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Advance Care Plans and North Queensland Public Hospital Doctors. A Grounded Theory

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A thesis submitted for the degree of Doctor of Philosophy

College of Medicine and Dentistry

James Cook University

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Acknowledgements

It is surreal to have reached the stage of my doctorate when I can acknowledge the considerable support I have received to this point. I commence by offering my heartfelt thanks to my advisory team: Assoc. Prof Robin Ray, Dr Desley Harvey, and Assoc. Prof Mandy Shircore. You have been ever-present through thick and thin, triumphs and tears (and there were many tears), and my optimism-pessimism cycles. I am grateful to have been guided by three strong and wise women who *leaned in* to my research topic from Day 1. Thank you, sincerely, for all you have done for me.

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trusted teachers and I am so grateful to have you. My partner Karen; when I promised you an interesting partnership, four years of neglect was not what I meant! Thank you for your infinite love, patience, and support. Our next chapter begins here.

Statement on Sources

I declare that this thesis is my own work and has not been submitted in any other form for another degree or diploma at any university or other institution of tertiary education. Information derived from the published or unpublished work of others has been acknowledged in the text and a list of references is given.

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Statement of the Contribution of Others

Nature of Assistance	**Contribution**	**Names**
Intellectual support	Advisors	Dr Robin Ray was my primary advisor, whilst Dr. Desley Harvey and Assoc. Prof. Mandy Shircore were my secondary advisors, each at James Cook University.
	Study design and data analysis	My advisory panel (above) contributed advice and guidance on study design and data analysis. My panel scrutinized my assumptions and offered suggestions as appropriate.
	Research process and methods	My supervisory panel (above) guided me in completing key milestone requirements and advised me, as needed, on research methods. I was also a participant in the James Cook University PhD cohort program which facilitated additional professional development.
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Co-authors of these publications have consented to article inclusion within this thesis.

Thesis Chapter	**Publication reference**	**Nature and extent of the intellectual input of each author**
2	**Craig, D. P.,** Ray, R., Harvey, D., & Shircore, M. (2020). Factors which influence hospital doctors' advance care plan adherence. *Journal of Pain and Symptom Management*, *59*(5), 1109-1126.	DC, RR and DH conceived of the study and participated in the study design. DC carried out database searches, literature review, data extraction and analysis of publications, and drafted the article. All authors edited and revised drafts and approved the final article.
4	**Craig, D. P**., Ray, R., Harvey, D., & Shircore, M. (2021). Advance care plans and the potentially conflicting interests of bedside patient agents: a thematic analysis. *Journal of Multidisciplinary Healthcare*, *14*, 2087. **Craig, D. P.,** Ray, R., Harvey, D., & Shircore, M. (2021). Multidisciplinary Clinicians and the Relational Autonomy of Persons with Neurodegenerative Disorders and an Advance Care Plan: A Thematic Analysis. *Journal of Multidisciplinary Healthcare*, *14*, 3385.	DC, RR and DH conceived of the study and participated in the study design. DC carried out database searches, literature review, data extraction and analysis and drafted the papers. All authors (DC, RR, DH and MS) contributed to refining theoretical concepts, edited and revised drafts, and approved the final article.

Abstract

People diagnosed with a neurodegenerative disorder contend with a threat to cognitive independence and autonomy, leading some to complete an advance care plan (ACP). ACPs are used in all Australian states and territories to give adults a voice in their future healthcare, despite incapacity. Yet in practice they do not guarantee patients a voice and literature exploring doctors' explanations for the ad hoc use of ACP is limited. This thesis reports on an Australian constructivist grounded theory research that examined the process of medical decision making on behalf of persons with a neurodegenerative disorder who had an ACP. The focus of the research was North Queensland public hospital doctors.

Data were gathered between November 2019 and November 2020 through 45 semi-structured interviews, either face-to-face, or via telephone, TEAMS or ZOOM for convenience and to adhere to COVID 19 distancing restrictions. Purposive sampling included people with a neurodegenerative disorder, family/advocates, allied health clinicians, nurses and doctors. Theoretical sampling during later data collection included allied health clinicians and doctors from specific disciplines. In total, seven participants identified as having a neurodegenerative disorder and an ACP; six as family of someone with a neurodegenerative disorder and an ACP (living or deceased); ten senior allied health clinicians; six senior nurses and 16 doctors (15 senior and one junior). Data were inductively analysed using constructivist grounded theory methods.

The findings of this research revealed that doctors are supportive of ACP "to give patients a voice", yet once incapacitated (whereby the ACP is intended to take effect), patients' power is diffused and their voice hangs in the balance whilst doctors make decisions. Doctors guide presumed best interests decisions within the context of *human factors* (arising from the potentially conflicting interests of patient agents and prioritisation of relational autonomy partnership with family); and *systemic factors* (arising from the law, education, resources, accessibility, workplace culture and delegitimisation). Data showed that hospital doctors are predominantly treatment focused and although they spoke of respecting the known wishes of their patients, they seek to make decisions that are consistent with good medical practice when the patients' prognosis is known.

In contrast to individualistic autonomy inherent within an ACP, doctors apply a relational autonomy view to decision-making when the patient cannot give informed temporal consent to medical care. In part to avoid bedside conflict, doctors instead partner with family for consent. Although doctors spoke favourably of ACP to give patients a voice and to relieve family of responsibility, they tend not to read an ACP unless the patient is recognised as dying and either no family is available, or family request unduly burdensome medical intervention on the patient's behalf.

Systemic factors identified within this research revealed that doctors perceive the law (as it applies to Queensland ACP) as complex, while at the same time endorsing doctors' authority by giving them the power to discern and then deliver good medical practice. University curricula do not adequately prepare doctors to understand Queensland law, and Queensland Health does not deliver mandatory medico-legal education at any stage of doctors' employment. Instead, doctors spoke of being trained to treat illness, and being ill-prepared to recognise approaching death or to incorporate patients' ACP at earlier stages of decision-making. Doctors blamed limited resources, inadequate ACP processes (including construction and ongoing management or revisions), and challenges accessing their patients' ACP. Collectively, doctors de-legitimising patient-owned ACPs and instead deferred to a Queensland Health resource: the Acute Resuscitation Plan. The theoretical conclusions of this research explain the diffusion of patients' power that occurs on entry into the hospital system when a patient is unable to provide temporal informed consent to healthcare. Instead, the voice of patients, as represented within an ACP, hangs in the balance whilst bedside patient agents exercise their substituted decision-making powers. This research raises doubt about the utility of ACP to speak for people with a neurodegenerative disorder and suggests the need for a systematic, comprehensive, multidisciplinary approach to addressing the needs of all stakeholders.

Dedication

To my mother Ngaire Frances Craig (1938-2009)

and my father Colin Craig (1938-2017).

I miss you.

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Glossary

Agency. The capacity, condition, or state of acting, or of exerting power.

Autonomy. Self-rule; an individual's right to accept or reject healthcare.

Advance Care Plans in Queensland:

1. **Statutory Advance Care Plans**:

    1.1 **Advance Health Directive (AHD)** Legally binding document wherein a competent adult (the principal) states healthcare wishes or directions to be followed during incapacity. Where the principal has given directions, healthcare must be dealt with under the AHD. The AHD offers both general and terminal, incurable or irreversible condition instructions (regulated by the Powers of Attorney Act 1998 (Qld)). Queensland law offers protection where doctors overrule directions in an AHD on the grounds that the direction is uncertain or inconsistent with good medical practice (Queensland Government, 2018b).

    1.2 **Enduring Power of Attorney** (EPOA) EPOA documents (long and short forms) are used by a principal to nominate a substitute decision-maker or administrator. Although the person may record specific healthcare instructions within an EPOA, its primary purpose is to appoint a substitute decision-maker to make best interests decisions on the principal's behalf (Advance Care Planning Australia, 2018).

2. **Non-statutory Advance Care Plans**:

    2.1 **Statement of Choices (Form A)** The Statement of Choices (Form A) is a Queensland Health document which a principal uses to record their non-binding healthcare wishes, values and beliefs (Queensland Government, 2019). It is intended to guide substitute decision-makers such as doctors and patient representatives (such as family, friends and advocates, referred to in this thesis as family) (Queensland Government, 2019).

    2.2 **Statement of Choices (Form B)** The Statement of Choices (Form B) is completed by a substitute decision-maker when the principal is incompetent. This form is intended to record the perspective of a substitute decision-maker regarding healthcare that the person would most likely want.

    2.3 **Acute Resuscitation Plan (ARP).** Queensland Health form to promote: resuscitation planning; communication with patients and families; and record of a decision-making pathway (Queensland Health, 2020). It is not a legal document, however it provides clinical authority to health professionals in the event of acute patient deterioration (Queensland Health, 2020). ARP guidelines remind doctors to consider existing ACP and subsequent alignment of ARP with known patient preferences (Queensland Health, 2020).

Advance Care Planning Tracker (ACP Tracker). A Queensland Health application intended to standardise ACP storage statewide. The *ACP Tracker* is found within *The Viewer* platform.

Consumers. Individuals (patients their family or representatives) who use a healthcare service.

Inpatient. Person admitted to hospital for treatment

Life-sustaining treatment. Intervention intended to sustain or prolong life and that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation.

Neurodegenerative Disorder. A wide range of conditions that result from progressive cell and nervous system damage (such as Alzheimer's Disease, Huntington's Disease, Lewy Body Dementia, Parkinson's Disease, Motor Neurone Disease).

Principal – the person named within an ACP who is the subject of the decisions.

Statutory Health Attorney. Person with automatic authority to make health care decisions on behalf of an adult whose capacity to make such decisions is permanently or temporarily impaired.

Substitute Decision-Maker. A person appointed or identified by law to make substitute decisions on behalf of a person whose decision-making capacity is impaired.

The Viewer. A Queensland Health medical records software platform accessible to: Queensland Health clinicians, private medical specialists, ambulance paramedics, general practitioners, and registered nurses within residential aged care facilities.

List of Abbreviations

ACD	Advance Care Directive. The term used in some states and countries indicating a formalised advance care plan, equivalent to Advance Health Directive
ACP	Advance Care Plan: document communicating preferences for future medical care
AD	Advance Directive
AHC	Allied Health Clinicians
AHD	Advance Health Directive
AHC/N	Allied Health Clinician/Nurse participant
ARP	Acute Resuscitation Plan
CPR	Cardiopulmonary Resuscitation. An emergency procedure consisting of chest compressions to support oxygenation of the brain of a person in cardiac arrest.
D	Doctor participant
DNR	Do Not Resuscitate
ED	Emergency Department
EOL	End of Life. The last days, weeks or months of life
EPOA	Enduring Power of Attorney
F	Family member participant
GP	General Practitioner: doctors who treat all common medical conditions and refer patients to hospitals or specialists for specialised treatment
ICU	Intensive Care Unit
KPI	Key Performance Indicator. Measures of health service and system performance, used for performance monitoring and assessment
NFR	Not For Resuscitation
NSW	New South Wales (Australia)
PVR	Person Values Report
PWND	Person With a Neurodegenerative Disorder
QLD	Queensland (Australia)
RN	Registered Nurse
WWLST	Withholding/Withdrawing Life-sustaining Treatment

My Chrysalis Stage

Undertaking this research process necessitated a significant reduction in the time I would otherwise have spent in my loved garden. Spending time outdoors became a reward at the end of a day seated at my computer, researching. On one such garden visit I noticed the formation of a chrysalis; its symbolic alignment with my research experience immediate. This chrysalis had spent its early days, as a caterpillar, in search of, and then consuming, all that it needed to go forth in life. Once satiated and sufficiently developed, the caterpillar anchored itself to one spot and secured its vulnerable self (within a *girdle*) to continue its metamorphosis out of view. In line with my doctoral research, this chrysalis has a thorny appearance to it, which, to my mind, symbolises the prickly and uncomfortable issues and stages I have encountered at some points in my own experience of transformation. When ready, the butterfly will slowly emerge from its casing, in a process that cannot be rushed, as every struggle is necessary to ensure the strength and survivability of the butterfly.

Chapter 1: Introduction

Formal advance care planning grew out of medical, ethical and legal debates associated with patient autonomy. Although a person's right to refuse or consent to treatment was acknowledged in case law as early as 1914 (Brown, 2003); the concept of a *Living Will* was first described in a 1969 publication by a human rights lawyer, Luis Kutner (Knight, 2021; Russell, 2017). Kutner described the Living Will as "analogous to a revocable or conditional trust" relationship between patient and doctor, with patients the grantors of trust and doctors the trustees of the patient's body (Kutner, 1969, p. 552). Considered a contract, Kutner intended the Living Will to facilitate patient autonomy as well as legal protection for healthcare providers (Knight, 2021; Kutner, 1969). Thus, a competent adult could establish an advance care plan [ACP] reflecting their fundamental right to prevent unwanted or unduly burdensome medical treatments upon their body.

The public's interest in advance care planning was piqued when they became aware of the capacity of modern medical technology to suspend life indefinitely (Australian Health Ministers' Advisory Council, 2011; Russell, 2014). Influential high-profile cases such as Karen Quinlan, Nancy Cruzan, Terri Schiavo and Tony Bland brought to public consciousness the relative powerlessness associated with mental incapacity during extreme illness (Russell, 2014). Many people identified a preference for death over suspended life (Wilkinson, 2018), and community expectations that individuals should be afforded the right to autonomous health and personal decision-making intensified (Russell, 2014). What followed was advance care planning legislative frameworks and formal ACP templates which were progressively utilised globally in countries such as Canada, the United States of America, New Zealand, the United Kingdom, Germany (Wilkinson, 2018) and Australia which accepted autonomy as a cultural norm (Australian Health Ministers' Advisory Council, 2011). ACPs are now used in all Australian states and territories to give adults a voice in their future healthcare.

Advances in medicine and socioeconomic conditions in Australia have increased longevity and the likelihood of death from chronic illness rather than infectious diseases (World Health Organization, 2018). Two-thirds of all deaths in Australia occur in people aged seventy-five years and over, with major neurocognitive disorder (also referred to as dementia) and cerebrovascular diseases the second and third leading causes of mortality in this group (Health & Welfare, 2021). At the same time, advance care planning as a means of making known one's wishes despite incapacity has been associated with advancing age and chronic illness (Allner et al., 2022; Detering et al., 2019; Frost, Cook, Heyland, & Fowler, 2011; Queensland Government, 2016). More recently, legislation allowing voluntary assisted dying was passed in Victoria, Western Australia, South Australia, Tasmania and Queensland, thus facilitating a medically assisted death in adults who meet the criteria (Queensland University of Technology (QUT), 2021). Collectively, these developments indicate evolving recognition of the rights of individuals to influence their medical care and death.

Advance care planning is broadly encouraged as a means by which individuals may achieve autonomy and retain their voice in healthcare decision-making (Detering, Hancock, Reade, & Silvester, 2010; Thomas, Lobo, & Detering, 2018). People who have a chronic illness such as people with a neurodegenerative disorder, or those approaching end of life, are directly targeted via state and federal campaigns designed to reduce the likelihood of unwanted and burdensome medical interventions in a person's last days, weeks or months (Advance Care Planning Australia, 2020; Scott, Reymond, Sansome, & Miller, 2022). However, ACP take-up rates by consumers remain low (Royal Commission into Aged Care Quality and Safety, 2019; Scott, Mitchell, Reymond, & Daly, 2013) and the realization of the benefits of ACP to patients, families and healthcare services are yet to be reflected in routine clinical activities (Scott et al., 2013). One underlying assumption is that the application of an ACP during decision-making may conflict with hospitals' purpose of treating patients through medical intervention (Brinkman-Stoppelenburg, 2014). However, possible explanations for the non/application of ACP of inpatients with a neurodegenerative disorder are numerous, given the skills and intelligence of doctors, the complexity of healthcare decision-making, the potentially vague or ambiguous nature of ACPs, and the possible emotional toll associated with a person's death (Craig et al, 2019). Therefore, the perspectives of the doctors who hold responsibility for the application of ACP for this cohort remain to be better understood.

1.1 Personal and Professional Rationale for Leading Change in ACP Practice

Before undertaking this research project, I had enjoyed almost a decade as a psychologist within a Queensland public hospital system. My role is one of a specialized psychological service delivering support to people diagnosed with dementia (and their caregivers) and my goal is to assist my clients to adapt to their new reality and live their post-diagnostic best life. Dementia is typically a stigmatising illness in which people are assumed to *lose themselves, fade away,* and caregivers face *a long goodbye*. In my experience, people with dementia often retain insight into the perception of themselves as a *burden* and of others tending to assert well-meaning and increasing control over decision-making. I bring a human rights lens to my role and strive to keep the rights and perspectives of people with dementia central to all that I do. I consider myself fortunate to be trusted with the innermost narratives of such vulnerable people and to join them in a metaphorical holding of their hands as they face certain progression towards disempowerment and death.

Taking a step back in time, in 2005 my mother was diagnosed with dementia at the age of 65. My family began learning by engaging with, and bearing witness to, changes in my mother's thinking and behaviour. We attended available information opportunities, read books written by people with dementia, and attended many medical appointments. By 2008, Mum would be in permanent residential care and in June 2009, she died. During most of her illness, I was a mature-aged university student of psychology with an interest in death and dying. As a result of my experiences with Mum and our aged care system, I determined I would work in the sector, and I secured my clinical dementia support position shortly before Mum died. This role gave me opportunities to merge my personal and professional experiences, to channel what I understood of my mother's dying experience, and to lead change. The change would come too late for Mum, but I was comforted by my belief that she would have willingly offered her suffering as a learning tool from which I could pursue the greater good of others.

Mum and Dad at a family wedding in New Zealand, March 2005, at around the time of Mum's diagnosis.

Image used with consent of the owner: Debbie Marshall.

In 2012 I established the Young Onset Dementia Support Group on Facebook as an unfunded support endeavour. The goal of this page was to facilitate people diagnosed with dementia to share their ideas and potentially support each other, find their voice, and educate others (Craig & Strivens, 2016). This role taught me a great deal about the lived experience of dementia, and further, it led to establishing contacts globally and commencing numerous meaningful friendships with people diagnosed with dementia, as well as those providing care and support. People with dementia were leading a movement for their human rights to be recognised, and for "*prescribed disengagement®"* (as coined by leading dementia advocate Kate Swaffer (Low, Swaffer, McGrath, & Brodaty, 2018, p. 807)) to cease. People with dementia were often articulate, insightful, and profoundly motivating as they implored healthcare professionals to do better.

In the years which followed I became increasingly involved in both local and statewide public health service committees associated with dementia, end of life, and advance care planning. I joined the Care at the End-of-Life strategy's statewide and Cairns committees to work towards improving end-of-life care. The genesis of these committees was a recognition by Queensland Health that care at end-of-life constitutes a core component of modern health services that needed improvement (Clinical Excellence Queensland). Queensland Health invested heavily in advance care planning, establishing both interest groups and infrastructure to encourage ACP activity and improve concordance of actual healthcare with patients' preferred care. In 2015 Queensland Health established the Office of Advance Care Planning to support the establishment of a standardised statewide system of ACP (Queensland Government, 2020c). Through this infrastructure, a unified system of ACP was intended to strengthen "the capacity of health care providers to respond efficiently and effectively to the end-of-life care needs of all Queenslanders" (Queensland Government, 2020c, p. 5). Through various media promotions, consumers were encouraged to engage in ACP, and clinicians were encouraged to lodge and retrieve ACP documentation through this centralised process (Queensland Government, 2020c; Scott et al., 2022). Some regions employed Advance Care Planners, and financial incentives were paid to hospital and health services for ACP activity (Scott et al., 2022). Collectively, as I became aware of efforts by stakeholders across the state to improve services to people approaching their end-of-life, my interest in furthering a mindful approach to human rights through autonomous advance care planning was enhanced.

As a clinician motivated to empower my clients, I began raising the topic of advance care planning as a means of extending one's power beyond anticipated incapacity. For some people, their right to maintain their voice and control over future decision-making through advance care planning proved to be an uplifting and empowering undertaking. I enjoyed the satisfaction of clients feeling confident that their preferences or directions would be known and understood during times of voicelessness due to incapacity, and ultimately illness leading to their death. However, over the years, families began complaining about doctors' non-compliance with binding Advance Health Directives. I soon realized that Queensland-based research showed doctors identified Queensland legislation as too complex (White, Willmott, Cartwright, Parker, & Williams, 2016; White, Willmott, Williams, Cartwright, & Parker, 2017; Willmott, White, Parker, & Cartwright, 2011a; Willmott, White, Parker, Cartwright, & Williams, 2016), suggesting the potential for doctors to make decisions without due consideration of an ACP. Despite Queensland Health encouraging consumers and clinicians to engage in ACP, mandatory education to ensure clinicians understood ACP was not in place, leaving patients again disempowered and voiceless in the face of dominant paternalistic medical decision-making practices.

What followed were two catalyst events that occurred in 2017. Firstly, my father died after three months of refusing medical interventions intended to delay his death. During this time, I experienced the health system from the perspective of a daughter and nominated health attorney. Despite my father's treatment refusal (both directly and through his Advance Health Directive, as well as through his health attorneys), he faced the persistent and insistent treatment focus of the hospital system. Some doctors were determined and used phrases such as "but we think you should..." or "we want you to….". My father favoured quality of life over longevity, and he was irritated by the relentless medical bias towards treatment which, at best, might have provided quantity of life over quality of life. From his hospital bed he described himself as "dying from the feet up", and he felt vulnerable, disempowered, and voiceless. In the second seminal event, a client who tried to avoid the postponement of her natural death endured numerous intrusive interventions she had attempted to avoid by generating an Advance Health Directive. Ultimately, her dying was medicalised in a way that would go on to haunt her family and potentially the clinicians involved in her care. These events occurred near each other, resulting in a feeling of personal and professional impotence and a lingering question about my responsibilities in both cases, and the usefulness of ACP.

If advocating for patient choices was difficult for me, I wondered how it was for people with less healthcare system literacy. This reality triggered in me a sense of ethical dilemma. Do I continue to inform people about their right to complete a plan when I am uncertain whether their efforts will be respected? Do I avoid the topic of advance care planning and in so doing, deny people their legal and human rights, and the opportunity to feel well prepared and empowered? I was a clinician encouraging people to trust our health service, yet I had come to distrust it myself. I began incorporating the advice that ACP efficacy would most likely be enhanced by advocacy from family and health attorneys, but I was uncomfortable. People who complete an ACP may do so independently of their family, potentially to remain in control of decision-making and minimize the power of others. Further, in law, people generating a plan are not obliged to gain decision agreement from a third party. I wondered whether the time invested in advance care planning was well spent by either consumers or clinicians? I also wondered whether an ACP that was disregarded or inappropriately set aside by doctors, complicated an already difficult time for families? Accordingly, I faced tough decisions about my future in a career I considered a vocation.

