenerative disorder who construct an ACP to retain a lawful voice despite incapacity remain at risk of being disempowered by a medical system that confers substantial power on doctors and seeks to delay patient death. Implications of this study suggest a need for hospital and health services, universities, and professional bodies to improve the psychological support of doctors of dying patients, and doctors challenged by the existence of an ACP which limits medical treatment.

Accessing ACP

Another frequent barrier to incorporating ACP into decision-making was ACP inaccessibility. Although inaccessibility has been noted by others,^{41,55,56} this research has extended scholarship by revealing that public hospital doctors were not

systematically trained to use the available technology designed to enhance accessibility. ACP management processes were thus poorly understood. Hospital systems have the responsibility for embedding ACPs in practice and facilitating accessibility of ACPs,⁵⁷ yet doctors are not mandated (in law or public hospital policy) to request ACPs be provided to treating medical teams. Further, public hospital doctors do not receive systematic instruction regarding ACP. In the absence of hospital staff utilizing records management systems effectively, timely access will remain a barrier to ACP application. To improve ACP accessibility, consumers should be encouraged to share their ACPs⁵⁸ to available storage systems, and multidisciplinary hospital clinicians should be systematically trained to utilize available resources to both access ACPs and document revisions where appropriate.

Limitations

This research has several limitations. Firstly, patient illness type was limited to neurodegenerative disorders, so ACP application in the context of other medical conditions was outside this research. Secondly, participants came from two major regional hospitals and health services, and data collection relied on self report. Doctors in other regions may respond differently to ACPs. Thirdly, the researchers did not achieve engagement from all subspecialties or equal representation of doctor seniority. Further, it is unclear to what extent doctors' positive attitudes towards ACP reflected the heightened interest in advance care planning associated with the COVID-19 pandemic.^{59–61} All doctors were supportive of ACPs (to varying degrees) and therefore those who disregard them entirely were underrepresented. It is also acknowledged that the research may lack cultural relevance to some groups within society who may offer alternative explanations for ACP nonapplication.⁶²

Conclusion

This research offers insights into systemic contributors to the nonapplication of ACP of hospitalized, incompetent persons with a neurodegenerative disorder. Underpinning the application of ACP in Queensland is complex legislation that doctors often do not understand and that they find difficult to apply to clinical situations, yet education on the subject remains voluntary. Despite the premise that ACPs give patients a powerful voice, hospital doctors' practice culture reflects a tendency to diffuse patients' power by claiming medical superiority in temporal decision-making. Systemic pressures have contributed to a practice culture that has delegitimized the patient's voice as expressed through an ACP. As such, the public healthcare system exerts considerable influence over the degree to which patient-owned plans are included in decision-making. If ACPs are to deliver to patients the pledged voice during voicelessness, barriers to the application of ACP must be addressed. By hearing the voices of patients who generated an ACP, healthcare systems would take a significant step towards meeting their obligation to partner with consumers in the delivery of patient centered, comprehensive care.

Abbreviations

ACP, Advance Care Plan; AHD, Advance Health Directive; ARP, Acute Resuscitation Plan; Qld, Queensland.

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