At that point, the health service invited me to develop an advance care planning and healthcare consent education program to support the upskilling of clinicians. My willingness to lead this was welcomed by a hospital and health service due to undertake accreditation under the new Safety and Quality Healthcare Standards which introduced new responsibilities towards comprehensive care at end-of-life and processes for managing ACPs (Australian Commission on Safety and Quality in Health Care, 2014a). Inspired by the work of White and Willmott et al., (White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, Cartwright, Parker, & Williams, 2014; White, Willmott, Williams, et al., 2017; Willmott, White, Parker, et al., 2016; Willmott, White, Tilse, Wilson, & Purser, 2013), and mindful of the content of complaints received by the hospital and health service, in 2018 I established an education program in partnership with our hospital and health service senior legal counsel. Together we delivered education throughout the year in a program that continues within nursing orientation programs today. Conducted as a Quality Activity, data from this initiative indicated worrying gaps in knowledge (Craig & Thompson, 2020). For example, participating doctors, nurses and allied health clinicians generally did not understand the lawful hierarchy of decision-making for an incompetent person, and they did not recognise that an Advance Health Directive represented the competent voice of the now incompetent patient. Only four per cent of participants correctly identified the legislated order of substituted decision-making, and only 26 per cent were able to identify the correct decision-maker when presented with a scenario. Although evaluation data did not separate participants into disciplines, a subgroup of 35 doctors completed the survey online and their responses, disappointingly, revealed comparable errors.

I perceived a link between these knowledge gaps and the feedback from families of clients. It was then that a senior doctor/mentor suggested that to lead change, I should undertake a PhD research study on the issue.

I reflected on the concept that once aware of a problem we can be a part of the problem or a part of the solution. If I was to continue to look into the faces of people with dementia, offer them opportunities to document plans and encourage them to trust us with their health care, I must also understand the limitations of ACP and the factors associated with non/application by hospital doctors. I wondered whether doctors, bound by principle-based ethics, preferred to make health care decisions uncomplicated by the existence of binding directions or potentially misinformed requests made in advance by the patient? It seemed clear that ACPs were well intended but often failed to meet the needs of patients, their families, and the doctors tasked with incorporating them into treatment decisions. Therefore, despite deliberate steps to retain a voice, people with a neurodegenerative disorder may die disempowered by a healthcare system ethically responsible for doing no harm.

I began this research with a degree of frustration associated with hospital doctors seemingly failing people with neurodegenerative disorders by disregarding patients' tangible efforts to influence future healthcare through an ACP. I set out to explore and then explain the relationships between concepts arising from the data. I was, and remain, mindful of the complex nature of my role as both a clinician insider and a frustrated consumer advocate researcher outsider. Predictably, navigating the line between these roles and responsibilities has been a psychologically and emotionally taxing experience. This research offered me the privilege of participating in, and listening to, approximately 38 hours of interview data from consumers, allied health clinicians, nurses, and doctors. These words were often on my mind as I slept and woke. I felt drawn into the world of each respondent; I bore witness to the angst of every perspective; and much of what I thought I knew about the mechanics of ACP application was drawn into question. Of course, the importance of cognisance of the impact of in-depth, qualitative research, both personally and on the research conducted, is well known (Exley, 2004) and guidance by academic advisors was invaluable. To this end, I took a leap of faith and entered the four-year PhD adventure, well supported by an advisory team whose clinical, professional and research experience *leaned in to* all aspects of this research.

1.2 Research Aims

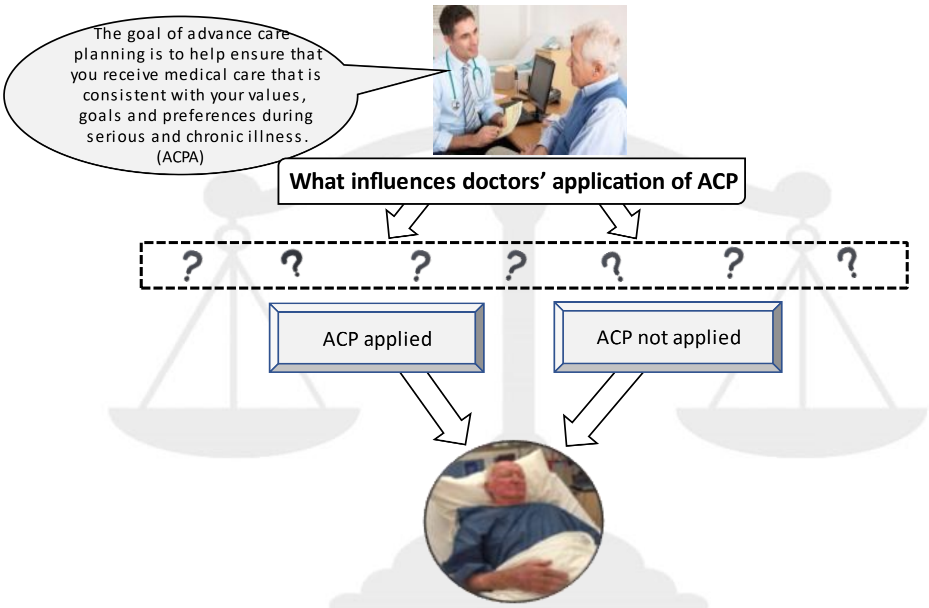
Although many people today die within a hospital setting, hospitals were not established for this purpose. Hospitals evolved as institutions where sick people would be given access to available medical expertise and care by doctors and nurses trained to help them. Therefore, Queensland's public hospitals have traditionally and justifiably held a strong medical focus on the treatment of disease and the preservation of life and health (Queensland Government, 2018b). Accordingly, I began my research intending to investigate North Queensland public hospital doctors' responses to the patient-owned, written healthcare statements (ACP) of people with a neurodegenerative disorder who presented to the hospital in an incompetent condition. The two ACP documents meeting research criteria were the Advance Health Directive and Statement of Choices.

In this research, I set out to:

- examine the enablers and barriers to doctors hearing the voice of the person with a neurodegenerative disorder who had prepared for incapacity by completing an ACP to speak for them, and
- to understand why doctors might choose an alternative mechanism of shared decision-making. On behalf of those for whom ACP has not delivered as proposed by advocates, I hoped to provide a theoretical framework through which stakeholders could better understand the lived experience of the non/application of ACP.

To achieve this, I engaged the following broad research questions:

1. What factors influence doctors to seek, read, consider and incorporate or exclude ACP from treatment decisions of people with a neurodegenerative disorder?
2. What is the process of applying an ACP to treatment decisions for people with a neurodegenerative disorder?
3. What is the role of the patient's representatives (family/friends/attorneys) in shared decision-making, when the person with a neurodegenerative disorder had completed an Advance Health Directive?



Colin Craig
Photo Credit Karen Bland

Figure 1.1: Diagrammatic representation of the research question

1.3 Background to Healthcare Decision-making during Cognitive Incapacity

The concept that people feel disempowered by the medical system is not new. Within the hospital setting, doctors have long made decisions on behalf of patients and maintained considerable power over the most vulnerable patients, particularly those without the cognitive capacity to communicate their autonomy (Buchanan, 1978; Pelto-Piri, Engström, & Engström, 2013; Savulescu, 1995). Such paternalism has been linked with care of people who are dying (Braswell, 2017), and those with highly stigmatised conditions such as mental illness (Henderson & Thornicroft, 2009; Lawrence & Kisely, 2010) and dementia (Cations et al., 2020; Swaffer, 2014, 2015). Dementia is the second leading cause of death in Australia, and it is estimated that prevalence will increase from 386,200 in 2021 to 849,300 in 2058 (Australian Institute of Health and Welfare, 2022). Despite the prevalence of dementia being such that many of us will either be diagnosed with dementia or have friends, family or associates who live with dementia, most would agree that dementia remains a highly stigmatised condition. Prominent dementia advocate, Kate Swaffer, herself living with dementia, argues that the stigma of dementia leads to lower standards of care for this group (Swaffer, 2014). Swaffer goes on to suggest that stigma primes people with dementia to become disempowered, whilst caregivers are encouraged to "take over and assume the power position in the relationship" (Swaffer, 2015, p. 5). She argues that "people with dementia must take control over their lives and futures and must take action, or others retain the control over us" (Swaffer, 2015, p. 5). Advance care planning seeks to provide people with dementia, people with a terminal or life-limiting illness, or in fact any competent adult at all, just such an opportunity to retain autonomy and control.

1.4 Autonomy

The concept of respect for a person's precedent autonomy lies at the heart of ACP. American philosophers Beauchamp and Childress espoused that autonomy (meaning self-rule) in healthcare stands as an individual's right to accept or reject healthcare (Beauchamp & Childress, 2001). This right is reflected in the common law and Queensland legislation: *Powers of Attorney Act 1998* (Qld) and *Guardianship and Administration Act 2000* (Qld). In a reaction against misplaced "bad old days" (Savulescu, 1995, p. 327) of medical paternalism and treatment futility, respecting a person's autonomy has obligated healthcare providers to obtain patients' consent to treatment, which, in many countries now includes the mechanism of ACPs (Killackey, Peter, Maciver, & Mohammed, 2020). Counter to the treatment focus of the hospital system, patients today may decline life-prolonging treatment through a binding ACP: the Queensland Advance Health Directive. This concept assumes that people are competent and can independently decide what kind of healthcare they would want in the future, and document their wishes in a meaningful way (Killackey et al., 2020). Individuals are the definitive experts in their values, goals and preferences and it is these elements that ACP seeks to make known to decision-makers. Accordingly, ACP is founded on individualistic ideals (Killackey et al., 2020), and offers competent adults an opportunity to address in advance the contentious issue of whose voice should be heard when decisions are required (Robins-Browne, Hegarty, Guillmen, Komesaroff, & Palmer, 2017).

1.5 Legislation and Autonomy

Advance directives must reflect the adult's authentic choices or they fail to represent autonomy. In Australia, three prerequisites must be satisfied at common law for an advance directive refusing treatment to be binding on a medical professional. At the time of completing the directive: the adult must have had the capacity to make and communicate their decision; been free of undue influence or other limiting factors; and intended the directive to apply in the given circumstances (Willmott, 2010). Therefore, when applying an Advance Health Directive to a clinical decision, these essential elements represent assumptions to which the treating doctor ascribes. Directions within an Advance Health Directive (such as to refuse certain treatments) can be accepted as consent to healthcare at any time during the adult's incapacity, although where a direction relates to withholding or withdrawing life-sustaining treatment, strict legal requirements must first be satisfied. Interestingly, Lindy Wilmott has argued that the principle of patient autonomy is often undermined by restrictions to the operation of ACP, such as the requirement in Queensland that a person much be "sufficiently ill" (Willmott, 2010, p. 9). In Queensland, an Advance Health Directive will only operate if the patient has a terminal illness and is expected to die within a year, is in a persistent vegetative state, is permanently unconscious, or there is no reasonable prospect for recovery. Wilmott further notes that the principles of autonomy and sanctity of life tend to conflict, yet internationally, legal rulings have consistently prioritised autonomy over the sanctity of life, even when expressed through ACP. In Queensland, legislation has limited the applicability of an Advance Health Directive in a way that redresses the autonomy versus sanctity of life power structure by prioritising the preservation of life until the patient is close to death (Willmott, 2010). In an asymmetry of power, doctors in Queensland are excused from applying directions that the doctor has reasonable grounds to consider: are uncertain, inconsistent with good medical practice, or circumstances may have changed since the Advance Health Directive was completed (*Powers of Attorney Act 1998* (Qld) s103).

It is worth remembering that by law in Australia, an adult's capacity is presumed unless proven otherwise. Although this confers considerable and well-intended power on individuals, it could also lead to unintended consequences if the adult had insufficient healthcare literacy for their ACP to reflect authentic choices. As a clinician, I have experienced that certification of the adult's capacity can occur within a brief clinical appointment wherein the doctor largely presumes the person's capacity and fails to recognise their limitations. Further, in Queensland, an eligible witness to an Advance Health Directive (such as a solicitor or Justice of the Peace) also attests to the adult's apparent capacity to understand the nature and likely effects of their decisions, however, the capabilities of such witnesses are not guaranteed (Willmott & White, 2008). Despite capacity being a legal construct, scholars Willmott and White (Willmott & White, 2008) and Barry (Barry, 2018) have warned that the practices of solicitors when certifying the capacity of persons to complete enduring documents too often fall short of best practice. Similarly, Justices of the Peace in Queensland are advised that witnesses must be satisfied that the *principal* understood the nature and effect of their decisions and has made them freely and voluntarily (Queensland Government, 2020a, p. 7).

Upholding autonomy is a fraught concept when decisions include withholding or withdrawing life-sustaining treatment of an incompetent patient. Complex healthcare consent is one clear example wherein a person's autonomy depends on their comprehension of the facts and is compromised when a person does not understand their options (Billings & Krakauer, 2011). To generate a valid Queensland ACP (either Advance Health Directive or Statement of Choices) there is no requirement in law that the person acquires or includes medical advice. Conceivably then, this may be problematic, given research indicates that people often make different decisions when given more information. For example, a randomised controlled trial by Volandes et al., (Volandes et al., 2012) which utilised video media to improve information translation pertinent to advance care decision-making of elderly aged care residents was associated with more residents choosing comfort-oriented care (80% vs 57%; P = .02) (Austin, Mohottige, Sudore, Smith, & Hanson, 2015). This result is hardly surprising in light of what Serrone et al., (Serrone et al., 2018) referred to as the Grey's Anatomy effect: modern television dramas (and undoubtedly other media (Buchbinder & Harris, 2021)) perpetuate myths about patient recovery after aggressive healthcare interventions (such as cardiopulmonary resuscitation (CPR)). The fact that education leads some people to change their decisions indicates that their autonomy was not reflected in earlier, perhaps ill-informed decisions.

1.6 Individual versus Relational Autonomy

Individualistic models of autonomy have been criticised for their failure to accommodate the reality that people engage in social processes to construct their views (Arstein-Kerslake, Watson, Browning, Martinis, & Blanck, 2017; Killackey et al., 2020; Russell, 2017). Individualistic views of autonomy can overlook the power of knowledge imbalances that typically underpin healthcare decision-making; they neglect the role of experience in expressions of autonomy; and risk eroding the very principle that ACP sought to protect (Killackey et al., 2020). Accordingly, some scholars argue that an individual's autonomy is improved by including the person's significant relationships, reflecting the relatively new concept of *relational autonomy* (Billings & Krakauer, 2011; Killackey et al., 2020; Russell, 2017). Relational autonomy imposes responsibilities on others to maintain the centrality of individuals in their healthcare (such as by respecting treatment preferences) and argues that autonomy is improved by engaging social support in the decision-making process (Killackey et al., 2020; Mackenzie, 2019). Relational autonomy is thus an umbrella term referring to a cluster of approaches that go beyond traditional theories of autonomy to recognise the context of people's lives, and importantly, to value knowledge of, and concern for, the patient (Gómez-

Vírseda, de Maeseneer, & Gastmans, 2019; Johnson, Butow, Kerridge, & Tattersall, 2016; Killackey et al., 2020; Russell, 2017).

1.7 Key Concepts of Relevance to This Research

Before proceeding it is important to explain the foundational concepts which permeate this research. Additional terms are clarified in a glossary.

1.7.1 Advance Care Planning

Advance care planning is defined as "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness." (Sudore et al., 2017). Advance care planning conversations offer opportunities for consumers to develop clarity regarding future healthcare priorities (Buck et al., 2019). Future health care refers to the care a person would or would not like to receive if they are unable to communicate preferences when a decision is required (Advance Care Planning Australia, 2020). Inability to communicate preferences may occur in the context of permanent or temporary incapacity due to illness and is typically associated with care at the end of life. Advance care planning is a voluntary process and may or may not result in a written document, however, a formalised written ACP provides a document that can be referred to by decision-makers to best understand the wishes of the incapacitated person (referred to in the *Powers of Attorney Act 1998* (Qld) as a principal) (Advance Care Planning Australia, 2020). Accordingly, ACPs are designed to represent the competent principal during incompetence.

1.7.2 Advance Care Plans (ACPs)

In Queensland, formalised ACP documents consist of the legally binding Advance Health Directive and Enduring Power of Attorney (long and short forms), and the non-binding Statement of Choices (Forms A and B) (Queensland Government, 2019). These documents are described in detail within the glossary.

Whilst Enduring Power of Attorney and Statement of Choices (Form B) both constitute *patient-owned ACPs*, these documents were excluded from this research because 1) Enduring Power of Attorney documents are used to nominate substitute decision-makers and do not typically include explicit healthcare instructions, and 2) the Statement of Choices (Form B) is completed by a third party. ACPs referred to in this thesis are the Advance Health Directive and Statement of Choices (Form A).

1.7.3 Advance Care Plans versus Advance Health Directive within this thesis

It is important to make clear at the outset that both terms *Advance Care Plan* and *Advance Health Directive* have been applied deliberately within this thesis. Where *Advance Care Plan* (ACP) is used, I am referring to the overarching concept of a person's written ACP, irrespective of the legal effect. Where *Advance Health Directive* is specified, Queensland legislation applies.

1.7.4 Capacity

Capacity is a legal term that refers to the ability of a person to understand the nature and effect of a specific decision in a particular area of their life (such as healthcare choices); freely and voluntarily make the decision; and communicate the decision (Queensland Government, 2017). Capacity can fluctuate and may be influenced by the complexity of the decision, the support available to the person, and the time the decision is made (Queensland Government, 2020b). Under the application of general principles (*Guardianship and Administration Act 2000* (Qld)), adults in Queensland are presumed to have capacity until proven otherwise. ACPs in Queensland can only operate when the principal (in this case the person with a neurodegenerative disorder) is without the capacity for the decision, and the ACP addresses the decision to be made (*Powers of Attorney Act 1998* (Qld) s36).

1.7.5 Family

The term *family* was initially applied within the published articles to minimize wordiness associated with the original terminology: "family, friends and advocates". Invitations to family participants used the term "family, carer or advocate" because the term "carer" is widely used and accepted. Accordingly, the words family and families are umbrella terms encompassing a family of choice and close significant relationships and are in no way intended to minimize the significance of non-family patient representatives. During data collection, clinicians referred to family as the patients' bedside representatives who were involved in the patient's care, however, several spoke of also establishing the identity of the patients' lawful substitute decision-maker/s.

1.7.6 Good Medical Practice

The Medical Board of Australia refers to good medical practice as doctors using their insight and professional judgement to practice medicine in a way that would meet the standards expected of them by their peers and the community (Medical Board of Australia, 2020). The *Guardianship and Administration Act 2000* (Qld) defines good medical practice as that which applies to the Australian medical profession, having regard to recognised ethical and professional standards, practices and procedures (Schedule 2, s5B). Queensland Health maintains that good medical practice requires that doctors adhere to the accepted medical standards, practices and procedures of the medical profession in Australia (Queensland Government, 2018b). All treatment decisions, including those to withhold or withdraw life-sustaining treatment, must be based on reliable clinical evidence, evidence-based practice, ethical standards and respect for the adults' wishes (Queensland Government, 2018b). The key objective of good medical practice is to serve the best interests of the patient (Queensland Government, 2018b).

1.7.7 Best Interests

Queensland Health's end-of-life guidelines state that "patient's best interests prevail" (Queensland Government, 2018b, p. 2). Beauchamp and Childress assert that the best interests standard constitutes a quality of life criterion, and, if the patient is incompetent, substitute decision-makers are responsible for determining the highest probable net benefit of available healthcare options (Beauchamp & Childress, 2001). For doctors, assessing best interests unavoidably crosses boundaries between clinical judgment and legal and ethical considerations within a subjective process (Queensland Government, 2018b). At the time of this research, the *Powers of Attorney Act 1998* (Qld) set out that in all circumstances, healthcare decisions must be consistent with the adult's best interests. After data collection, the *Powers of Attorney Act 1998* (Qld) repealed Schedule 1 which removed "best interests" terminology from the Act. The best interests term remained only within the *Guardianship and Administration Act 2000* (Qld) and only concerning children.

1.7.8 Power

In this research I define power as an individual's ability to affect something; thereby one person influencing another (Laverack, 2004, p. 34). I interpret *exercising choice* as a demonstration of power (Laverack, 2004), and *empowerment* as an act of achieving increased confidence by acquiring a sense of control over one's life or circumstances (Oxford English Dictionary, n.d. Definition 1). An individual who generates an ACP is thus applying their command of their values and seeking influence or control over the behaviour of others, such as doctors and substitute decision-makers. Accordingly, generating an ACP can be viewed as a principal exercising *power over* another person or situation "to produce intended and foreseen effects" (Laverack, 2004, p. 33; Wrong, 1988, p. 2). Traditionally, doctors have held power-over medical decisions; a power afforded to them by their status as medicine and human condition experts, rather than patient experts. The purpose of ACP is to empower consumers and to address the doctor-patient power imbalance.

1.8 Queensland Health – Organisational Structure

Queensland Health has a complex organisational structure that subdivides into 16 hospital and health services governed by their respective Boards (Queensland Government). Queensland Health refers to policies as "high level, principles-based statements that communicate the department's intent", which in turn are supported by standards and clinical guidelines (Queensland Government, 2021). Each hospital and health service maintains responsibility for clinical governance and the development and implementation of regional procedures for clinicians to follow. Clinicians are responsible for familiarising themselves with procedures (such as ACP and End-of-life procedures), which vary between hospital and health services or may not yet exist. Accordingly, current processes may not always meet the needs of patients, families, or clinicians.

1.9 Selecting a Research Methodology

No individual is more directly impacted by the process and consequences of the non/application of ACP to healthcare decisions than an incompetent hospitalised patient with a neurodegenerative disorder. Hospital doctors are the people most responsible for applying the ACP when making inpatient healthcare decisions. Doctors are not automatons or working within homogeneous groups, but rather, they are individuals interpreting complex life and death situations from their perspectives, influenced by personal, professional, historical, social, cultural and situational standpoints. As a practicing psychologist, I am motivated to achieve a deeper understanding of the *what, when, where, why and how* of human behaviour, and where appropriate, to lead behavioural change. Therefore, I needed a methodology through which I could interpret the stories of participants, and ultimately, tell a story that offers readers an opportunity to reflect on the status of autonomy of people with a neurodegenerative disorder who prepared for incapacity by generating an ACP.

To achieve my research goal of understanding the complexities of ACP application during the hospitalisation of people with a neurodegenerative disorder, I required a research methodology that would enable me to interpret the realities of key stakeholders. Sadly, families had asked, “Why were we told to get an Advance Health Directive when the doctors did not follow it”? Whilst doctors are often referred to as difficult to engage as research participants (Cook, Dickinson, & Eccles, 2009; VanGeest, Johnson, & Welch, 2007; Willmott, White, Cartwright, et al., 2016), I had a demonstrated interest in offering doctors an opportunity to explain their perspectives and I considered it feasible that people with an interest in ACP would indeed contribute to research. With this in mind, I explored qualitative methodologies and ultimately settled on constructivist grounded theory, informed by sociologist Kathy Charmaz. Espoused for its substantial focus on social processes through which poorly understood phenomena may be interpreted (Birks, Hoare, & Mills, 2019; Charmaz, 2014), constructivist grounded theory offered me tools to analyse the conditions affecting doctors’ application of ACP of people with a neurodegenerative disorder and ultimately, the construction of a theory grounded in the data. More specifically, constructivist grounded theory was chosen because of Charmaz’s systematic yet flexible approach to data collection and analysis, and her positioning of the researcher as a creative and intuitive co-participant in all aspects of the research (Charmaz, 2014; Mills, Bonner, & Francis, 2006). Charmaz’s open acknowledgement, even welcoming, of the influence of both researcher and participant on data analysis felt honest and well aligned with my position as simultaneous clinician and researcher. Importantly, her emphasis on keeping the participants and their words at the heart of all aspects of the research aligned with my vocational quest to keep the words and values of people with a neurodegenerative disorder at the centre of their healthcare decision-making.

1.10 Theoretical Perspectives Informing Research Design and Analysis

Given my goal of building a theoretical understanding of the application of ACP, I required a qualitative methodology that would enable me to make sense of complex, often sensitive, subjective experiences (Charmaz, 2014; Liamputtong, 2017; Mills & Birks, 2014). My curiosity was fostered by early multicultural influences, an interest in mortality, and experiences as both a family member and health professional. My background afforded me the privileged position of engaging (daily) with how individuals make sense of their world. Accordingly, I ascribe to the view that our beliefs are "historically and culturally affected interpretations rather than eternal truths" (Crotty, 1998, p. 64). I concluded that I needed a methodology that emphasised subjectivity in alignment with my relativist ontology and interpretive epistemology (Charmaz, 2014). I established that constructivist grounded theory would give me the tools I needed to construct a theory that explains an issue of considerable personal and professional importance.

In line with constructivist grounded theory, this research assumes the existence of multiple realities; the mutual construction of data through researcher-participant interaction; and that data is generated, relativistic, situational and partial (Charmaz, 2014). Interpretive understanding of hospital doctors' perspectives about applying or setting aside the ACP of incapacitated persons with neurodegenerative disorder required the generation of rich data and an approach that catered for the analysis of individuals' views. Data needed to be "detailed, focused and full", revealing participants' "views, feelings, intentions, and actions", thus providing a solid basis for building a significant analysis (Charmaz, 2014, p. 23). Constructivist grounded theory provided a useful structure for gathering the requisite data, for seeing the situation anew through the data, and ultimately for creating a theory that offers "credibility, originality, resonance and usefulness" (Charmaz, 2014, p. 326).

1.11 Thesis Structure

This thesis contains seven chapters that incorporate three publications (see Chapters Two and Four). Because of this, some replication was inevitable within these articles and every effort was made to minimise this. For consistency and ease of reading, the publications have been incorporated into the thesis formatting, therefore, figures, tables and reference styles have been adapted to align with the overall thesis. No other changes have been made and reference lists remain after each article.

In keeping with grounded theory methodology, I have included diagrams as *concrete images* of my ideas to assist readers to judge the power of the theoretical categories and the connections between them (Charmaz, 2014). Through these diagrams, readers might observe a degree of conceptual overlap between some categories, reflecting the nature of qualitative research which often defies discrete categorisation and instead, sections interweave. Whilst consumers are encouraged to exercise their agency in healthcare, bedside agents experience nuanced complexity in meeting their responsibilities to consumers, leading some to face longstanding moral torment. To this end, I hope readers find this thesis credible, original, and useful for driving change.

Chapter One has introduced readers to my professional and personal motivations for undertaking this research. This chapter also prepares readers by explaining the concepts and key terms and the law which underpins advance care planning.

Chapter Two contains the published scoping review which outlines scholarship within the past two decades that has addressed doctors' perspectives on the application of patient-owned ACPs. This review was restricted to countries with comparable legislation, and it details the potential usefulness and yet limited application of ACP globally.

Publication.

Craig, D. P., Ray, R., Harvey, D., & Shircore, M. (2020). Factors which influence hospital doctors' advance care plan adherence. *Journal of Pain and Symptom Management*, *59*(5), 1109-1126.

Chapter Three explains the constructivist grounded theory methodology and data collection and analysis processes undertaken in this research.

Chapter Four begins the results section of the thesis by presenting the *Human Factors* evident in the data. It begins with the final participant sample characteristics and brings together the unpublished data of people diagnosed with a neurodegenerative disorder who prepared for incapacity by completing an ACP, and two publications that incorporated findings from both clinicians and family participants.

Publications.

Craig, D. P., Ray, R., Harvey, D., & Shircore, M. (2021). Advance care plans and the potentially conflicting interests of bedside patient agents: a thematic analysis. *Journal of Multidisciplinary Healthcare*, *14*, 2087.

Craig, D. P., Ray, R., Harvey, D., & Shircore, M. (2021). Multidisciplinary Clinicians and the Relational Autonomy of Persons with Neurodegenerative Disorders and an Advance Care Plan: A Thematic Analysis. *Journal of Multidisciplinary Healthcare*, *14*, 3385.

Chapter Five presents results within what I have called *Systemic Factors* identified by this research. Systemic factors relate to the application of ACP within the context of Queensland's law, doctor's education about ACP, limited resources, accessibility of ACP, workplace culture, and the delegitimisation of patient-owned ACPs. These results will be submitted for publication in two parts during the post-thesis submission period.

Chapter Six discusses the systemic factors results detailed in Chapter Five.

Chapter Seven synopsises my research findings and presents a grounded theory of the application of ACP to healthcare decisions of patients with a neurodegenerative disorder in North Queensland public hospitals. My theoretical model explains a diffusion of patients' power which occurs on entry into the hospital system when a patient is unable to provide temporal informed consent to healthcare. Instead, the voice of patients, as represented within an ACP, hangs in the balance whilst bedside patient agents exercise substituted decision-making.

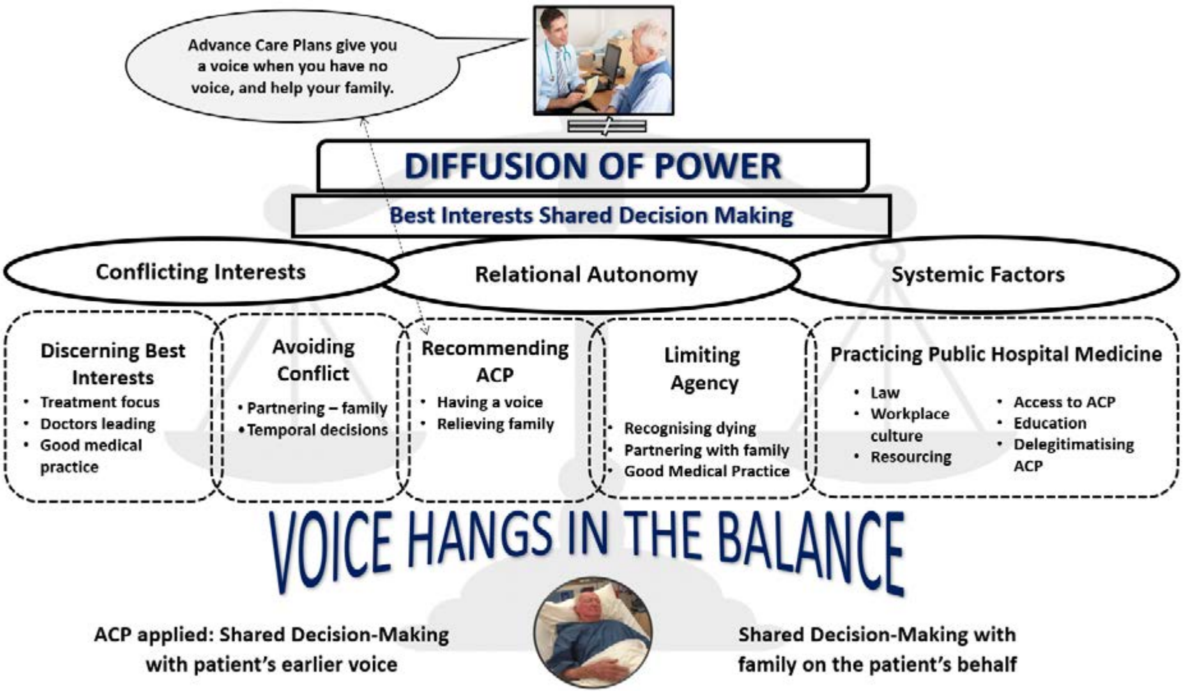


Figure 1.2: Diagrammatic representation of findings explained within this thesis

Diagrams used throughout this thesis are superimposed over justice scales to symbolize that the law underpins decision-making and the operation of ACPs. Further, I have used an image of my father, Colin Craig, taken in November 2016 during his final illness. This photo is used with the consent of my family, and the photographer, Karen Bland. Use of the doctor-patient *image included at the top of these graphics was licensed under Shutterstock agreement (see Appendix A for photo agreements).*

Chapter 2: Literature Review

2.1 Introduction

Before undertaking data collection, it was important to establish what was already known about doctors' attitudes towards the application of patient-owned ACPs. With assistance from a James Cook University librarian, I conducted a comprehensive literature search narrowed to the patient population at the centre of my research: people with a neurodegenerative disorder. This search revealed no results which met my research criteria although dementia was included within vignettes in some cases. Consequently, illness type was removed from the literature search, resulting in 2746 hits to be explored. The subsequent review of published articles revealed a dearth of relevant detailed data, leading me to conclude that qualitative research which helps to explain a complex phenomenon was warranted. Further, research restricted to neurodegenerative disorders would add important context for this particularly vulnerable population who face almost certain loss of capacity as the illness progresses. The resulting literature scoping review was published in the Journal of Pain and Symptom Management in 2020, as seen in Figure 2.1.

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Review Article

Factors Which Influence Hospital Doctors' Advance Care Plan Adherence

Check for updates

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Abstract

Context. Advances in medicine have seen changes in mortality in Western countries. Simultaneously, countries such as Australia, Canada, U.S., New Zealand, U.K., and Germany have encouraged consumer-directed care and advance care plan (ACP) completion, giving patients a voice despite incapacity. Adhering to ACPs relies on the decision-making of treating doctors, making hospital doctors key partners, and their perspectives on ACP adherence critical.

Objectives. The aim of this review was to explore and map existing research on factors associated with hospital doctors adhering to adult patients' ACPs.

Methods. A scoping review of English language publications within CINAHL, Emcare, Medline, PsycInfo, and Scopus was conducted, following PRISMA Extension for Scoping Reviews (PRISMA-ScR) guidelines. ACPs were defined as adult patient-generated, written health care directions or values statements. Studies of any design, which reported original research associated with hospital doctors adhering to ACPs, were included.

Results. Twenty-seven publications were included in the final analysis. Results suggested ACPs were thought potentially useful; however, adherence has been associated with doctors' attributes (e.g., specialty, seniority), attitudes toward ACP (e.g., applicability), and legal knowledge.

Conclusion. Current literature suggests doctors hold largely positive attitudes toward ACPs that provide useful patient information that enables doctors to make appropriate treatment decisions. Doctors often perceive limitations to ACP applicability due to legal requirements or ambiguity of patient outcome goals. J Pain Symptom Manage 2020;59:1109–1126.

Key Words
Advance directive, consent, hospital doctors, living will, patient choice, scoping review

Figure 2.1: Cover page: Factors which influence hospital doctors' Advance Care Plan adherence

What follows is the publication in full, with only minor formatting changes (as explained earlier) for consistency and readability within this thesis.

Key message statement:

This review describes factors associated with hospital doctors adhering to the written wishes/directions of patients who prepared for autonomous decision-making in advance. This study highlighted the potential usefulness of ACPs, despite limited applicability (in some situations) and ambiguous content which fails to address the needs of treating doctors.

2.2 Background

In Western countries, advances in medicine and socioeconomic conditions have increased longevity and the likelihood of death from chronic illness rather than infectious diseases (World Health Organization, 2018). The World Health Organization indicates the top three causes of death in high-income countries are lifestyle-related: ischaemic heart disease, stroke and dementia (World Health Organization, 2018). In Australia, two-thirds of all deaths occur in people aged seventy-five years and over, with debilitating dementia and cerebrovascular diseases the second and third leading causes of mortality in this group, respectively (Australian Institute of Health and Welfare, 2018).

At the same time, growing national and international interest in Advance Care Planning (Detering et al., 2019; Jimenez et al., 2018; Thomas et al., 2018) indicates burgeoning recognition of the rights of individuals to seek to influence their future treatment. In recent decades, countries such as Australia, Canada, USA, New Zealand, the United Kingdom and Germany have encouraged consumer-directed care and invested heavily in Advance Care Plan (ACP) promotion (Thomas et al., 2018). The purpose of advance care planning is to support adults of any age or stage of health to understand and make known their values, goals and preferences, so that future medical care is consistent with preferences (Sudore et al., 2017). Advance care planning is often associated with advancing age and chronic illness (Detering et al., 2019; Frost et al., 2011; 2016). ACPs are intended to communicate treatment choices of patients with impaired capacity to consent to health care (Commonwealth of Australia, 2019). To influence one's end-of-life treatment choices, when no longer competent to communicate consent, could be perceived as a final act of autonomy. Despite the potential power of a plan to communicate on a person's behalf, uptake nationally and internationally appears relatively low, albeit increasing (Detering et al., 2019; Thomas et al., 2018; White, Tilse, et al., 2014).

An individual's right to autonomy and maximal participation in their health care is a fundamental human right which is reflected in modern medical codes of ethics (World Medical Association, 2018). It is worth noting that the Medical Board of Australia (2014) explicitly lists *facilitating advance care planning* (2.1.5) and *respecting patients' rights to make their own decisions* (3.12.8) within their code of conduct (Medical Board of Australia, 2014). Further, the common law and legislation regulate an individual's right to consent to receive, withhold or withdraw health care, and the extent to which an ACP must be followed. Treatment directives are often prima facie binding, however, the degree to which they apply varies across jurisdictions. In Queensland (Australia) for example, under the *Powers of Attorney Act 1998* (section 103), doctors are not obliged to follow a directive where doing so is considered inconsistent with good medical practice. As partners in patients' medical care, hospital doctors are required to incorporate known patient preferences into treatment plans.

Despite ethical obligations that doctors incorporate patient wishes in medical decision-making, hospital doctors can face significant challenges when patients are unable to comprehend the facts and give proximal informed consent (Jimenez et al., 2018; Schoene-Seifert et al., 2016; Willmott et al., 2013). Individuals are often able to complete an ACP without medical advice, and accordingly, the usefulness of content and reliability of patient understanding of treatment consequences may be unclear (Gutierrez, 2012; Leder et al., 2015; Willmott et al., 2013). Hospital doctors require timely access to clear information and may perceive ethical dilemmas making decisions in conjunction with an ambiguous ACP (Marco et al., 2009). Ethically (and by legislation to varying effect), doctors are required to incorporate known ACPs in decision-making or risk treating in a manner which is at odds with the patient's directions/wishes (World Medical Association, 2018). Given the potential complexity of medico-legal decision-making, hospital doctors may perceive a conflict between clinical, legal and ethical decision-making (Cartwright et al., 2016; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, Williams, et al., 2017; Willmott et al., 2016), with implications for ACP-prepared patients (Jimenez et al., 2018). With the relatively recent emergence of consumer expectations of ACP-styled autonomy (Thomas et al., 2018) and ACPs of variable content and clarity (Jimenez et al., 2018), some hospital doctors may not yet be adept at incorporating ACPs in medical practice. As key stakeholders in ACP fulfilment, the factors associated with hospital doctors' adherence will be critical to plan effectiveness. To this end, hospital doctors' perspectives remain to be better understood.

2.3 Objectives

This review is intended to scope what is known about the factors associated with hospital doctors adhering to the ACPs of their adult patients.

2.4 Methods

A Scoping review was conducted, following the Arksey and O'Malley (Arksey & O'Malley, 2005) methodology.

2.4.1 Selection Criteria

Original, full text peer reviewed research that described factors associated with hospital doctors' adhering to the written ACPs of adult inpatients were included. ACP nomenclature reflected the country of origin and included Advance Health Directive (AHD), Advance Directive (AD) Living Will (LW) and Personal Values Report. ACPs were defined as written plans authored and owned by the adult patient (e.g. binding directive or written statement of wishes/values) which expressed the individual's healthcare consent/refusal or treatment preferences. Studies which included mixed participant types required data to be sufficiently separated. Only countries with comparable legislation giving the patient the power to make prima facie binding advance health care decisions were included. Papers were excluded if they were: published before 2000, opinion or discussion articles, case reports, publications in languages other than English, general practitioner doctor type, paediatric patient type, contained insufficient data clarity (e.g. failure to separate data where mixed participant types were used) and grey literature. General practitioners were excluded as they are not typically hospital doctors.

2.4.2 Selection of Sources and Evidence

A librarian assisted literature search was conducted between November 2018 and January 2019 using CINAHL (n = 116), Emcare (n = 896), Medline OVID (n = 499), PsycINFO (n = 328) and Scopus (n = 906) databases. Hand searching from reference lists of key articles and Google Scholar search was also conducted. MeSH terms were explored in Medline before keywords: doctor/physician, attitude/belief, advance care plan/living will/advance directive, decision-making, and hospital (with Boolean phrases) were searched. The year 2000 was used as a parameter with the intention to incorporate earlier seminal studies if any were identified during article review. No earlier papers meeting criteria were found. Papers published in languages other than English were excluded due to resource restrictions.

Initial screening was conducted by the lead investigator based on title and abstract. Secondary screening using full text was independently completed by two authors (DC and RR). Studies without legislation permitting prima facie binding advance health care decisions at the time of the study (Albania, Brazil, Germany/Sweden, Israel, Japan, South Korea and Taiwan) were removed. Such legislation was ascertained by online search or reported by study authors. Where data were thought potentially relevant but unclear (e.g. insufficient reporting of participant or data type), authors were contacted via email and invited to provide original data. However, no further data were provided. Wherever possible, non-hospital doctor data was excluded from review in studies which included a mixed sample (Cartwright et al., 2014; Gutierrez, 2012; Schoene-Seifert et al., 2016; Willmott et al., 2013; Zenz & Zenz, 2017). Research conducted in Queensland (Cartwright et al., 2016; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017; Willmott et al., 2016) relating to Australian specialist doctors did not collect data specifying the workplace type, however, the authors indicated a high probability that participants were treating hospital doctors and these articles were retained. Areas of uncertainty were discussed with co-authors (DH and MS) until consensus was reached.

2.4.3 Data Charting Process

For each study, descriptive data were extracted including author, year, study location, participants, study purpose, methodology, outcomes relevant to hospital doctors' adhering to ACPs (Table 2.1). The lead investigator (DC) reviewed the selected papers and coded initial thematic nodes. Papers were imported into NVivo (QSR International's NVivo 12 software) and line by line data and text was coded to thematic nodes: *attitudes towards ACPs, the impact of ACPs on treatment decisions, and the role of law in decision-making*. Utilising both NVivo and Excel spreadsheet, the lead investigator performed coding of data and text to inductively identify further concepts and themes. Codes were then compared within and across papers, classified and sorted to derive concepts and themes which added depth and variation to the initial nodes.

Table 2.1: Descriptive data of included articles

Author, date, location	Study participants	Study purpose	Methodology	Relevant outcomes
Cartwright et al. 2014 Australia (Cartwright et al., 2014)	150 GPs and 110 acute sector physicians most often involved in end-of-life e.g., ICU, emergency, anaesthetics, geriatricians, palliative care physicians, oncologists.	To assess medical practitioners' knowledge and self-reported practices in relation to ACP. ACP included use of nominated proxy decision-maker *(not relevant to this study).*	Quantitative, descriptive cross-sectional, self-completed questionnaire. Hypothetical vignette scenario. Knowledge measured by four questions and presented with two scenarios.	*Not all data separated.* Respect for patient wishes was high. A majority respect patient's autonomy and 77% would follow wishes. Older doctors were the least likely to follow ACP (28% aged <60 years would treat regardless of AD). Found age, and religious affiliation associated with response to the scenario.
Cartwright et al. 2016 Australia (Cartwright et al., 2016)	867 specialists from palliative care, emergency, geriatrics, renal, respiratory, ICU and medical oncology in Victoria, NSW and Qld, aged 29 to 83 years; 66% male/34% female.	To investigate the knowledge, attitudes and practices of medical specialists most often involved in withholding/withdrawing life-sustaining treatment (WWLST) from adults who lack capacity.	One in a series of articles relating to one foundation study. (White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, et al., 2014; White, Willmott, Williams, et	Major knowledge gaps amongst medical specialists. Palliative care and geriatrics specialists demonstrated the greatest knowledge of, and most positive attitudes towards the law, however

Author, date, location	Study participants	Study purpose	Methodology	Relevant outcomes
			al., 2017; Willmott et al., 2016) Quantitative, descriptive, self-completed questionnaire including 2 hypothetical scenarios (1 relating to AD).	36% (from palliative care) concerned law associated with inappropriate decisions. Differences between specialty groups reached significance for six of the eleven statements.
Corke et al. 2009 Australia (Corke et al., 2009)	275 Fellows and Trainees of the Australasian Joint Faculty of Intensive Care Medicine.	To evaluate how end-of-life (EOL) treatment decisions might be influenced by ACP: the appointment of a medical enduring power of attorney *(not relevant to this study)* or an ACP requesting aggressive treatment.	Mixed methods, descriptive, cross-sectional self-completed questionnaire using staged hypothetical clinical scenario, and forced choice and open questions (themes were developed).	Doctors found ACP useful (38%-47%) but had concerns re currency (>2 yrs old). 'Many' doctors perceived EOL decisions as medical decisions and ACPs as only a guide. No difference between doctor groups. Claimed patient centered decision-making.
Gutierrez, 2012, USA (Gutierrez, 2012)	14 critical care nurses, 10 ICU physicians (7 attending, 3 fellow). Ages given in a table but too small a group.	To explore the AD related experiences of critical care nurses and physicians; identify AD benefits/limitations; make	Qualitative ethnographic study using informal and formal semi-structured interviews,	All physicians held a negative view of AD. Most described ADs as useless: vague/confusi

Author, date, location	**Study participants**	**Study purpose**	**Methodology**	**Relevant outcomes**
		recommendations. *Nurses not relevant to this study.*	and review of medical records.	ng terminology, inapplicable to situation, & unable to prevent unwanted treatments outside hospital. AD seen as potentially useful for shifting responsibility for decisions to the patient.
Hadler et al. 2016, USA (Hadler et al., 2016)	69 resident and attending surgeons and anaethesiologists after interdepartmental grand rounds panel discussion of complex, end-of-life issues.	To assess attitudes of physicians towards consenting critically ill adults with AD to operating rooms.	Quantitative, descriptive, cross-sectional, self-completed multiple-choice questionnaire based on actual case studies.	Respondents perceived AD as only one part of decision-making. Only 34.8% (45.5% attending, 15.8% trainees) confirm presence of AD before treatment decisions. 36.3% anesthesiologists vs 60% surgeons would decline to perform a case if AD limited care.

Author, date, location	Study participants	Study purpose	Methodology	Relevant outcomes
Hardin & Yusufaly 2004 USA (Hardin & Yusufaly, 2004)	117 physicians:77 faculty (74% male), 40 residents (63% male) of a University Medical Center and affiliated hospitals. Age range: faculty 29-83, residents 25-46.	To assess physicians' compliance with AD using hypothetical AD, and examine their clinical reasoning.	Quantitative, descriptive, cross-sectional, self-completed surveys: 6 hypothetical scenarios with explicit AD with potential conflict between AD and (1) prognosis, (2) family/ friends wishes, (3) quality of life.	65% of decisions were inconsistent with AD (from 68% faculty & 61% residents). AD cited as determinative in 37% all physicians. 45% residents vs 32% faculty cite AD as reason, faculty cite quality of life 38% vs 28% residents. Physicians influenced by multiple factors. Level of training and experience did not significantly affect choices.
Henderson & Corke 2015 Australia (Henderson & Corke, 2015)	124 ICU consultant and registrar doctors practicing in Australia and New Zealand. 78.1% were specialists.	To determine if a patient's Personal Values Report (PVR) has a positive impact on doctors' decisions regarding treatment.	Quantitative, quasi-experimental, prospective cohort, self-completed questionnaire (open/closed questions) using hypothetical case-centered scenario.	97.6% agreed that PVR useful. Pre-PVR, 52% chose ventilation and admit to ICU, post-PVR only 8.1% chose this option (6/10 did so to allow family time to arrive). PVR impacted palliative care referral. Only 4/124 would not follow PVR. No

Author, date, location	Study participants	Study purpose	Methodology	Relevant outcomes
				significant difference by seniority
Jouffre et al. 2018 France (Jouffre et al., 2018)	66 resident ICU physicians (30 females, mean age 28, 6 months minimum ICU experience)	To explore whether personalising ADs affects ICU residents' decisions and perception of the patient.	Quantitative, experimental design. Random assignment to 1 of 3 conditions manipulating patient information using hypothetical vignette.	Physicians found AD highly relevant to decision-making. Personalising AD: reduced likelihood of it being followed; participants were less likely to stop treatment and more likely to postpone decision; no effect on consulting family. Knowing more about the patient increased perception of personal agency and experience.
Keon-Cohen et al. 2017 Australia/ NZ (Keon-Cohen et al., 2017)	290 consultant and trainee anaesthetists (Australian and New Zealand Clinical Trials Network).	To assess anaesthetists' attitudes towards NFR and ACPs in perioperative setting after legislative changes enacting the binding nature of ADs.	Quantitative, descriptive, cross-sectional questionnaire of public and private anaesthetist doctors.	75% reported low knowledge; 90% agreed ACDs important; 92% had prior exposure to ACD; 45.7% follow NFRs; 37% operating room staff

Author, date, location	Study participants	Study purpose	Methodology	Relevant outcomes
				should always commence CPR; 9% NFR or ACDs should always apply in iatrogenic complications vs 60% sometimes or rarely; 62% inadequate training; 90% agreed patient's wishes and doctors' understanding of ACPs is important; and 89% ACP should be routine part of admission. Applicability of ACPs to anaesthesia is unclear. No difference between metropolitan and regional doctors.
Leder et al. 2015 Germany (Leder et al., 2015)	25 ICU resident physicians (32% female), 14 ICU senior doctors (14.3% female), 19 relatives of ICU patient in four ICUs (mixed surgical, cardiological, & neurological) of a university hospital,.	To explore the extent to which physicians and patients' relatives agree on the applicability of AD in the acute setting.	Mixed methods prospective study by structured interview (open/closed questions) and follow-up interviews of relatives.	Relatives found AD more useful than physicians and favoured literal interpretation. Physicians and relatives differed in opinion of applicability

Author, date, location	Study participants	Study purpose	Methodology	Relevant outcomes
				of AD to situation. Most ADs do not suit ICU (terms too broad).
Marco et al. 2009, USA (Marco et al., 2009)	928 randomly selected USA emergency physicians from all 50 states. 41% practicing <10 years, 33% 10-20 years, 26% > 20 years.	To determine current CPR practice of Emergency Physicians (EPs) compared to a similar study performed in 1995.	Quantitative, descriptive, cross-sectional, self-completed questionnaire regarding AD & CPR practices. Comparator study conducted in 1995.	78% cited AD as highest impact of CPR decisions. 58% make CPR decision in fear of litigation or criticism. 98% attempted CPR in circumstances EP would not want CPR, 92% influenced by legal concerns; 86% honour AD. Compared to 1995 study, 8% more physicians honour legal AD.
Mirarchi et al. 2011, USA (Mirarchi et al., 2012)	768 faculty (38%) & residents (62%) from General Surgery (4%), Family (27%), Internal (12%) & Emergency (57%) Medicine. Mean age 36, 56% males.	To determine whether adding code status to a LW improves understanding and treatment decisions.	Quantitative, repeated measures quasi-experimental, self-completed online questionnaire using 5 fictitious LW scenarios with/without a code status & medical	Only 22% correctly assigned 'full code' to typical LW scenarios. Most doctors equated a LW with DNR, despite illness criteria for LW enactment not being met. Correctly

Author, date, location	Study participants	Study purpose	Methodology	Relevant outcomes
			context information.	answering doctors were older (41.5 ± 28.9 vs 34.5 ± 9.4) and more experienced (by up to 32%). Physician specialty differences up to 27% (Internal Medicine vs other specialties $p<0.001$).
Mirarchi et al. 2008, USA (Mirarchi et al., 2008)	73 physicians: 11 Surgery, 21 Emergency, 14 Family 12 Internal Medicine, 7 other, and 295 nurses, 91 emergency/paramedics, 4 unknowns. Mean age 38, 62% females, Intranet survey of one Level II trauma center.	To determine if a LW implies a code status before clinical interaction, & to assess how the term DNR is defined (the latter not relevant to this review).	Quantitative, descriptive, cross-sectional self-completed online questionnaire (2 versions: physician vs non-physician). Participants assigned a code status (DNR vs full treatment) to a LW, without clinical information.	*Not all data separated*. Most doctors equated a LW with DNR, despite illness criteria for LW enactment not being met. 64% incorrectly coded LW as DNR. No difference between genders. Modest effects of age & prior ACP training, & 21% divergence between specialties (55%-76% incorrectly coded a LW as DNR).

Author, date, location	Study participants	Study purpose	Methodology	Relevant outcomes
Mitropoulos 2019 Australia (Mitropoulos et al., 2019)	560 doctors (45.2% Alfred Health Vic, 54.8% ANZSGM members). Median years working 13, 49.3% males. 73.8% physicians or physician trainees, 11.4% ICU doctors, 6.1% surgical doctors.	To study level of agreement amongst doctors using ACDs to guide decisions for older patients, and evaluate factors e.g. doctors' demographics, vignette complexity, ACD content.	Quantitative, quasi-experimental, self-completed questionnaire using 3 hypothetical scenarios and 2 de-identified ACDs (1x symptom relief, 1x commence full treatment).	30.5% did not know legal standing of ACD (7% geriatrics, 42% critical care, 53% physician & 82% surgical), 63% working >10 years more likely to know law on ACD. 33% had not used an ACD, 33% had used 1-3 ACDs & 34% had used > 3 ACDs to make a clinical decision. The level of agreement on treatment decisions for older patients when using ACDs varied by vignette complexity, ACD content, specialty and seniority of physicians. No gender differences.
Qureshi et al.2013, USA (Qureshi et al., 2013)	Six stroke physicians (1 neurosurgeon, 1 neurointensivist, 4 vascular neurologists) not involved in the treatment of the patients associated with file review.	To identify the impact of existing ACD on treatment decisions within and between physicians involved in the care of stroke patients.	Quantitative, quasi-experimental. Summary of 28 consecutive stroke patients' clinical records/treatm	AD impacted use of ICU (ICU monitoring withheld 32% vs 8% if no ACD) and treatment of cardiac arrest (IV

Author, date, location	Study participants	Study purpose	Methodology	Relevant outcomes
			ent decisions rated by independent physicians +/- AD and repeated 1 month later using a crossover design. Dichotomous forced choice responses.	medication & defibrillation withheld 29% vs 19% if AD present). AD did not impact routine, moderate or high complexity treatments, nor treatment decision variance between physicians. AD documentation inadequate, and interrater reliability poor. Study did not support the use of AD as a means of influencing treatment decisions in stroke patients.
Schaden et al. 2010 Austria (Schaden et al., 2010)	139 ICU physicians (62% anaesthesiology/ICU, 30% internal medicine). 31% had no experience with AD. 10% had dealt with >10 AD in past year.	To explore Austrian ICU physicians' experiences with, and their acceptance of, AD legislation two years after enactment.	Quantitative, descriptive, cross-sectional, self-completed questionnaire of AD & CPR practices.	48% reported conflicts due to AD owing to ethical values and/or within the treatment team and/or relatives. Physicians largely honoured AD but they were unclear about laws. 73% thought ADs helpful, 47%

Author, date, location	**Study participants**	**Study purpose**	**Methodology**	**Relevant outcomes**
				recommended patients have one.
Schoene-Seifert et al. 2016 Germany (Schoene-Seifert et al., 2016)	735 (61 dementia experienced physicians, 191 dementia experienced nurses, 197 dementia-related 'next of kin', 186 dementia inexperienced community members).	To explore beliefs in relation to whether health professionals should respect valid ACP if the person has advanced dementia and appears content.	Quantitative, quasi-experimental, self-completed questionnaire using 3 variations of 1 hypothetical scenario.	73.9% physicians follow AD. *Data not adequately separated for full exploration of physician-specific outcomes.* Explicit directions (in AD) in relation to the patients' presentation associated with greater adherence to AD.
Stark-Toller & Budge. 2006 UK (Stark Toller & Budge, 2006)	43 specialist registrars (five palliative care, 14 oncology, 13 GP and 11 geriatrics).	To investigate doctors' response to, and understanding of, the legal status of AD.	Quantitative, quasi-experimental, self-completed questionnaire using six hypothetical vignettes (reported on two) with two conditions (+/- AD requesting full treatment).	Participants increased care due to AD. 77% strongly supported use of AD. 51% did not know law. 44% indicated medical school education not important influence on decision-making. AD requesting treatment can increase care however most trainees chose different level of care. 51%

Author, date, location	Study participants	Study purpose	Methodology	Relevant outcomes
				did not know legal standing of AD.
Westphal & McKee 2009 USA (Westphal & McKee, 2009)	53 surgical and medical ICU physicians within a single USA hospital. Physicians from a variety of subspecialties who care for patients in Surgical ICU (SICU) or Medical ICU. Not intensivists. 87% male.	To examine ICU physicians' and nurses' (1) knowledge about ADs and DNR, and (2) the personal factors that underlie beliefs and practices related to ADs.	Quantitative, descriptive, cross-sectional, self-completed questionnaire.	Physicians do not attach significant weight to law. Only 45% physicians ask for LW. 53% routinely read them. 90% consider the contents when making recommendations to family & 98% thought wishes should be followed.
White et al. 2016 Australia (White et al., 2016)	867 specialist doctors from palliative care, emergency, geriatrics, renal, respiratory, ICU and medical oncology in Victoria, NSW and Qld, aged 29 to 83 years; 66% male/34% female	To build understanding of the effects of law on medical specialists' decision-making in relation to WWLST from adults who lack capacity.	One in a series of articles relating to 1 foundation study. (Cartwright et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017; Willmott et al., 2016)	Reasons for actions which may not have been lawful: 38% clinically indicated; 21% family; 16% personal ethics. Remaining factors: (professional guidelines 9%, managing resources 5%; demands on clinical time 3%; religious affiliation 1%; other 7% (e.g.

Author, date, location	Study participants	Study purpose	Methodology	Relevant outcomes
			Quantitative, descriptive, self-completed questionnaire including 2 hypothetical scenarios (1 relating to AD).	views of colleagues, concern about being sued).
White et al. 2014, Australia (White, Willmott, et al., 2014)	867 specialist doctors from palliative care, emergency, geriatrics, renal, respiratory, ICU and medical oncology in Victoria, NSW and Qld, aged 29 to 83 years; 66% male/34% female	To investigate the knowledge of medical specialists most often involved in end-of-life care in relation to the law on WWLST from adults who lack capacity.	One in a series of articles relating to 1 foundation study. (Cartwright et al., 2016; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, Williams, et al., 2017; Willmott et al., 2016) Quantitative, descriptive, self-completed questionnaire including 2 hypothetical scenarios (1 relating to AD).	Doctors who practice in the EOL field have WWLST law knowledge gaps. The mean knowledge score 3.26/7. State (NSW, Victoria, Qld respectively) & specialty were strongest predictors of legal knowledge (palliative care 3.77/7 & geriatrics 3.69/7 specialists most knowledgeable, respiratory 2.68/7 least). Female sex & country of birth (Australia) weaker predictors of higher knowledge. Years of practice, age,

Author, date, location	Study participants	Study purpose	Methodology	Relevant outcomes
				country of degree & religion did not predict knowledge (data not shown).
White et al. 2017 Australia (White, Willmott, Cartwright, et al., 2017)	867 specialist doctors from palliative care, emergency, geriatrics, renal, respiratory, ICU and medical oncology in Victoria, NSW and Qld, aged 29 to 83 years; 66% male/34% female	To explore the effects of (interstate) laws and AD on medical specialists' decision-making in relation to WWLST from adults who lack capacity.	One in a series of articles relating to 1 foundation study. (Cartwright et al., 2016; White et al., 2016; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017; Willmott et al., 2016) Quantitative, descriptive, self-completed questionnaire including 2 hypothetical scenarios (1 relating to AD).	A majority (63%-72%) said they would provide treatment despite an AD refusing it. 70%-73% saw AD as relevant but other factors more relevant. Law appears to play a limited role in end-of-life decision-making with doctors prioritising patient-related (e.g. quality of life); clinical (whether treatment indicated); & personal ethical considerations.
White et al. 2017 Australia (White, Willmott, Williams, et al., 2017)	Subset of the foundation study (White, Willmott, et al., 2014): 649 acute sector specialist doctors from NSW and Victoria. Qld doctors excluded due to variation in law (AD can be	To determine whether medical specialists who know the law in relation to end-of-life care are more likely to follow it. This paper focused on AD.	Subset of a series of articles relating to 1 foundation study (Cartwright et al., 2016; White et al., 2016; White, Willmott,	Medical specialists prioritise clinical factors when confronted with a hypothetical scenario where legal compliance is

Author, date, location	Study participants	Study purpose	Methodology	Relevant outcomes
	overridden on the basis of good medical practice).		Cartwright, et al., 2017; White, Willmott, et al., 2014; Willmott et al., 2016). Quantitative, descriptive, self-completed questionnaire including 2 hypothetical scenarios (1 relating to AD).	inconsistent with what they believe is clinically indicated (72.3%). Strongest predictor specialty (palliative 50%/geriatrics 45.9% vs respiratory 20.8% & ICU 23.6%). Legally knowledgeable specialists more likely to comply with law but not motivated by law. Ethical considerations a more important influence.
Willmott et al. 2016 Australia (Willmott et al., 2016)	867 specialist doctors from palliative care, emergency, geriatrics, renal, respiratory, ICU and medical oncology in Victoria, NSW and Qld, aged 29 to 83 years; 66% male/34% female	To analyse medical specialists' attitudes towards the law on WWLST.	As with (Cartwright et al., 2016; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017), self-completed questionnaire. Mixed methodology:	Doctors attitudes towards the law were complex. Agreed law has a place in medicine. Palliative care, geriatricians & doctors aged >60 most positive attitudes to law, ICU least. No significant differences by State, gender, years in

Author, date, location	Study participants	Study purpose	Methodology	Relevant outcomes
			quantitative descriptive data, & open responses analysed qualitatively.	practice, religious affiliation, country of birth or country of degree.
Willmott et al. 2013, Australia (Willmott et al., 2013)	11 'treating or nominated' doctors & 26 AHD completers.	To explore the views of patients & doctors in relation to the Qld Advance Health Directive form.	Mixed methods using reference group, semi-structured interviews/focus groups & questionnaire.	Decisions more influenced by ethical & clinical factors than legal ones. Doctors motivated to provide best care. Themes: AHDs useful if aligned with Doctor's opinion of good care. Prefer outcome statements. Can aid communications with family. Can be unclear, request treatments not in best interest, & may not represent patient current wishes.
Wong et al. 2011, Australia (Wong et al., 2012)	388 doctors (190 fellows, 176 trainees) members of the Australasian College for Emergency Medicine.	To examine decisions & attitudes of ED doctors in relation to hypothetical AD.	Quantitative, descriptive, cross-sectional, self-completed questionnaire using 3	Complex treatment by ED doctors (AD present) vary by situation & doctor

Author, date, location	Study participants	Study purpose	Methodology	Relevant outcomes
			hypothetical scenarios. Presented & then re-presented with an AD.	seniority (consultants appeared less likely to provide vigorous treatment when patients do not want full treatment). ED doctors more influenced by clinical factors than legal obligations and usually do not seek ACP. 97% suggested a universal form and storage location. Gaps in legal knowledge. Ethical obligation the most influential factor affecting respondents' decisions.
Zenz & Zenz 2017 Germany (Zenz & Zenz, 2017)	126 physicians & 276 nurses with AD experience AD. Age range ≥ 35 - >65.	To explore palliative care professionals' views on AD.	Cross-sectional, descriptive, self-completed questionnaire [modified from Schaden et al 2010 (Schaden et al., 2010)].	Of physicians, 96.8% had treated a patient with AD, 83.3% <10. 80.% ask for the AD. 6.3% had personal issues of values conflict, 15.9% reported team

Author, date, location	Study participants	Study purpose	Methodology	Relevant outcomes
				conflicts & 39.7% family conflict. 81.7% found AD helpful, & 50.8% have their own.
Abbreviations: ACP - Advance Care Plan; AD - Advance Directive; AHD - Advance Health Directive; DNR - Do Not Resuscitate; ED - Emergency Department; EOL - End-of-Life; GP - General Practitioners; ICU - Intensive Care Unit; NFR - Not For Resuscitation; NSW - New South Wales (Australia); QLD – Queensland (Australia); PVR - Personal Values Report; WWLST - Withholding/Withdrawing Life-sustaining Treatment; USA – United States of America				

The resulting four themes were: attributes of doctors (specialty, seniority, age and religious affiliation); doctors' attitudes towards ACPs (ACPs as a guide, ACP content, potential benefits, potential negatives); factors associated with the ACP-related law (knowledge of law, attitudes towards law), and impact of ACPs on treatment.

The aim of this scoping study was to provide a descriptive account of available research, and accordingly, quality of evidence within the studies was not appraised (Arksey & O'Malley, 2005).

2.5 Results

2.5.1 Selection of Sources of Evidence

In total, 2772 articles were identified in the search strategy. The PRISMA flow diagram (Figure 2.2) outlines the process of refinement. Five hundred and thirty-one duplicates were excluded from the review. At the first stage screening, 2181 records were excluded as inclusion criteria not met. At full-text review a further 33 records were excluded. Twenty-seven studies published between 2004 and February 2019 met inclusion criteria.

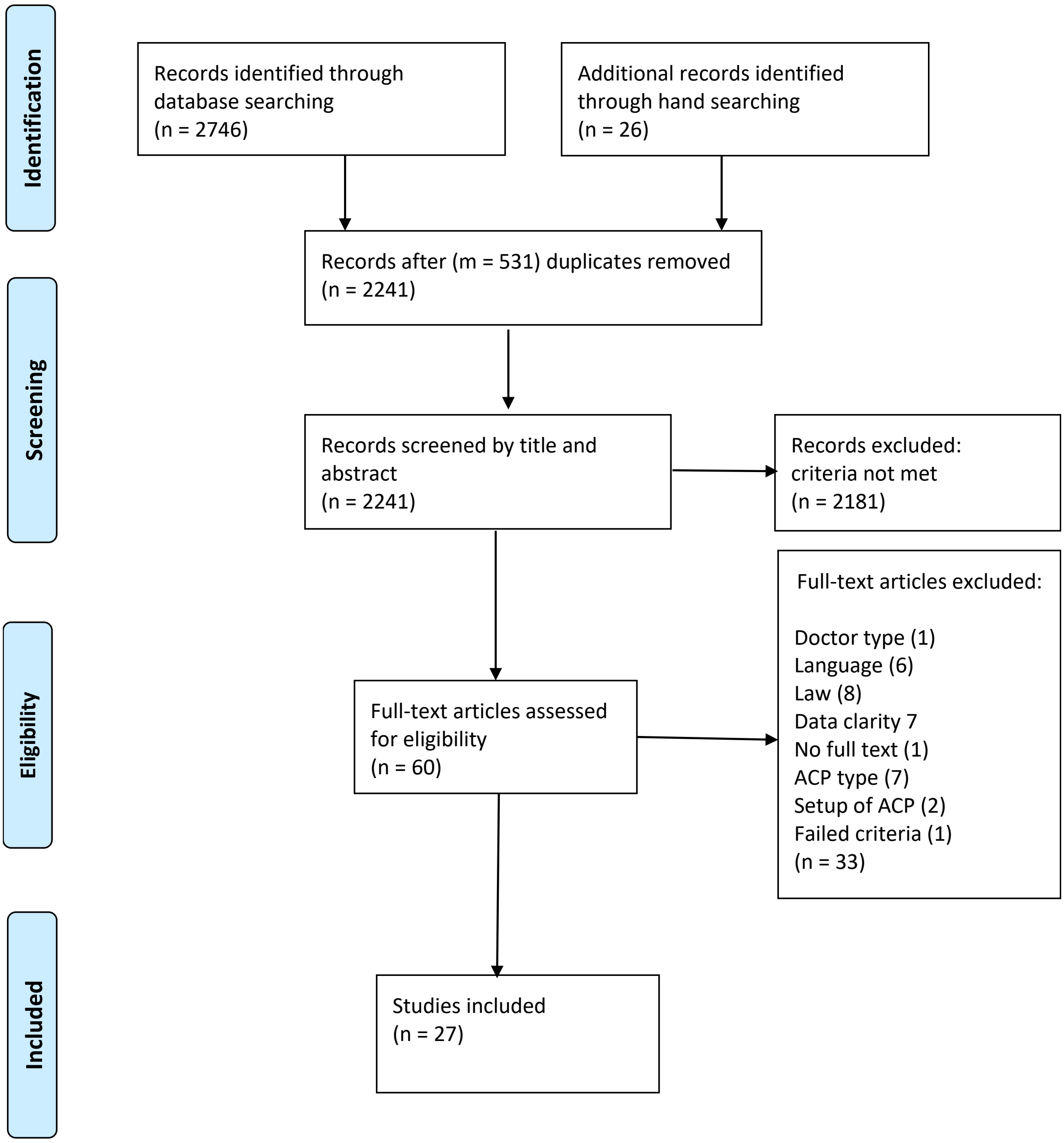

Figure 2.2: PRISMA flow diagram of search results.

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009).*P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

2.5.2 Characteristics of Sources of Evidence

Study country of origin and research methods used are summarised in Table 2.2. Thirteen studies were from Australia, although six of the 13 (Cartwright et al., 2016; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017; Willmott et al., 2016) addressed individual facets of the same foundation study. Most used quantitative research methods (n = 22). Of these, 15 were cross-sectional questionnaire style uncontrolled studies (Cartwright et al., 2014; Cartwright et al., 2016; Hadler et al., 2016; Hardin & Yusufaly, 2004; Keon-Cohen et al., 2017; Marco et al., 2009; Schaden et al., 2010; Westphal & McKee, 2009; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017; Wong et al., 2012; Zenz & Zenz, 2017), six were quasi-experimental (Henderson & Corke, 2015; Mitropoulos et al., 2019; Qureshi et al., 2013; Schoene-Seifert et al., 2016; Stark Toller & Budge, 2006) and one was experimental (Jouffre et al., 2018). Four studies utilized mixed methodology, two by questionnaire and interview (Leder et al., 2015; Willmott et al., 2013) and two using questionnaire and free text (Corke et al., 2009; Willmott et al., 2016). Only one study was fully qualitative and used formal (semi-structured) and informal (discussion whilst working) interviews (Gutierrez, 2012). Twenty-five of the studies were published between 2008 and 2019, indicating contemporary interest in the area.

Table 2.2: Country of origin and research methods summary of included studies

Characteristics	Number of studies (%)	Contributing studies
Country of origin		
Australia	13 (48.1)	(Cartwright, Montgomery, Rhee, Zwar, & Banbury, 2014; Cartwright, White, Willmott, Williams, & Parker, 2016; Corke et al., 2009; Henderson & Corke, 2015; Keon-Cohen, Myles, & Story, 2017; Mitropoulos, Parikh, Austin, Hunter, & Cairney, 2019; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White et al., 2014; White, Willmott, Williams, et al., 2017; Willmott, White, Parker, et al., 2016; Willmott et al., 2013; Wong, Weiland, & Jelinek, 2012)
United States America	8 (29.6)	(Gutierrez, 2012; Hadler, Neuman, Raper, & Fleisher, 2016; Hardin & Yusufaly, 2004; Marco, Bessman, & Kelen, 2009; Mirarchi, Costello, Puller, Cooney, & Kottkamp, 2012; Mirarchi, Hite, Cooney, Kisiel, & Henry, 2008; Qureshi et al., 2013; Westphal & McKee, 2009)
Germany	3 (11.1)	(Leder et al., 2015; Schoene-Seifert, Uerpmann, Gerß, & Herr, 2016; Zenz & Zenz, 2017)
France	1 (3.7)	(Jouffre, Ghazal, Robert, Reignier, & Albarracín, 2018)
Austria	1 (3.7)	(Schaden, Herczeg, Hacker, Schopper, & Krenn, 2010)
United Kingdom	1 (3.7)	(Stark Toller & Budge, 2006)
Research methods		
Qualitative		
Formal/informal interviews	1	(Gutierrez, 2012)
Mixed Methods		
Questionnaire/interview	2	(Leder et al., 2015; Willmott et al., 2013)
Questionnaire/free text	2	(Corke et al., 2009; Willmott, White, Parker, et al., 2016)
Quantitative		
Experimental	1	(Jouffre et al., 2018)
Quasi-experimental	6	(Henderson & Corke, 2015; Mirarchi et al., 2012; Mitropoulos et al.; Qureshi et al., 2013; Schoene-Seifert et al., 2016; Stark Toller & Budge, 2006)

Characteristics	Number of studies (%)	Contributing studies
Country of origin		
Descriptive	15	(Cartwright et al., 2014; Cartwright et al., 2016; Hadler et al., 2016; Hardin & Yusufaly, 2004; Keon-Cohen et al., 2017; Marco et al., 2009; Mirarchi et al., 2008; Schaden et al., 2010; Westphal & McKee, 2009; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White et al., 2014; White, Willmott, Williams, et al., 2017; Wong et al., 2012; Zenz & Zenz, 2017)

Twenty-six studies employed methodology which relied on self-report, with 17 of these (Cartwright et al., 2014; Cartwright et al., 2016; Corke et al., 2009; Hardin & Yusufaly, 2004; Henderson & Corke, 2015; Jouffre et al., 2018; Mirarchi et al., 2012; Mirarchi et al., 2008; Mitropoulos et al.; Schoene-Seifert et al., 2016; Stark Toller & Budge, 2006; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017; Willmott et al., 2016; Wong et al., 2012) using hypothetical vignettes to gauge responses to scenarios. One (Mitropoulos et al., 2019) included genuine de-identified ACPs, and one (Hadler et al., 2016) used actual case studies, however participant responses remained hypothetical. One small ethnographic study (Gutierrez, 2012) included a medical record review. Only one (Qureshi et al., 2013) tested the impact of an AHD using independent specialists' ratings of patients' medical records, however the treating doctors' experience was not captured.

2.6 Themes Arising from Literature

Four major themes were identified as factors associated with hospital doctors adhering to the written ACPs of inpatients.

2.6.1 Attributes of Doctors

Doctors are not a homogeneous group, but rather, they are individuals who reflect varied experience and influences. Most studies clustered doctors according to the purpose of the study, and owing to the nature of ACP adherence, participants were typically recruited from palliative care, geriatric medicine, medical oncology, renal, emergency departments (ED), Intensive Care Units (ICU), and respiratory specialties. (See Table 2.3).

Table 2.3: Participant practice area

Participant specialty/hospital unit	Number of studies	References
Specialist doctors (palliative, geriatrics, medical oncology, renal, emergency, ICU, respiratory)	6	(Cartwright et al., 2016; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017; Willmott et al., 2016)
Specialist physicians (palliative, geriatrics, oncology, emergency, ICU, anaesthetics) and GPs	1	(Cartwright et al., 2014)
Physicians (surgery, emergency, family, internal medicine), nurses and first responders.	1	(Mirarchi et al., 2008)
Attending, resident/fellow doctors (surgery, family, internal & emergency medicine).	1	(Mirarchi et al., 2012)
Physicians (and nurses) attending Palliative Care symposium	1	(Zenz & Zenz, 2017)
ICU physicians/doctors	7	(Corke et al., 2009; Gutierrez, 2012; Henderson & Corke, 2015; Jouffre et al., 2018; Leder et al., 2015; Schaden et al., 2010; Westphal & McKee, 2009)
Surgeons and anaesthetists	1	(Hadler et al., 2016)
Anaesthetists	1	(Keon-Cohen et al., 2017)
Faculty and residents	1	(Hardin & Yusufaly, 2004)
Emergency physicians/doctors	2	(Marco et al., 2009; Wong et al., 2012)
ANZSGM & health district doctors - all specialties and training levels of doctors	1	(Mitropoulos et al.)
Stroke physicians	1	(Qureshi et al., 2013)
Dementia specialist physicians, (and nurses and consumers)	1	(Schoene-Seifert et al., 2016)
Palliative, oncology, general practice and geriatric medicine specialist registrars	1	(Stark Toller & Budge, 2006)
'Treating doctors' (hospital based)	1	(Willmott et al., 2013)

Abbreviations: ANZSGM – Australia and New Zealand Society of Geriatric Medicine; GP – General Practitioner; ICU – Intensive Care Unit.

2.6.2 Influence of Specialty

Doctor specialty has been associated with variable ACP adherence. ICU doctors were the focus (Corke et al., 2009; Gutierrez, 2012; Henderson & Corke, 2015; Jouffre et al., 2018; Leder et al., 2015; Schaden et al., 2010; Westphal & McKee, 2009) or included in studies (Cartwright et al., 2014; Cartwright et al., 2016; Mitropoulos et al.; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017; Willmott et al., 2016) because of the nature of their involvement in end-of-life decision-making and therefore their status as key stakeholders in ACP adherence. Studies generally stated that ICU doctors found ACPs potentially useful and influential, depending on applicability to the situation (Corke et al., 2009; Leder et al., 2015; Schaden et al., 2010; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017; Willmott et al., 2016). End-of-life decisions within ICU were perceived as predominantly medical ones (Corke et al., 2009; Leder et al., 2015); doctors appeared to be influenced by qualitative information within an ACP (Henderson & Corke, 2015; Jouffre et al., 2018); illness complexity and uncertain prognosis associated with ICU had not been anticipated with the ACP (Leder et al., 2015); ACPs are often unavailable in emergencies and/or ACP adherence criteria (such as palliative illness) had not been met (Gutierrez, 2012; Mirarchi et al., 2012; Mirarchi et al., 2008; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017; Willmott et al., 2016).

One paper highlighted additional complexities facing anaesthetists, with ‘not for resuscitation’ orders often suspended during anaesthesia due to the nature of ventilation requirements (Keon-Cohen et al., 2017). Conversely, doctors from palliative care and geriatrics fields (where end-of-life has considerable focus) did not evidence the same depth of difficulty adhering to ACPs (Cartwright et al., 2014; Cartwright et al., 2016; Schoene-Seifert et al., 2016; Stark Toller & Budge, 2006; Zenz & Zenz, 2017). One study (White, Willmott, et al., 2014) found specialties were the strongest predictors of associated legal knowledge, with palliative care and geriatric doctors scoring significantly better than ED, renal and respiratory specialists on seven knowledge questions. Mirarchi et al. (Mirarchi et al., 2008) reported 76 percent of emergency physicians incorrectly coded DNR, despite criteria for LW enactment not being met.

2.6.3 Doctor Seniority

Doctor seniority data presented mixed results. Eighteen of the 27 studies provided participant seniority data (Cartwright et al., 2014; Cartwright et al., 2016; Gutierrez, 2012; Hadler et al., 2016; Hardin & Yusufaly, 2004; Henderson & Corke, 2015; Jouffre et al., 2018; Keon-Cohen et al., 2017; Leder et al., 2015; Mirarchi et al., 2012; Mitropoulos et al.; Stark Toller & Budge, 2006; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017; Willmott et al., 2016; Wong et al., 2012) and seven described differences between doctor groups by seniority (Hadler et al., 2016; Hardin & Yusufaly, 2004; Henderson & Corke, 2015; Leder et al., 2015; Mirarchi et al., 2012; Mitropoulos et al.; Wong et al., 2012). Of the seven, Wong (Wong et al., 2012) reported that senior doctors appeared the least likely to offer vigorous treatment (in concordance with patients' ACPs), whilst Henderson (Henderson & Corke, 2015) found no significant group differences. Conversely, Mitropoulos (Mitropoulos et al.) suggested that senior doctors were more likely to offer full treatment including ICU admission in both 'symptom relief' and 'CPR and treatment if appropriate' conditions in two out of three vignette scenarios. In a study of LW interpretation, Mirarchi et al, (Mirarchi et al., 2012) reported that Attending doctors (doctors who have completed residency) were more able than Fellow and Resident doctors (doctors undertaking specialty training) to identify correct code status in LW scenarios, although both groups had a high error rate. Hardin (Hardin & Yusufaly, 2004) reported group differences in treatment decision justification, with Residents citing Advance Directive (AD), and Faculty (specialist doctors) citing quality of life as key factors. Leder (Leder et al., 2015) recorded intergroup differences in interpretation of AD validity, and Hadler (Hadler et al., 2016) found that Attending doctors were more likely than Residents to review ACPs in preparation for treatment decisions.

2.6.4 Age

Seventeen studies included age data of participants (Cartwright et al., 2014; Cartwright et al., 2016; Gutierrez, 2012; Hardin & Yusufaly, 2004; Jouffre et al., 2018; Mirarchi et al., 2012; Mirarchi et al., 2008; Schoene-Seifert et al., 2016; Stark Toller & Budge, 2006; Westphal & McKee, 2009; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017; Willmott et al., 2016; Wong et al., 2012; Zenz & Zenz, 2017), and only three (Cartwright et al., 2014; Mirarchi et al., 2012; Willmott et al., 2016) specifically recorded age as a statistically significant factor in results. Cartwright et al. (Cartwright et al., 2014) reported that doctors aged over 60 years were the least likely to adhere to ACPs, yet Willmott (Willmott et al., 2016) found this age group held the most positive attitudes towards ACPs. Mirarchi (Mirarchi et al., 2012) reported older doctors, and those with more experience, were more likely to correctly code a LW response. One large Australian study (White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017) suggested that age did not predict doctors' 'end-of-life law' knowledge.

2.6.5 Religious Affiliation

Relatively few studies articulated religious affiliation variables amongst doctors (Cartwright et al., 2014; Stark Toller & Budge, 2006; Westphal & McKee, 2009; White et al., 2016; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017; Willmott et al., 2016). One (Cartwright et al., 2014) reported that religious affiliation was associated with participants treating patients regardless of documented ACPs, with those who identified as having no affiliation (83%) significantly more likely than doctors of 'other religions' (60%) to follow the directive. Another study (White et al., 2016) conveyed that religious beliefs were cited as the least relevant factor associated with doctors following or not following a hypothetical AHD. Three studies (Stark Toller & Budge, 2006; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017) found no statistically significant differences (one (Stark Toller & Budge, 2006) potentially due to their small sample size), and Westphal (Westphal & McKee, 2009) included religious affiliation within demographic data only.

2.7 Attitudes of Doctors towards ACPs

2.7.1 ACP as a Guide to Decision-making

Sixteen studies provided data addressing doctors' attitudes towards ACPs (Cartwright et al., 2014; Corke et al., 2009; Gutierrez, 2012; Henderson & Corke, 2015; Jouffre et al., 2018; Keon-Cohen et al., 2017; Leder et al., 2015; Schaden et al., 2010; Schoene-Seifert et al., 2016; Stark Toller & Budge, 2006; Westphal & McKee, 2009; White, Willmott, Cartwright, et al., 2017; Willmott et al., 2016; Willmott et al., 2013; Wong et al., 2012; Zenz & Zenz, 2017). Attitudes of doctors were mixed, with opinion largely associated with the degree to which the ACP was seen as supporting doctors to make appropriate treatment decisions (Cartwright et al., 2014; Corke et al., 2009; Henderson & Corke, 2015; Jouffre et al., 2018; Keon-Cohen et al., 2017; Schaden et al., 2010; Schoene-Seifert et al., 2016; Stark Toller & Budge, 2006; Westphal &

McKee, 2009; Willmott et al., 2013; Zenz & Zenz, 2017). largely associated with the degree to which the ACP was seen as supporting doctors to make appropriate treatment decisions (Cartwright et al., 2014; Corke et al., 2009; Henderson & Corke, 2015; Jouffre et al., 2018; Keon-Cohen et al., 2017; Schaden et al., 2010; Schoene-Seifert et al., 2016; Stark Toller & Budge, 2006; Westphal & McKee, 2009; Willmott et al., 2013; Zenz & Zenz, 2017). One of these (Hardin & Yusufaly, 2004) suggested the potential usefulness of an ACP as a guide, albeit with 'serious limitations'. Two studies (Keon-Cohen et al., 2017; Schaden et al., 2010) described doctors' assertions that patients should be encouraged to complete ACPs to guide future decision-making. One study (Zenz & Zenz, 2017) noted that 50 percent of doctors reported completing their own ACP.

2.7.2 ACP Content

Several studies noted doctors' concerns about ACP content. Content that specified treatment decisions was seen as unhelpful compared to patient outcome goals, the latter being seen as supporting doctors to make goal-aligned treatment decisions (Gutierrez, 2012; Henderson & Corke, 2015; Willmott et al., 2013). One (Schoene-Seifert et al., 2016) described explicit ACP directions being associated with greater plan adherence. Another (Wong et al., 2012) revealed participants wanted clear and recent information within an ACP, and similarly, patient instructions were said to be vague, contradictory and difficult to interpret (Leder et al., 2015; Willmott et al., 2013). Two studies (Gutierrez, 2012; Leder et al., 2015) noted that owing to the (commonly) standardised, non-individualised format and hypothetical nature inherent in ACPs, the contents of ACPs are often not applicable to the situation associated with hospitalization.

Several studies addressed both within and between-group ACP interpretation or applicability differences. Within doctor groups, a low level of AD interpretation agreement was recorded (Leder et al., 2015; Mitropoulos et al., 2019; Qureshi et al., 2013). Qualitative analyses confirmed interpretation difficulty for doctors (Gutierrez, 2012; Willmott et al., 2013), and some noted assertions that outcomes statements rather than treatment limitation would increase interpretability and ACP adherence (Schoene-Seifert et al., 2016; Willmott et al., 2013).

ACPs vary by legal standing, format, and content, and these factors appear to explain some variance in study results. For example, two studies (Henderson & Corke, 2015; Jouffre et al., 2018) explored the effect of providing ICU doctors with patients' written personal values information. Both studies described the addition of patients' personal information as leading to doctors' increased confidence in their decision-making. Henderson and Corke (Henderson & Corke, 2015) evaluated decisions before and after the provision of a personal values statement, finding a significant pre-post change towards following the patient's wishes. Conversely, Jouffre et al. (Jouffre et al., 2018) manipulated the personal information contained within ACPs of three experimental groups and found that personalised information led doctors to resist adhering to an ACP.

2.7.3 Potential ACP Benefits

Several studies referred to potential benefits associated with ACPs, including enhancing doctor-family communications and reframing decisions in terms of honouring patient's wishes (Gutierrez, 2012; Willmott et al., 2013). One study (Henderson & Corke, 2015) highlighted the value of clarifying patient values, and one (Qureshi et al., 2013) suggested that ACP content could be improved by patients involving doctors to guide their planning.

2.7.4 Unforeseen Consequences of ACPs

One study (Willmott et al., 2013) warned of the possible unforeseen consequences associated with ACP adherence in which unintended effects could include denial of appropriate palliative treatments. In a subsequent study (Willmott et al., 2016) which noted largely positive views about ACP laws, 50 per-cent of participants alleged that following the law could lead to inappropriate treatment. Two studies (Mirarchi et al., 2012; Mirarchi et al., 2008) highlighted a tendency for doctors to misinterpret ACPs to mean DNR.

2.7.5 Factors Associated with the Law

Numerous studies addressed issues associated with doctors' knowledge of, and implied compliance with, ACP law (Cartwright et al., 2014; Cartwright et al., 2016; Corke et al., 2009; Jouffre et al., 2018; Leder et al., 2015; Mitropoulos et al.; Schaden et al., 2010; Schoene-Seifert et al., 2016; Stark Toller & Budge, 2006; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017; Willmott et al., 2016; Willmott et al., 2013; Wong et al., 2012; Zenz & Zenz, 2017). Five studies (Cartwright et al., 2014; Cartwright et al., 2016; Keon-Cohen et al., 2017; Schaden et al., 2010; Stark Toller & Budge, 2006) exposed doctors' limited knowledge of ACPs, and 12 studies (Cartwright et al., 2014; Cartwright et al., 2016; Keon-Cohen et al., 2017; Mitropoulos et al., 2019; Schaden et al., 2010; Stark Toller & Budge, 2006; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, et al., 2014; White, Willmott, Williams, et al., 2017; Willmott et al., 2016; Wong et al., 2012) indicated that doctors have limited knowledge of ACP related law. Attitudes towards ACP laws were addressed by ten studies (Cartwright et al., 2014; Cartwright et al., 2016; Hadler et al., 2016; Marco et al., 2009; Westphal & McKee, 2009; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, Williams, et al., 2017; Willmott et al., 2016; Wong et al., 2012). Doctors were most often described as motivated by clinical and/or ethical decision-making, rather than by the law (Cartwright et al., 2016; Corke et al., 2009; Gutierrez, 2012; Hadler et al., 2016; Hardin & Yusufaly, 2004; Keon-Cohen et al., 2017; Leder et al., 2015; Marco et al., 2009; Schaden et al., 2010; Westphal & McKee, 2009; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, Williams, et al., 2017; Willmott et al., 2016; Willmott et al., 2013; Wong et al., 2012). Only one study (Leder et al., 2015) (from Germany) implied that doctors had accepted the law in relation to AD.

2.7.6 Impact of ACPs on Treatment Decisions

Within the known methodological limitations (such as self-report and hypothetical vignette), 24 studies (Cartwright et al., 2014; Cartwright et al., 2016; Corke et al., 2009; Gutierrez, 2012; Hadler et al., 2016; Hardin & Yusufaly, 2004; Henderson & Corke, 2015; Jouffre et al., 2018; Keon-Cohen et al., 2017; Marco et al., 2009; Mirarchi et al., 2012; Mirarchi et al., 2008; Mitropoulos et al., 2019; Qureshi et al., 2013; Schaden et al., 2010; Schoene-Seifert et al., 2016; Stark Toller & Budge, 2006; Westphal & McKee, 2009; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, Williams, et al., 2017; Willmott et al., 2013; Wong et al., 2012; Zenz & Zenz, 2017) described the implied impact of ACPs on treatment decisions. Seven studies reported that doctors declared largely adhering to ACP wishes/directions (Cartwright et al., 2014; Marco et al., 2009; Schaden et al., 2010; Schoene-Seifert et al., 2016; Stark Toller & Budge, 2006; Westphal & McKee, 2009; Zenz & Zenz, 2017); and conversely, others stated ACPs appeared to have little effect (Cartwright et al., 2016; Gutierrez, 2012; Hardin & Yusufaly, 2004; Keon-Cohen et al., 2017; Willmott et al., 2013). Five publications (based on three studies) (Corke et al., 2009; Hadler et al., 2016; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, Williams, et al., 2017) showed that doctors may be influenced by ACPs but often do not adhere to them. Similarly, two studies (Mitropoulos et al., 2019; Wong et al., 2012) conveyed that doctors altered hypothetical treatment decisions in response to an ACP, however responses varied by doctor attributes and situational complexity. Mirarchi et al, (Mirarchi et al., 2012; Mirarchi et al., 2008) demonstrated that doctors confuse LWs with DNRs and may fail to respond appropriately in emergent situations. In the only disease-specific study to audit the impact of AHDs on doctors' decisions (post stroke) (Qureshi et al., 2013), AHDs were judged by the specialist doctor participants as generally inadequate and not applicable in stroke scenarios.

An ACP can only impact treatment where the plan is reviewed and considered. Studies reporting this factor revealed mixed results, with doctors not typically determining the existence of ACPs in four studies (Hadler et al., 2016; Westphal & McKee, 2009; Wong et al., 2012) and routinely doing so in only one (Zenz & Zenz, 2017). Two studies evaluated the impact of adjunct personal information which may not be recorded within ACPs, such as patient sociodemographic information (Jouffre et al., 2018), and a patient statement of values (Henderson & Corke, 2015). Results were conflicted, with doctors in one study more likely to adhere to the ACP (Henderson & Corke, 2015) versus reduced adherence to the ACP in the other (Jouffre et al., 2018).

2.8 Discussion

In an age of consumer entitlement to engage in advance care planning, through which an individual expresses future healthcare consent, refusal or preference, hospital doctors maintain a critical decision-making role in ACP adherence. Conflicts can occur between patient/family, doctor and legislation when complex medico-legal and ethical situations occur during loss of decision-making capacity of the patient (Gutierrez, 2012; Hardin & Yusufaly, 2004; Leder et al., 2015). ACPs are designed for decision-making during the vulnerability of incapacity. They are often associated with end-of-life decisions, and accordingly, adherence and non-adherence could be associated with life or death consequences. This scoping review identified 27 primary studies describing factors which influence ACP adherence by hospital doctors. We identified four major themes related to medical decision-making: attributes of doctors, doctors' attitudes towards ACPs, factors associated with the ACP-related law, and the impact of ACPs on treatment decisions.

Data suggest that doctors often do not adhere to their patients' ACPs, with differences by specialty one key variable. This is hardly surprising, with a reported contrast of applicability of ACPs during acute illness (e.g. within ICU or ED) versus old age, frailty or terminal illness. Notwithstanding the perceived limited value of ACPs in ICU or ED, these specialists held largely positive attitudes towards the concept of an ACP as a tool to understand patient wishes. Doctors from palliative and geriatric care units engaged the most positively with ACPs and were also the most knowledgeable about related law. It seems feasible that doctors specializing in known end-of-life fields experience less difficulty adhering to ACPs of patients who are unavoidably approaching death, compared to specialists with a predominantly curative focus. One interpretation could be that ACPs provide a means by which doctors justify clinical decisions, but only to the extent that ACPs accord with doctors' preferences. Plans which are discordant with doctors' choices may be thought unhelpful. Accordingly, specialist doctors may be more or less challenged by ACP adherence, in part due to nuances in the cause of death within particular specialties.

Other factors help to explain the variability of results. Doctor seniority yielded mixed results and could indicate an interplay between experience, age, perceived patient outcome, and decision-making culture. In non-urgent cases, failure to incorporate ACPs in decision-making (which represents patient preferences or choices), is a denial of patient rights. Despite this, many do not routinely review ACPs (Cartwright et al., 2014; Wong et al., 2012), or include them in health care decisions (Hadler et al., 2016; Leder et al., 2015; Westphal & McKee, 2009; Wong et al., 2012). Even doctors who suggested ACPs were useful provided a (hypothetical) treatment which was at odds with the ACP (Hardin & Yusufaly, 2004; Jouffre et al., 2018; Stark Toller & Budge, 2006). Studies (Mirarchi et al., 2012; Mirarchi et al., 2008) which reported doctors wrongly assigning DNR status in response to ACP suggests serious interpretation errors by doctors. Doctors' age was not a key focus of most studies and only two linked age with ACP non-adherence (Cartwright et al., 2014; Mirarchi et al., 2012). Similarly, religious affiliation did not provide a substantial explanation for differences, with only one study (Cartwright et al., 2014) concluding religious affiliation contributed to outcomes. Given the vast array of potential demands on doctors to make timely life and death decisions, differences between cohorts are understandable. What remains unclear is the role of treatment culture (including paternalism versus shared decision-making) and the extent to which the experiences associated with medical specialties may help to explain the responses of doctors.

Doctors' limited knowledge of health care consent laws and their attitudes towards these laws, as described in several of the studies, hypothetically offers further explanation of ACP non-adherence. The tension between the role of doctors and involvement of the law in medical decision-making was evident (Jouffre et al., 2018; Marco et al., 2009; White et al., 2016; White, Willmott, Williams, et al., 2017; Willmott et al., 2016), despite the necessary role of law in society generally. Health care legislation is particularly complex, yet it is often inadequately addressed during both undergraduate education and post-graduate training (Hadler et al., 2016;

Keon-Cohen et al., 2017; Leder et al., 2015; Stark Toller & Budge, 2006). It is therefore comprehensible that some doctors feel frustrated by the additional considerations the law requires of them. Studies referred to doctors failing to comply with the law where a conflict between legislation and other factors coexisted (White et al., 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, Williams, et al., 2017). What remains largely unknown is the degree to which ACPs are reviewed and adhered to in practice, and experience and perspectives of hospital-based doctors faced with an unfamiliar patient's prior hypothetical plan.

ACPs are intended to inform treatment decisions when a person is unable to fully participate in proximal decision-making, yet they are by necessity hypothetical in nature. Doctors often expressed a positive attitude towards the concept of ACPs; however, these hypothetical prior plans were preferred only as an adjunct to medical decision-making. Positive or negative attitudes towards ACPs reflected the extent to which doctors judged the document as applicable (Gutierrez, 2012; Leder et al., 2015; Willmott et al., 2016) and aligned with the doctor's judgement (Corke et al., 2009; Zenz & Zenz, 2017). Some doctors expressed concern that people completing an ACP may not understand medical/health care choice consequences and may have completed it without medical advice. Further, doctors reported difficulty interpreting ACPs. Therefore, the execution of ACPs as a mechanism for the provision of information, possibly consent, may fail to satisfy hospital doctors. In such cases, doctors may face a complex ethical dilemma.

Generally, we assume that patients are experts in their lived experience and hospital doctors are experts in medical conditions, not necessarily the patient experience. Whilst competent adults have the right to refuse treatment within an ACP (with some variability in legal effect), doctors reported a preference for patients to state acceptable outcome goals which doctors could consider during medical decision-making. Specifically, if the doctor is aware of acceptable/not acceptable patient outcomes, the doctor can work towards this goal when prescribing medical care. The influence of ACP outcome statements on medical decision-making, however, remains to be further explored.

2.9 Limitations

Several limitations must be acknowledged. Firstly, significant efforts were made to search a range of databases, reference lists and Google Scholar using inclusive terminologies, however, sources of bias will exist. The initial screening of 2239 studies was a considerable undertaking which was completed twice by a single researcher (DC) before a secondary screening of 58 studies was undertaken by two researchers (DC/RR). Although reference lists were crossmatched to the final studies, it is possible that some relevant research was overlooked. Secondly, by limiting publications to full-text English language from the year 2000, other relevant studies may have been overlooked. Finally, study quality was not systematically assessed, and as with all scoping reviews, conclusion reliability is vulnerable to the biases of included studies.

2.10 Conclusion

This review was intended to inform approaches to improve the effectiveness of advance care planning by scoping what is known of the perspective of hospital doctors. The included studies indicated a dearth of qualitative research through which the perspective of hospital doctors, as critical stakeholders, have been explored in depth. We conclude that the factors most associated with doctors adhering to inpatients' ACPs are: attributes of doctor (e.g. specialty, seniority), attitudes towards ACPs, factors associated with the law, and the extent to which an ACP is thought applicable to a situation. Hospital doctors make critical decisions in complex circumstances including ambiguity about patient wishes/directions and outcome goals, and confusion about the legal effect. Overall, doctors appeared supportive of the concept of incorporating their patients' wishes in decision-making. In practice, inpatients might find ACP implementation is dependent on the specialty and seniority of their doctor, doctors' legal knowledge, interpretation of plan contents, and the perceived applicability of the ACP. Collectively, the issue of ACP adherence from the perspective of hospital doctors warrants an in-depth investigation.

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*Search terms applied to this review are provided in Appendix B

2.11 Chapter 2 Summary

In summary, this review led me to believe that despite the increasing implementation of ACP legislation globally, scholarship on the application of ACP in practice has prioritised quantitative methodology. Consequently, I found a paucity of research that explained doctors' beliefs, attitudes, and behaviours about the utility of ACPs in hospital practice. I determined that ACP had been requested by society and implemented by legislation without a corresponding examination of the perspective of hospital doctors who are responsible for applying ACPs. Assuming *knowledge is power* (credited to philosopher Francis Bacon (Brown, 1989, p. 3), the scarcity of qualitative research is problematic and potentially a threat to the voice (power) of the patient (the principal). Further, no studies identified within the review limited their illness focus to neurodegenerative disorders; therefore, conclusions about doctors' application of ACP within this specific consumer cohort were limited. To this end, I felt confident that my exploration of ACP application factors from hospital doctors' points of view would make a worthwhile contribution to scholarship.

Chapter 3: Methodology

3.1 Introduction

To explore the factors that influence hospital doctors' application of Advance Care Plans (ACPs), I needed a methodology that aligned with my philosophical position as a researcher and clinician (Birks & Mills, 2015; Bryant & Charmaz, 2007). I assumed a social constructivist standpoint and engaged in a qualitative, exploratory research design using constructivist grounded theory. Social constructivism recognises that individuals understand the world through experiences (Creswell, 2009), which, in this research, related to hospital doctors' application of the ACP of patients with a neurodegenerative disorder. I chose the grounded theory methodology for its capacity to explain a situation about which little is known, as demonstrated in the literature review, in a way that would inform practice (Birks & Mills, 2015; Mills & Birks, 2014; Wong, Liamputtong, & Rawson, 2017). By developing a theory, I hoped to provide a framework through which stakeholders could better understand the phenomena of decision-making for people with a neurodegenerative disorder who have an ACP. In this chapter, I justify my use of constructivist grounded theory and explain how the research was conducted.

3.2 Constructivist Grounded Theory Methodology

3.2.1 Relevance of Constructivist Grounded Theory to This Research

As stated at the outset of this thesis, constructivist grounded theory accommodated my underlying ontological and epistemological assumptions of the social and interpretive nature of experience (Charmaz, 2014). I came into this research accustomed to hearing how people make sense of their world; what they feel, think, and experience; and how they rationalise what they do. Within my clinical practice I am most comfortable engaging in a person-centred practice framework that takes full advantage of my lifelong commitment to introspection, empathy, and compassion. Additionally, I was about to navigate the line between being a clinician and advance care planner public hospital *insider*, and a curious daughter and researcher *outsider* who wanted to investigate a complex and contemporary phenomenon of doctors applying ACPs. After discussing my research goals and skills with my advisory panel, two advisors introduced me to grounded theory. Grounded theory is a method used to systematically, yet flexibly, guide the collection and analysis of qualitative data to construct theory from, and grounded in, the data (Bryant & Charmaz, 2007; Charmaz, 2014).

There are three prevailing grounded theory traditions: Classic, Straussian and Constructivist (Charmaz, 2014; Kenny & Fourie, 2015). Although these traditions share foundational similarities, they also reflect divergent philosophical underpinnings and some variation in their approach to data analysis (Kenny & Fourie, 2015). Classic and Straussian paradigms reflect positivist and post-positivist leanings (respectively), whilst constructivism (also referred to as interpretivism) assumes that people *construct* their reality (Lincoln, Lynham, & Guba, 2011). All variants of grounded theory include: engaging in constant comparative data analysis; a quest to identify emergent themes; discovery of social processes; inductive construction of abstract categories to explain processes; sampling to refine categories; and integration of categories into a theoretic framework that explains the studied process (Charmaz & Belgrave, 2012). Ultimately, the choice of which grounded theory to use needed to reflect my skills and expertise, as well as my ontological and epistemological beliefs.

I intended to explore the participants' perspectives through interviews, an approach which made sense, given my experience as a psychologist (Gough & Lyons, 2016). Within my clinical role I had observed that one-to-one meetings offer individuals rich opportunities for reflection, an advantage I required within my research also. I made an early strategic decision not to use focus groups because of anticipated challenges engaging multiple doctors simultaneously. I chose the constructivist grounded theory framework because I believed that it equipped me with the most flexible yet rigorous approach to conducting interviews, interpreting participants' explanations, and answering my research question. I was drawn to Charmaz's (2014) approach which welcomed the relativist ontological assertion that realities are multiple and constructed, and her emphasis on maintaining participants' words and presence throughout (Mills et al., 2006). Further, in contrast to Classic and Straussian grounded theory, constructivist grounded theory recognises that qualitative researchers are immersed co-participants who contribute to all aspects of the data collection and analysis including the construction of explanatory theory (Charmaz, 2014). Accordingly, constructivist grounded theory promoted the notion that I could explain factors that influence doctors' application of ACP, thereby illuminating the reasons why ACPs may not give patients a voice. Using Charmaz's (2014) methods encouraged me to be reflexive, to embrace my unique contributions to the research process, and to develop and present my interpretation of a socially and emotionally complex phenomena (Gough & Lyons, 2016; Gough & Madill, 2012). This was important to me because I witnessed a sense of confidence felt by people with a neurodegenerative disorder who made advance decisions through ACP, yet I had experienced ACPs being overlooked within the public hospital system.

The constructivist grounded theory proved to be a valuable methodology for both obtaining and engaging in the analysis of my data. With the subject matter embedded in a social context, subjectivity was inseparable from social existence (Charmaz, 2014). Just as participants offered their interpretation of their experiences, I too brought subjectivity to both the interview and analysis in a process Charmaz refers to as a co-construction. As the research progressed it became clear that tensions underpinned the presumed best interests in decision-making relating to incapacitated people with a neurodegenerative disorder. This research design enabled an inductive exploration of the perspectives of persons with a neurodegenerative disorder, family, allied health clinicians, nurses and doctors, with a primary focus on doctors as key patient agents in the context of applying ACP. In this methodology, I found the structure for seeing the situation anew through the data, and ultimately, for creating a theory that I believe offers a credible, original, resonating and useful contribution to scholarship (Charmaz, 2014; Mills & Birks, 2014).

3.2.2 Use of Literature

The use of literature review within grounded theory has been contentious. Glaser and Strauss (1967) asserted that the literature review should occur only after theory generation to avoid researchers inadvertently shaping the outcome (Charmaz, 2014). Conversely, Charmaz (2014) argued that qualitative researchers are inevitably influenced by their various experiences and knowledge, including at least a basic familiarity with the literature on their research topic. Pragmatically, institutions often require that researchers conduct a literature review to justify the research, satisfy academic milestones and inform applications for research grants (Charmaz, 2014). Accordingly, Charmaz refers to conducting an early literature review before putting the literature to one side during theory generation. In line with constructivist grounded theory, I completed a literature review before conducting my research (see Chapter Two) and repeated this process after writing my grounded theory to ensure I included all relevant scholarship. Within this subsequent review, only two new studies (Arruda, Abreu, Santana, & Sales, 2020; Moore et al., 2019) helped to inform the theory chapter.

3.3 Participant Selection and Recruitment

3.3.1 Research Location

Clinicians were recruited from two regions: Cairns and Hinterland Hospital and Health Service and Townsville Hospital and Health Service areas of North Queensland, Australia. Cairns and Hinterland Hospital and Health Service covers an area of 142,900 square kilometres and serves a population of approximately 250,000 people (Cairns and Hinterland Hospital and Health Service, 2021a). Additionally, the region boasts the largest major referral hospital in Far North Queensland which treats patients from the Torres Strait in the north, to Tully in the south (Cairns and Hinterland Hospital and Health Service, 2021b). Townsville Hospital and Health Service is home to Townsville University Hospital and covers an area of 149,500 square kilometres (Townsville Hospital and Health Service) supporting a population of approximately 240,000 people (Townsville Hospital and Health Service, 2021). During data collection, neither health service employed specified Advance Care Planners nor included mandatory ACP training within professional development or orientation programs. Consumer participants were not limited by geography; however, all were residents of Australia.

3.3.2 Inclusion and Exclusion Criteria

Given the power inherent in the application of ACP to medical care, I set out to explore the perspectives of key stakeholder groups (persons with a neurodegenerative disorder who had an ACP, family/advocates, clinicians) to enable me to better understand the complex factors associated with either the application or non-application of ACP to decisions. To keep people with a neurodegenerative disorder central to their own story, I first sought interviews with representatives of this cohort to investigate their motivations for generating an ACP and their subsequent expectations of doctors. Secondly, I sought adult family, allied health clinicians, nurses and doctors willing to share their experiences of hospital healthcare decision-making for people with a neurodegenerative disorder who had an ACP and were incompetent during hospitalisation. I strategically chose to include clinicians from two distinct Health Service regions to increase the participant pool and to ensure the anonymity of clinicians. This was important because some subspecialties involve small units where clinicians' data may be recognisable, hence including participants from another region increased the security of data. Consumer groups were not limited by geography because my objective was to understand their motivations when completing their ACP, or the apparent influence of the ACP during decision-making. Participation eligibility was established by me during the recruitment processes and confirmed during the pre-interview consent discussion.

Table 3.1: Inclusion and exclusion criteria

Participant group	Inclusion	Exclusion
Doctors from Cairns & Hinterland and Townsville Hospital and Health Services	Queensland Health Hospital doctors who have treated patients who meet the inclusion criteria, when the patient could not consent to, or refuse health care	Medical students, and non-English speakers.
Allied health clinicians and nurses from Cairns & Hinterland and Townsville Hospital and Health Services	Clinicians who have participated in inpatient care of a person who meets the patient criteria, when the patient could not consent to, or refuse, health care.	Allied health students, nursing students, and non-English speakers.
Persons with a neurodegenerative disorder from any region	Adults with capacity, self-reporting as diagnosed with a neurodegenerative disorder and having a written ACP. *In line with ethical approvals, participants with fluctuating capacity (measured using clinical judgement) required co-consent from a lawful substitute decision-maker.	A person with a neurodegenerative disorder who 1) could not consent and 2) had compromised or fluctuating capacity who did not have a substitute decision-maker; and non-English speakers.
Family from any region	Adults with capacity, self-reported as a family/carer/advocate of a person with a neurodegenerative disorder and who 1) was aware of health care prescribed/provided to a person meeting the patient criteria, in the context of a known ACP and patient's incapacity, and/or 2) could describe the reasons why the person with a neurodegenerative disorder completed an ACP.	Non-English speakers.

3.3.3 Participants with a Neurodegenerative Disorder

To establish participation consent of persons with a neurodegenerative disorder, I was guided by the principles within the *Guardianship and Administration Act 2000* (Qld) (explained in Chapter One) with which I had considerable experience. As a memory clinic-based psychologist for people with dementia, I was experienced in, and qualified to, assess capacity as part of the recruitment and consenting processes. Accordingly, I used my clinical skills to engage potential participants in discussion of sufficient detail to satisfy myself of the person's consent capacity. Before interviews, I required potential participants to demonstrate that they understood the project by explaining it in their own words and to demonstrate that participation was their choice. Potential participants were considered ineligible if they were confused about ACP, could not consent, or where capacity was fluctuating or unclear and they did not have the added consent of a lawful substitute decision-maker. Capacity was considered ambiguous for one participant, resulting in additional consent by a lawful substitute decision-maker (spouse) being obtained with the participant's approval. In another case, a person who identified as living with a neurodegenerative disorder was excluded because of his inability to demonstrate an understanding of the concept of an ACP (which he confused with his Will). In a regrettable decision made as a new researcher, an early decision was made to exclude participants who could not speak English, however, no potential participants meeting this criterion volunteered.

3.3.4 Approach to Awareness Raising, Recruitment and Sampling

All potential participants were advised that the research would explore the factors associated with doctors applying the ACP of inpatients with a neurodegenerative disorder to develop an explanatory theory. Consumers (patient and family participants) were offered a $50.00 gift card to acknowledge their time and contribution. With health service governance consent, clinicians were invited to participate in work time (see Appendix C). No other compensation was provided to participants.

In keeping with grounded theory, the initial sampling of participants was purposive. To reach consumers I approached support groups (one related to Motor Neurone Disease [MND] and another to Parkinson's Disease). At each meeting, I introduced the research and provided attendees with ethics-approved information sheets (see Appendix C). Additionally, social media page administrators of various neurodegenerative disorder support groups and community groups were contacted and asked to share the research invitation on their platform. Two dementia-related support groups did share the invitation publicly, and one Multiple Sclerosis support group shared the research invitations with selected members privately. Potential participants were invited to contact me, at which time I provided any further explanation and consent forms (see Appendix D for consent forms).

To reach clinicians, I contacted the hospital and health service departments and discipline directors by email and invited them to forward the research invitation to staff. Participants made snowball recommendations and hospital newsletters included posts promoting the research. Initial sampling involved recruiting allied health clinicians and nurses (from any hospital unit) who met inclusion criteria. Following the first six allied health clinician and nurse interviews, sampling targeted doctors from units where cognitive incapacity and end-of-life are typically encountered, such as from palliative care, emergency, geriatrics, respiratory and renal medicine, intensive care, medical oncology, neurology, and general medicine. Interviews with allied health clinicians, nurses and doctors progressed simultaneously for the duration of data collection.

Theoretical sampling was utilised to obtain further pertinent data as the research progressed (Charmaz, 2014). In some cases, clinicians reported that they did not meet inclusion criteria themselves, however, they offered insights that helped to guide theoretical sampling, and some provided potential snowball recruitment referrals. Theoretical sampling occurred iteratively as the requirement for further information within emerging categories became apparent. For example, some doctors identified other subspecialties (such as respiratory and renal, surgeons, cardiologists, and oncologists) as important disciplines to include in the research. Additionally, some doctors advised that overseas trained doctors would be likely to provide useful insights into medico-legal aspects of the research. Similarly, the importance of including the perspectives of social workers and speech pathologists became evident during data analysis, resulting in the theoretical sampling of these disciplines. Charmaz defines theoretical sampling as “seeking and collecting pertinent data to elaborate and refine categories in your emerging theory” (Charmaz, 2014, p. 192). Theoretical sampling occurred by emailing information sheets to departmental directors and responding to snowball recommendations from participants. In all cases, potential participants were invited to contact me for further information or to discuss participation. Theoretical sampling continued until the research team agreed that sufficient data had been obtained and no new insights were evident, therefore data saturation according to Charmaz’s definition had been achieved. Charmaz (2014) asserts that saturation can be concluded when new data no longer sparks new theoretical insights or properties and the researcher has defined, checked, and explained relationships between and within theoretical categories.

3.3.5 Recruitment Challenges

Several recruitment challenges occurred which were not resolved. Firstly, given there is no legal requirement that people discuss their ACP with family, I considered it likely that some consumer participants would have generated an ACP without discussing it with family, however this scenario was not reflected by participants. Further, some individuals may generate an ACP to exclude family from future decision-making, although I found no direct evidence of this within the literature and no such perspective was presented by participants with a neurodegenerative disorder. Given the role of ACP in upholding a person's autonomy, it is unfortunate that I was unable to recruit participants with a potentially novel perspective such as those described.

Secondly, I had anticipated restricting family participants to the North Queensland region. However, this group was difficult to recruit, leading to a research amendment removing geographical restrictions. Additionally, family members who may have chosen to set aside an ACP did not participate in this research. This was unfortunate, given that clinicians often referred to family members as key antagonists to the non-application of ACP to treatment decisions. It is possible this cohort did not realise their eligibility to participate in the research, given that the research sought to address what families observed during hospitalisation when the ACP might reasonably have been expected to take effect.

Thirdly, I was unable to recruit participants from some of the medical subspecialties which were recommended, namely doctors from the respiratory and renal speciality, and surgeons. Only one doctor contacted me to advise that he was aware of the research and the importance of it but he was not confident that he had a relevant experience which amalgamated an incompetent person with a neurodegenerative disorder and an ACP. Additionally, for reasons unknown, junior doctors were difficult to recruit. Despite the snowball referral efforts of several participating consultants, only one junior doctor participated and in so doing, provided invaluable insights contained within the longest of all doctor interviews.

Finally, in a surprising response from the administrator of a Facebook neurodegenerative disease support group, the promotion of the research was declined because the illness in question was listed last amongst several examples of neurodegenerative disorders used to promote this research. Despite my offer to amend relevant materials to change the order of examples, no further correspondence from the administrator was received. Similarly, other attempts to contact a Facebook administrator associated with a different disorder went unanswered. This was unfortunate, given some people with a neurodegenerative disorder have strongly argued for a "nothing about us without us" approach (Bryden, 2016, p. 7; Dementia

Alliance International, 2015) and Facebook promotions might have provided consumers with an opportunity to contribute their voices to this research.

3.4 Data Collection

3.4.1 Interview Structure

A foundational interview guide was initially developed based on the collective personal, professional and research experience of myself and my primary advisor (RR), as well as the outcome of the scoping review. Using a grid that provided prompt topics (such as the impact of the law and the role of the family in decision-making), questions were phrased to suit the participant type, such as doctors versus consumers (see Appendix E). A pilot study of the initial interview guide commenced in October 2019 and included five participants across both regions: two senior doctors, an allied health clinician, a family member, and a person with a diagnosis of dementia. The purpose of the pilot stage was to establish the effectiveness of the guide and to invite participants' feedback, such as suggested prompts I could consider in future. Data from one pilot interview were excluded from analysis because the doctor involved consented only to a practice interview and to provide me with constructive feedback. The subsequent four participants (interviewed between November 2019 and January 2020) consented during the preliminary discussion to support the pilot phase and have their data included in the research. Guides were adapted slightly to incorporate suggestions received from pilot participants, such as asking participants about their attitudes toward death and dying. Similarly, consumer interviews commenced in November 2019 to support interview development. Consumers were asked to explain their expectations of future decision-makers in the context of having an ACP. Throughout the research, data from allied health clinicians, nurses and consumers were used to help inform questions that were asked of doctors and for triangulation of the analysis (Creswell & Poth, 2018).

Data were collected through in-depth, semi-structured interviews. Owing to the nature of my relationship with one participant, my primary advisor (RR) conducted that interview and securely transferred the digital recording to me on completion of the interview. Before each interview, consideration of what was already known about the participant (such as the discipline of the clinician or diagnosis of the consumer) was used to tailor an interview guide. Questions were primarily open in nature and designed to elicit participants' perspectives on aspects such as medical practice concerning ACP; attitudes towards, and knowledge of, ACP and associated law; the role of various stakeholders in decision-making; and the impact of patient diagnosis. I emphasised that I sought all perspectives: I wanted to understand all factors and ultimately to lead change in support of all parties. Although the foundation questions remained largely the same, modifications to guides ensured that subsequent interviews explored emerging areas and thus helped in the construction and refinement of the resulting theory (Charmaz, 2014; Chun Tie, Birks, & Francis, 2019).

During interviews, participants were invited to explain further, develop their ideas or clarify points raised, which at times took interviews in unexpected directions and provided new topics to be canvassed (Charmaz, 2014). For example, doctors frequently confused patient-owned ACP with hospital-completed Acute Resuscitation Plans (ARPs) and although my definition of ACP was reiterated to participants, in time this blurring of ACP boundaries led to theoretical insights. Additionally, some doctors included reference to stroke as a common neurodegenerative condition, the inclusion of which was initially, arguably, unclear. This response pattern led to a revision of my ethical approvals to broaden the research's illness criterion from disease to disorder. This amendment, approved in October 2020, clarified the inclusion of stroke (see Appendix F for all research ethics and site-specific approvals).

3.4.2 Conducting the Interview

As a clinician, in-depth interactions with consumers take a different form from that of the qualitative researcher. My skills as an interviewer, therefore, were developed progressively during the research. Interpersonal communication skills typically used as a clinician (such as active listening) were honed to develop trust. However, my transition to researcher required a reflexive approach to my dual relationships to address any potential ethical conflict. To manage this, I provided full disclosure of my dual roles and research goals, engaged in external review with my primary advisor (RR) and resisted advising participants when asked (National Health Medical Research Council, 2007 updated 2018; Yanos & Ziedonis, 2006). In several cases, I provided suggestions after the interview to support the needs of the participants. For example, one participant expressed a desire to revise her Advance Health Directive and I recommended that she discuss this with her GP, whilst some clinicians asked how to locate ACPs within medical records and this question was answered. All participants were asked whether they consented to a second interview or further contact to clarify ideas if required, and all agreed. One doctor was approached via email for clarification of his comments, and in conjunction with his responses, minor amendments were made to his data to ensure clear communication of his ideas. In several cases, participants were contacted a second time to clarify demographic information.

Data gathering for this research was unexpectedly accelerated by the onset of COVID-19. Interruptions to the health service business as usual resulted in the cancellation of meetings and travel which allowed doctors greater availability than anticipated. Despite initially expecting that recruitment would occur over three years, this phase was contained within one year. As a result, some interviews occurred close to each other. In one case, two interviews were scheduled for the same afternoon because two doctors offered their time on the same day. Although this was always a risk, I did not want to delay any interviews in case the situation changed, such as work pressures increased and participation was disrupted. On the day that these interviews took place, the first interview was delayed when the doctor arrived late due to clinical obligations. This resulted in only minutes to spare between both interviews, during which I did not have time to reflect, record field notes and prepare adequately for the second interview. Feeling in any way ill-prepared was personally taxing because I was mindful that participants were generously giving their time, and I expected perfectionism of myself in return. Following constructivist grounded theory reflexivity, I engaged in reflection and recorded field notes and impressions within memos as soon as possible after interviews.

3.4.3 Interview Location

Participants were invited to choose their preferred mode of interview (face-to-face, online or by telephone) and if face-to-face, their preferred location (such as in a health service office or the consumer participant’s home). Some participants engaged from another region which limited their choice of mode. Interviews occurred at the time most convenient to participants, however, to accommodate physical distancing, Queensland Health promoted the use of the Microsoft Office TEAMS platform, and this became the preferred modality for clinician interviews.

Although face-to-face meetings were initially my preferred mode of interview, for clinicians, the occasional interruptions of others entering the room impacted the flow of discussion. In contrast, embracing available technology (such as TEAMS) provided participants with additional control, such as doctors briefly muted the interview if they were interrupted by a call or similar disturbance. Clinicians’ ability to mute the connection ensured their conversation was not overheard and confidentiality was not compromised. Further, TEAMS provided me with more opportunities to write notes during the interview. The use of communication technologies such as computer-based programs and social media has been recognised as valuable tools in qualitative research because they can assist researchers to engage participants and reduce geographical barriers (Gemignani, Brinkmann, Benozzo, & Cisneros Puebla, 2014; Jowett, Peel, & Shaw, 2011).

In relation to consumer interviews, participants in Cairns were interviewed face-to-face in either their home or a private office within my workplace, and most participants from other regions engaged via a James Cook University-facilitated secure ZOOM portal. No visual recording of screen-based interviews occurred. Home-based interviews had the advantage of helping participants to feel comfortable, such as by sharing a pot of tea and I was shown photos of the deceased person with a neurodegenerative disorder to help me connect with their story. Two participants were interviewed together (a person with a neurodegenerative disorder and his wife) in line with their preferences, and one person with a neurodegenerative disorder requested an urgent telephone interview to take advantage of his relatively strong communication ability on that day. In one ZOOM interview, however, the recording failed when I used a headset to ensure I could most clearly hear the participant. My error was realised immediately after the interview, and I apologised to the participant (a person with a neurodegenerative disorder) who responded that she had enjoyed the discussion and she would welcome another interview. This was agreed and a second interview occurred five months later. Additionally, email also proved to be a useful tool. One consumer wrote a detailed letter expressing his feelings and beliefs about his experience which he invited me to incorporate into his interview data, however, emails did not add further content to the interview data.

3.4.4 Duration of Interviews

The duration of interviews ranged from 17 to 73 minutes and averaged 50 minutes. The 17-minute interview was that of a person with a neurodegenerative disorder who had difficulty speaking and kept his answers brief. This participant was given every opportunity to take his time when responding, and he expressed that he had answered as desired and did not have anything further to add. The longest interview was that of a family member who had experienced the non-application of an Advance Health Directive within the research region. All interviews were digitally recorded on two Olympus WS-852 digital voice recorders. I transcribed four initial (pilot) transcriptions and 15 interviews that occurred during later stages. All remaining interviews were professionally transcribed by an external transcription service, made possible by limited university funding, which provided welcome relief from the time-consuming task of transcribing digital recordings. All transcripts were checked against the audio file, errors corrected, and additional impressions written into memos.

3.5 Data Analysis

3.5.1 Initial and Focused Coding

In keeping with the principles of constructivist grounded theory, coding progressed in a nonlinear, iterative process which evolved from initial through to focused coding and category development (Birks & Mills, 2015; Charmaz, 2014; Saldaña, 2016). The coding of interviews was approached chronologically, and I utilised NVivo Pro software© (Version 12) to assist me to organise the data. Initially, all transcripts were coded in full, line by line (Charmaz, 2014). Reflecting my inexperience, this approach often resulted in multiple codes per line. As a researcher new to grounded theory, I was mindful of Charmaz's contention that I must maintain an open mind, stay close to the data, and make constant comparisons between data. I reasoned that it was better to be too thorough (if that was possible) than to make a misguided conceptual leap. Further, I remained cognisant that codes must arise from the data (not my expectations) and that I must not force data to fit preconceived codes. My primary advisor (RR) independently coded nine transcripts (20 per cent), and the resultant similarities and differences were discussed and resolved as a team. Wherever possible, in vivo codes that captured the words or phrases used by participants were embedded as codes. As my experience developed and I could identify how my codes coalesced (Charmaz & Thornberg, 2021), I moved beyond literal line by line coding to coding full sentences, paragraphs or sections. Fortnightly discussions with advisors provided ongoing opportunities as a team to discuss data collection, my impressions, and emerging ideas which led to a refinement of areas of interest. Often, discussions were conceptualised in the form of diagrams which were again shared with advisors, discussed, and refined.

As indicated earlier in this chapter, for a period of two weeks (April to May 2020) I faced an influx of data which left insufficient time between interviews to adequately analyse the new data. During the times when doctors were available and interviews occurred in proximity, I maintained only dot point data summaries and memos until I could resume my typical, detailed record-keeping. I replayed the recorded interviews as soon as possible and at least twice, elaborated on memos recorded initially as dot points, and proceeded to compare data with data and extant codes (Charmaz, 2014). I read and reflected on transcripts until I knew many sections verbatim.

As interviews were coded and memos documented, initial codes were studied and compared against each other and the data (Charmaz, 2014). After seven months of data analysis, I had amassed an unwieldy sum of codes. To help me to manage this stage, I returned to helpful texts such as Charmaz (2014) and Saldana (2016) for guidance. Through reflexivity, engaging with texts and discussion with my advisory team, it was decided that I would review all codes and discern the issues that appeared most pertinent to participants. I engaged several questions which helped me to identify themes arising in the data (Charmaz, 2014). For example, I considered what processes were evident; how the processes developed; how the participant acted, what his/her behaviour might indicate; when, why and how the process might change; and what the consequences of the process appeared to be (Charmaz, 2014). I revised my codes and recognised that many were descriptive rather than analytic. With a renewed focus, I prioritised using gerunds to assist me to recognise the actions inherent in the process and I identified which codes to explore as tentative categories (Charmaz, 2014). Initial codes which made the most analytic sense and appeared to be the most important were marked as focused codes, and some codes were then subsumed within these focused codes (Charmaz, 2014; Charmaz & Thornberg, 2021). I set aside codes that appeared unhelpful and organised data within higher-level analytic categories. As espoused by Charmaz (Charmaz, 2014; Charmaz & Thornberg, 2021), selecting categories sped up the process of working with larger clusters of data. Nevertheless, exemplar memos dated 6 September 2020 and 18 June 2021 highlight some of my early grappling with analytic concepts which Charmaz contends is an important part of constructivist ground theory (see Appendix G).

Through the grounded theory process of constant comparative data analysis, it became evident that during early coding, the relevance of some ideas had simply not been fully recognised. Over time and with practice, I gained the experience necessary to become more proficient in grounded theory methods. I learned to prepare for coding transcripts by first reading the transcript to identify potentially irrelevant data which I changed to a red font. Red font text would not (initially) be coded. Similarly, I highlighted data that surprised, intrigued or disturbed me (which indicated pertinent data of potentially high relevance), thus flagging that I should pay close attention to this text (Charmaz, 2014). When reviewing transcriptions during constant comparative analysis processes, previously uncoded (red) data were reconsidered relative to emerging themes. Collectively, through this process I was able to work more efficiently than I did during early coding endeavours, reducing the chances that fatigue would cause me to overlook pertinent data. Once all transcripts were coded and focused codes developed, the first ten interviews were reviewed. This enabled a renewed examination of data through the lens of experience and awareness of the concepts most apparent in the data (Charmaz, 2014).

3.5.2 Memos, Maps and Diagrams

Memoing occurred throughout the research process and, together with diagrammatic representations of the analytic memos and mind maps, was associated with crystalising concepts and bringing ideas to life. Memoing of ideas has long been encouraged in grounded theory (Kenny & Fourie, 2015), and as a note-taker in other areas of my life, memoing provided a familiar and validated means of recording ideas and concepts. I revisited memos periodically and in so doing, felt reassured about the persistence of some themes. Memos also helped me to recognise ideas which, whilst interesting, could be set aside for the time being.

Memos, mind maps and diagrams constituted a constant form of transforming ideas from my mind into a visual format, almost irrespective of where I was or what I was doing at the time. As a regular runner, many of my clearer ideas occurred mid-run, leading me to stop roadside and record these ideas on my phone. Further, I would wake in the night reflecting on ideas to be recorded and analysed later. Whilst most memos were captured in NVivo Pro software$^{\copyright}$ (Version 12), occasionally notes were written on serviettes in cafes (owing to having described a concept to a companion) or whilst reading an article. I wrote memos describing my impressions after interviews; possible patterns or questions to be explored further; and my hopes, fears, and emotions. One example of an early concept mapping diagram can be seen in in the following image (Figure 3.1).

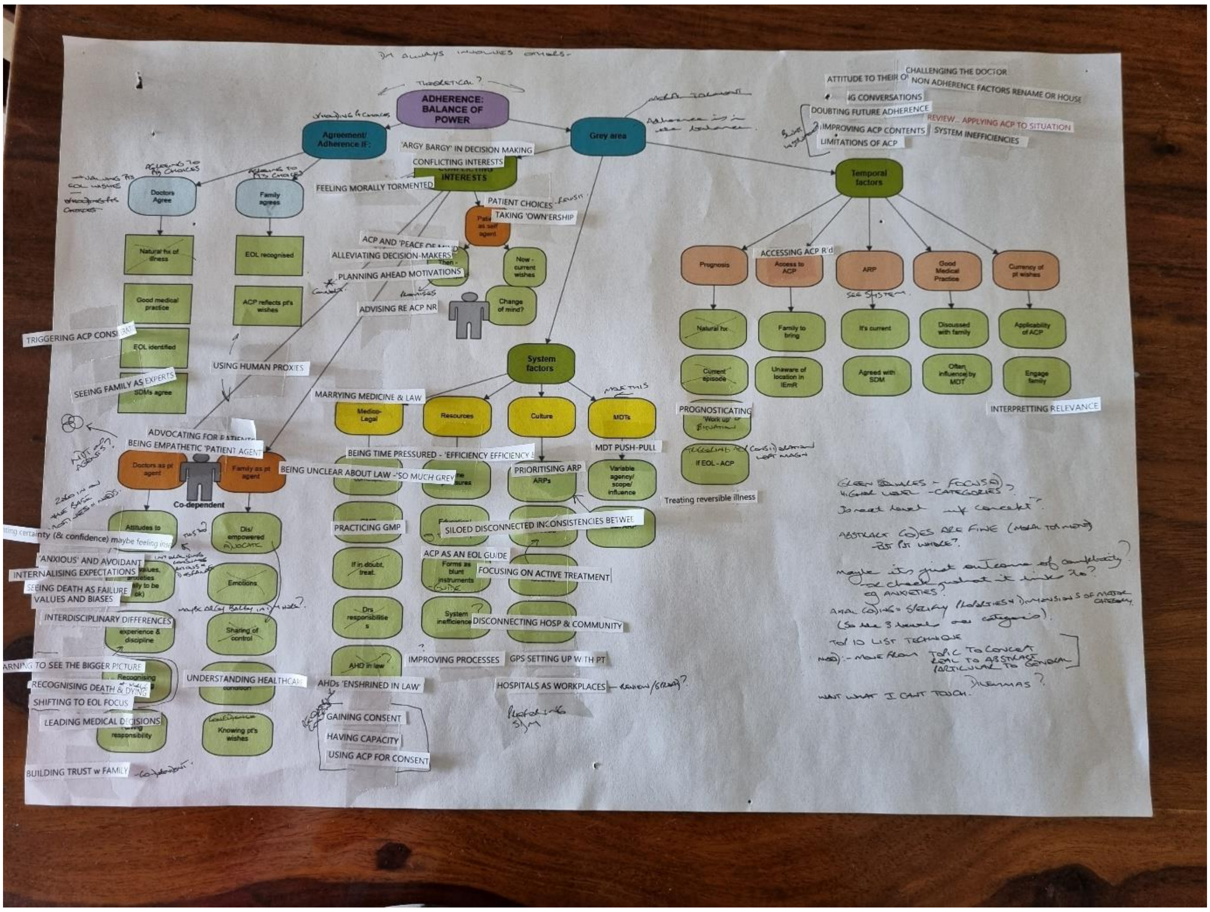


Figure 3.1: Example of a theoretical concept map

3.6 Constructing Theory

The construction of my theory was an iterative process that involved a combination of both gradual and rapid developmental phases. Out of respect for people who seek a voice through ACP, I maintained a single-minded focus on the research. From research inception, I took a reflexive, methodologically self-consciousness approach by scrutinising how my clinical role, experiences, interests, assumptions, decisions and interpretations impacted the data (Charmaz, 2014; Charmaz & Thornberg, 2021). My analytic musings dominated my time and energy. I immersed myself in my focused codes, memos, and diagrams, and discussed concepts and rationales with advisors during fortnightly meetings. These meetings with three critical thinkers provided opportunities and obligations to share alternative perspectives, debate ideas, and justify my position. Accordingly, these discussions established the scaffolding alongside which I progressed my theorising towards a worthy framework to explain the factors which influence the non/application of ACPs of incapacitated patients with a neurodegenerative disorder in North Queensland public hospitals.

3.7 Ensuring Research Quality

Charmaz and Thornberg argued that "grounded theory needs its own set of criteria for evaluating quality due to its unique features" (Charmaz & Thornberg, 2021, p. 313). Although debate exists regarding how to define and evaluate such quality within qualitative research (Charmaz & Thornberg, 2021), Charmaz (2014) suggests four essential quality criteria as foundational within constructivist grounded theory. These are credibility, originality, resonance, and usefulness. I engaged Charmaz's (2014) example self-reflection questions to satisfy myself and my advisory panel with the quality of this research (see Appendix H).

3.7.1 Credibility

Credibility refers to the degree to which the research claims are believable and recognisable as legitimate (Nowell, Norris, White, & Moules, 2017). In this research, credibility is demonstrated through the rich and diverse descriptions gathered through in-depth interviews with purposively and theoretically sampled participants from multiple regions, medical specialties, age ranges and years of experience. Although doctors were the primary focus of the research, data were also gathered from consumers, allied health clinicians and nurses to enhance the triangulation of analysis (Creswell & Poth, 2018). Constant comparative data analysis which compared codes and categories was undertaken throughout the research process and represented within memos and diagrams. Pertinent participant quotes were provided to ensure transparency of the links between data and analysis. The trustworthiness of this process was enhanced by my prolonged immersion in the research and auditable trail of theory development (Birks & Mills, 2015; Charmaz, 2014). Additionally, all aspects of coding and theory development were discussed with my advisory panel during fortnightly meetings (Creswell & Poth, 2018). As a research team, we asked incisive questions about the data and made comparisons between data, themes and categories to ensure a thorough analysis (Charmaz & Thornberg, 2021). These meetings included transparent and reflexive discussions whereby the influence of my clinical and personal experiences on theory development was openly and honestly addressed. The transformation of my perspective from frustrated to empathetic was recorded within memos.

3.7.2 Originality

Charmaz (2014) described *originality* as the extent to which the research provides new insights of social and theoretic significance that challenge, extend or refine ideas, concepts, and practices. I commenced with a literature review which concluded that, to the best of my knowledge, this research is the first grounded theory research addressing the research question. Later, by referring categories back to the literature, I was able to establish how this research addressed gaps in knowledge and extended scholarship on the topic. Throughout the process, advisors encouraged me to *rise above* descriptive or *not quite right* codes and to develop my unique insights into fresh, original, conceptual renderings of the data. Advisors typically asked me to explain myself because it was in explaining and justifying my position that the logic or weakness of my arguments became clear. To transfer explanations into written form for an audience, diagrammatic representations (of varying quality) were drafted, helping me to gain clarity. In turn, diagrams were discussed as a research team, and I refined them iteratively. Collectively, these processes were critical to the development of a theory that offers new insights into the complex concept of applying an ACP.

3.7.3 Resonance

Charmaz (2014) asks researchers to consider whether the grounded theory makes sense to participants, whether it *resonates* with them, and whether it offers them the opportunity to achieve deeper insights into the subject matter. At research inception, I made a pragmatic decision not to offer member checking, based on practicalities and advice from advisors and other qualitative researchers (Hagens, Dobrow, & Chafe, 2009). Although member checking provides participants with the opportunity to edit or clarify transcriptions, the practice could also inadvertently create inconsistencies and bias if data were removed (Hagens et al., 2009). However, participants were offered a copy of published results and when asked by participants to share findings with them I did so by providing the published article (included within Chapter Four). One participant contacted me to discuss his response to the publication wherein he confirmed his agreement with my conclusions. Further, this participant expressed that he had developed greater insights by engaging with perspectives other than his own. Several participating doctors approached me for complex ethical advice in the months following their interview and receipt of the published article, which I interpreted as respect for my research conclusions. Additionally, discussions with advisors often centred on the degree to which my renderings resonated with advisors. Collectively the research team reflected considerable experience within Queensland Health, academia, nursing, social work, law, end-of-life and neurodegenerative disorders. As a result of these often-divergent standpoints, discussions were typically robust, and findings were enriched by rigorously developed and refined analysis (Charmaz, 2014).

3.7.4 Usefulness

The quality criterion of *usefulness* challenges researchers to establish the value of the research beyond the research parameters. Charmaz (2014) distilled this notion by asking how the research will contribute to making the world a better place. The purpose of this research was to provide a useful framework for consumers, clinicians, organisations, and researchers to understand the influence of ACP in healthcare decision-making for patients with a neurodegenerative disorder. As such, the findings and theory offer new insights into the complexities of decision-making on behalf of incapacitated patients with a neurodegenerative disorder who sought to retain a voice in healthcare. Increasing the knowledge of all stakeholder groups is ethically important and overdue, given the national focus on encouraging ACP generation without adequately exploring the factors which impact clinical application. Consequently, this research has the potential to enlighten consumers about the limitations of ACP and inform the development of policy and education programs for organisations. Implications of the research are addressed further in the final chapter of this thesis.

3.7.5 Ethical Considerations

3.7.6 Ethical Approval

This research was granted multisite ethical approvals by Townsville Hospital and Health Service Human Research Ethics Committee (reference HREC/2019/QTHS/54125) and James Cook University (reference H7930) (seen in Appendix F). In October 2020, three minor amendments were approved. Firstly, the research title was altered to include *neurodegenerative disorder* rather than *neurodegenerative disease,* thus clarifying the inclusion of stroke. Secondly, inclusion criteria for family participants clarified that this group was not limited to the North Queensland context. Finally, the amendment allowed family members to speak on behalf of a person with a neurodegenerative disorder about the person’s motivations when generating an ACP. All relevant documents such as information and consent sheets and flyers were amended to incorporate these changes (Appendix F). Additionally, although ethical approvals were granted in the context of using the Skype application for computer-based face to face interviews, Queensland Health subsequently promoted the use of Microsoft TEAMS as an alternative to Skype, and James Cook University provided students with secure ZOOM application access for meetings. Accordingly, TEAMS or ZOOM applications were used as an alternative to Skype to meet (but not record) interviews, and research materials reflecting this development were approved during the amendment.

3.7.7 Informed Consent

Before being interviewed, potential participants were provided with a Participant Information Sheet (Appendix F) and encouraged to discuss any aspect of the research. Questions from participants were answered honestly and each was reminded that they were under no obligation to participate, and they remained free to withdraw at any time. Consumers were assured that their choice to participate would have no influence on the healthcare provided to them, whilst clinicians were advised that their participation would not impact their employment. All participants were warned of the limits of confidentiality, such as the possibility that in exceptional circumstances I may be required by law to disclose information.

All participants gave consent including indicating their understanding of the research purpose and agreement to participate. Participants consented to their anonymised data being published as a part of a PhD research. In cases where participants were interviewed from another location and did not return the consent form in time, their agreement was obtained verbally twice: once before and once after commencing the recording. After each interview, I invited participants to provide me with feedback about their experience (Creswell & Poth, 2018).

3.7.8 Confidentiality and Anonymity

To ensure participants' confidentiality and anonymity were and would continue to be protected, I took the following steps in line with human research ethical conduct (National Health Medical Research Council, 2007 updated 2018):

- All identifiers within interview transcripts were removed and instead, participants and any named persons or institutions within the data were coded or otherwise anonymised.
- Interview recordings were loaded onto a password-protected university server and the original recording held on a digital device was destroyed.
- The professional transcription service signed a confidentiality agreement before recordings were sent via secure electronic transfer.
- Returned transcripts were checked for identifying features (such as the names of others or institutions) which were then amended within transcripts.

- Identifier codes were used throughout publications, and no information was (or will be) provided that in any way could lead to identifying participants.
- In several cases, speech patterns (such as English as a second language or unique/identifying expressions) were modified within published quotes to remove unnecessary words (without changing the meaning) which otherwise might have jeopardised the anonymity of the participant.
- At no time was information shared regarding which participants engaged in the research.
- Consent forms were scanned and stored electronically on password protected university server where they will remain for 15 years. All raw data has been transferred to James Cook University's secure repository where it will remain for five years from the completion of the research. At that time, it will be deleted.

3.7.9 Protection from Harm

Advance care planning is often associated with end-of-life and may be perceived as a distressing concept. As a result, this research carried a slight risk of harm to participants when speaking about their potential end-of-life, or when reflecting on their role in someone else's death. Similarly, disclosing actions taken and decisions made in the context of a power imbalance between an incapacitated patient and bedside agents (doctors, allied health clinicians, nurses, families) carried a small risk of distress to participants if they were uncomfortable recollecting events. As a psychologist, I felt confident that I would recognise discomfort and manage interviews sensitively and responsively. The approved research distress protocol was to propose suspension or cessation of the interview and offer immediate support. All participants were advised that I would refer them to appropriate counselling services if required, however, no participants appeared distressed, and no onward referrals were activated. Time spent being interviewed was also considered a potential burden which was managed by efficiently completing interviews at a time and place of participants' choice.

3.8 Methodological Limitations

Beyond the proposed strengths of a constructivist grounded theory which I have described earlier in this chapter, there are also several limitations of note in this research. Firstly, the patient population of interest was restricted to people living with a neurodegenerative disorder and therefore the resulting theory may not be transferable to other illness types. The decision to restrict the research this way was made early on advice from my primary advisor (RR) and was intended to help contain, or focus, the illness type and therefore generate a theory of relevance to this large and vulnerable population. My decision to do this was later supported when some participants spoke of thinking differently about medical approaches to people dying from neurological disorders than they do about people dying from malignancy.

Additionally, I asked consumer participants to self-report having a neurological disorder diagnosis, and therefore people claiming to have a neurodegenerative disorder and family could have been untruthful. However, there was no evidence to suggest that this occurred, and in all cases, consumers appeared motivated to support research that could lead to worthwhile change. Sadly, some people with a neurodegenerative disorder who wished to contribute to the research were refused participation because they had not completed the construction of an ACP. Instead, we engaged in a discussion in view of giving the person a chance to speak to a researcher.

Further, non-English speaking participants were excluded from this research which may have inadvertently restricted divergent perspectives relative to shared decision-making and ACP. Whilst the research did achieve good representation from senior clinicians from diverse geographical and ethnic backgrounds which proved to be invaluable, no consumers identifying as Aboriginal or Torres Strait Islander peoples, or peoples of ethnic groups, participated. Therefore, the potentially rich views of some consumer groups were not available.

Chapter 4: Human Factors

4.1 Introduction

In the preceding chapter, I explained the constructivist ground theory methodology which enabled me to gather and analyse rich data provided by research participants. Through a process of constant comparative analysis, coding, and theme generation, I conceptualised two overarching themes to explain doctors' application of ACP for people with a neurodegenerative disorder entering the public hospital system: *Human Factors*, and *Systemic Factors*. In this chapter, I present findings and subsequent theoretical concepts associated with the first of these themes, the Human Factors, whilst the Systemic Factors will constitute Chapters Five and Six. I explain that despite having constructed an ACP to retain a powerful voice in healthcare decision-making, patients' (former) power is diffused by (present) bedside agents. In essence, doctors seek to protect their patients by leading temporal shared decisions in the presumed best interests of patients, most often in partnership with family and without reading the ACP. In this research, human factors gave rise to doctors avoiding conflict with families; and navigating the potentially conflicting interests of patient agents. As a result, the patient's voice is juxtaposed to the voices of bedside agents who retain a powerful voice in temporal decision-making which results in the exercising of social power and leads to *wicked* problems.

This chapter contains two international, open access publications reporting results from interviews with doctors, allied health clinicians, nurses, and family members. The first was titled Advance Care Plans and the Potentially Conflicting Interests of Bedside Patient Agents: A Thematic Analysis, and the second, Multidisciplinary Clinicians and the Relational Autonomy of Persons with Neurodegenerative Disorders and an Advance Care Plan: A Thematic Analysis. Due to the subject complexity and consideration of word counts and readability, these articles were initially drafted to publish in tandem as paired articles. However, feedback from the journal prompted me to reconsider this approach. Manuscripts were subsequently revised and submitted to separate journals. This process, whilst time-consuming, resulted in valuable feedback from reviewers that led to adopting the term *relational autonomy* in the second only of the publications. In time, both articles were published in the same journal, the Journal of Multidisciplinary Healthcare.

The complexity of the topic and the aims of the research precluded the inclusion of data from people with a neurodegenerative disorder in these publications. However, it remains important that these voices are heard. I begin this chapter by presenting the voice of people with a neurodegenerative disorder, rightly placed as central to shared healthcare decision-making.

4.2 Final Participant Sample

A total of 45 people shared their experiences: seven participants with a neurodegenerative disorder, six family members, 10 senior allied health clinicians, six senior nurses/nurse practitioners, and 16 doctors (15 senior medical officers and one junior doctor). Of the 45 participants, 25 were known to me before data collection, with most associated with my role as a psychologist, educator and/or member of various committees. Almost two-thirds of doctors were males whilst nurses and allied health clinicians were predominantly female (see Table 4.1). Participant characteristics and interview details were limited to protect anonymity and guard against re-identification.

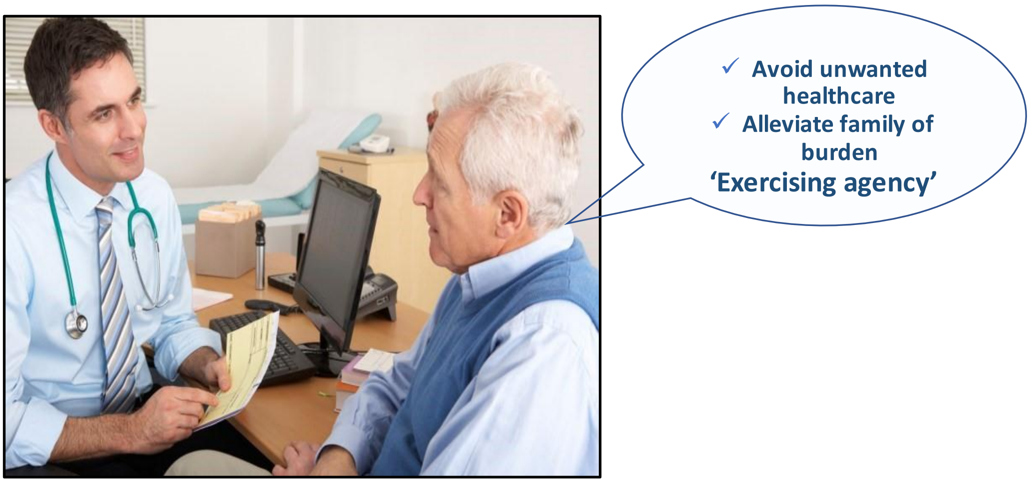
Table 4.1: Final Participant Sample characteristics

Characteristics	n	Characteristics	n	Characteristics	n	Characteristics	n
Doctors	16	Senior Allied Health clinicians/Nurses	16	Person with a neurodegenerative disorder	7	Family	6
Cardiology	1	Dietitian	1	Dementia	4	Dementia	2
Emergency Department	2	Occupational Therapist	2	Motor Neurone Disease	2	Motor Neurone Disease	1
General Medicine	3	Physiotherapist	1	Other	1	Other (e.g. Huntington's Disease, Stroke)	3
Geriatrics	5	Psychologist	1				
Intensive Care	1	Social Worker	4	Region		Region	
Neurology	1	Speech Pathologist	1	North Queensland	3	North Queensland	4
Oncology (medical)	1	Nurses (bedside, management, nurse practitioner)	6	Greater Queensland	1	Greater Queensland	1
Palliative Care	1			Interstate	3	Interstate	1
Psychiatry	1						
Seniority							
Registrar	1						
SMO	15						
Gender		Gender		Gender		Gender	
Female	6	Female	14	Female	2	Females	4
Male	10	Male	2	Male	5	Males	2
Age range		Age range		Age range		Age range	
30-39	6	30-39	5	50 - 59	1	50 - 59	2
40-49	4	40-49	6	60 - 69	4	60 - 69	3
>50	6	>50	5	>70	2	>70	1
Years of experience		Years of experience					
5-10	3	5-10	5				
11-20	7	11-20	6				
> 20	6	> 20	5				

Characteristics	n	Characteristics	n	Characteristics	n	Characteristics	n
Religiosity		Religiosity		Religiosity		Religiosity	
Not religious	11	Not religious	5	Not religious	2	Not religious	1
Non-specific faith	2	Non-specific faith	5	Non-specific faith	1	Non-specific faith	1
Christian	3	Christian	4	Christian	1	Christian	2
		Not stated	2	Not stated	3	Not stated	2

By the end of February 2020, six interviews involving all participant groups had occurred and been transcribed and coded. This early data collection stage prioritised the recruitment of groups other than doctors to help inform questions posed to doctors at a later stage of data collection. During March, Hospital and Health Services were preparing for COVID-19 cases and many usual activities of the hospitals (such as elective surgery, staff travel, and some meetings) were suspended. Consequently, clinicians reported having more flexibility than usual to engage in research, leading to an unexpectedly escalated engagement rate. Additionally, the threat of COVID-19 appeared to be associated with increased participant interest in this research. Some social media, grey literature (Advance Care Planning Australia, 2021) and academic publications (Block, Smith, & Sudore, 2020; Curtis, Kross, & Stapleton, 2020; Gupta et al., 2021; Martin-Khan et al., 2020; Sinclair, Nolte, White, & Detering, 2020) linked COVID-19 with the timeliness of advance care planning, indicating a potentially increased interest in ACPs at that time.

4.3 Participants with a Neurodegenerative Disorder



✓ Avoid unwanted healthcare
✓ Alleviate family of burden
'Exercising agency'

[Shutterstock image]

Figure 4.1: Participants with Neurodegenerative Disorders' rationale for generating an ACP.

4.3.1 Rationale for Generating an ACP

The knowledge that neurodegenerative disorders pose a threat to the autonomy and the voice of diagnosed individuals, is discussed within both the introduction and the publications contained within this chapter. What follows is the unpublished rationale that people with a neurodegenerative disorder offered for generating their ACP. Primarily, these participants sought to exercise agency by generating an ACP.

4.3.2 Exercising Agency through ACP

Participants with a neurodegenerative disorder were mindful of their illness trajectory and anticipated future impairment of decision-making competence. Accordingly, they were motivated to exercise their legal right to guide future healthcare decisions. All stated they had trustworthy and supportive families with whom they discussed their healthcare directions and priorities. All participants had generated an Advance Health Directive and anticipated families (or health attorneys) being involved as surrogates for any decisions beyond the scope of the Advance Health Directive. By completing an Advance Health Directive, people with a neurodegenerative disorder exercised their agency with two clear objectives arising from the data: avoiding unwanted healthcare, and alleviating family from responsibility.

4.3.2.1 Theme One: Avoiding Unwanted Healthcare

The primary motivation of participants with a neurodegenerative disorder [PWND] was to maintain autonomy in decision-making, and to avoid unwanted healthcare. Participants were aware that their death was inevitable, and they were fearful of their potential loss of healthcare decisional control.

> I'd looked to the future quite a bit…I didn't want to be left being fed morphine for the rest of my life... I think what brought it into the fore for me was that I'd done a few programs on palliative care… it's face the facts Sonny, you're going to die. PWND6

> There's something about dementia that makes people want to do it [generate an Advance Health Directive]. I think it's that loss of cognitive capacity component. It really scares people. Hell, what's going to happen if I can't [make decisions]. PWND5

> Say I get cancer. Unless there's a 90 per cent chance of the operation being successful for a long-term positive outcome, I don't want to know anything about it. I've got this condition for a start, which is not a good future outlook, and a lot of cancer treatments, they're as sick as a dog and they might live for 2 years extra. Not interested in the drugs. I mean I've had a good life of being here for 63 years. How much longer do you want to live for when you're gonna have a few problems, you know? PWND3

Although participants utilised an Advance Health Directive as a means of limiting medical intervention that could obstruct their natural dying, not surprisingly, they had limited understanding of Advance Health Directive applicability in practice. Despite possible direction uncertainties, adherence to the Advance Health Directive was interpreted as compulsory.

> I think it's up to the individual as to what they want. I'll tell you now that mine is that I don't want any interference, I don't want any chemical help… I've always been an advocate of it [Advance Health Directive] because then it's very clear, the aged care facility knows what my rights and what my expectations are. They hand that onto the hospital, to the doctor, to everyone else. They know they can't go against it because it's there, it's in black and white… But it's only, in my mind, at end-of-life, whereas pneumonia wouldn't be end-of-life. Unless you were in advanced stage of dementia. PWND4

Only one participant expressed that she distrusted doctors and did not expect them to apply her Advance Health Directive. This assumption led her to appoint non-family substitute decision-makers (attorneys) based on their advocacy skills and likely ability to adequately represent her healthcare intentions.

> I don’t think a hospital … a medical person, or even a paramedic would follow it… because my family don’t have any medical background, my close girlfriend [Name], who was also a registered nurse, she helps with the medical stuff with [Partner]. She’s very well versed in what my needs are. But you know, if I was on my own and in an accident and they were away… look, I’ve been told three times now by healthcare practitioners they will not follow my Advance Care Directive. PWND5

Others stated their Advance Health Directive would be legally binding and that doctors must adhere, although they were unaware of applicability requirements which might impact adherence.

> I think of it as being used to the letter of the law… It stands as a legal document and you have to abide by those wishes. When we had ours done… the lady was actually a solicitor and she said to us “Once this is done and signed by the appropriate people, it's law. No one can change it”… But it’s only, in my mind, it's only if at some end-of-life, whereas pneumonia wouldn't be end-of-life unless you were in advanced stage of dementia. PWND4

4.3.2.2 Theme Two: Alleviating Family of Responsibility

The second facet of patient agency was motivated by a desire to alleviate family of responsibility and guilt associated with end-of-life decisions. Participants anticipated end-of-life-related difficulties awaiting their family and they sought to carry responsibility for decisions and minimise the burden on others by removing decisional ambiguity. By making their own binding decisions, participants had taken personal responsibility, giving them peace of mind.

> A large quantity is to spare the family from having to be in the position where they’ve got to make the decision “okay, pull the plug”. The person has already made that decision for themselves and written it in an Advance Healthcare Directive. F1

> It’s a bad time for them [family], and someone’s going to be asking them “what do you want done? How does he want it?” It’s a lot of pressure on the person at that stage of life. It’s just important that it spells it out, takes the pressure off. PWND1

> It’s just so [Partner] wouldn’t have to worry about it and won’t feel guilty. PWND2

> My family told me to they didn't want to be holding the bag and not knowing what they should be doing, so it was a family thing that we discussed. PWND6

However, when asked whether their Advance Health Directive should be applied strictly or whether their family should be involved in temporal decision-making, participants considered their families should remain involved. They were agreeable to, and presumed that, family and doctor shared temporal decision-making would occur.

> I would be confident in what my [family] would make that call… Yeah it comes back to how close you are to your family. And yes, they're going to respect your wishes, but as you say, if it's pneumonia and there is a chance of it being cured, then I would imagine, see I've never thought about that scenario, but I would imagine that the EPOA would have the right to say, "well, okay, that's the end-of-life. If you told me that Dad can be fixed, but these drugs, and after that he'll return to the way that he was", then I would imagine the EPOA would have the right. PWND4

> Well, that would depend on my cognitive position at the time. I mean it's OK for me now, I'm able to converse properly, but they will, I'd leave it to them in their judgment. That's why I chose [Name], a nursing sister who knows about life and death and [Name], who knows me intimately, as [family]. I don't have any qualms… Because it has a legal connotation, they would have to deal with my family. PWND6

Preventing interrelational conflict was also a consideration, with one participant generating her Advance Health Directive in part to mitigate decisional risks associated with conflict between her mother and her partner.

> At that stage my mother was in the picture and they fight like cats and dogs [Name] and Mum, so I didn't want her [mother] to take over... and just to be able to leave things all in a row and not have to worry. PWND2

Similarly, demonstrating awareness that individually autonomous decisions have consequences for family members, participants commonly referred to considering their family's wishes early in the ACP process.

> I would recommend that you do think about and considered doing your advance care directives… get some legal advice, talk to your doctor and make the decision that's best for you and your family. PWND5

Of concern, participants spoke of having changed their minds in the years since completing an Advance Health Directive, yet they had not amended their documentation.

> Well, I did sort of limit it not to have much treatment but at that stage when I filled it in, I had gone down quite rapidly. And now that I actually picked up a big bit and plateaued out in the ten years, there's some things that probably don't mean as much to me because I did it in 2010 when I thought I was dying. PWND2

Interestingly, one participant reflected on the potential that she might change her mind and be rendered voiceless by her earlier binding decisions. This participant appeared resigned to a future state of hopelessness, despite having generated an ACP.

> I don't doubt that I might change my mind. I think that we as a species of human being mammals have an innate desire to live.
> Researcher: do you ever fear having changed your mind and not being able to communicate that to the people in the room?
> Not once. I figure it's too late by then. What does it matter?… If I'm in a late-stage dementia, what does it matter if I change my mind, actually? But, you know, I suppose if…. I've learnt to manage life communicating differently, that might be different. I don't know. I hadn't thought about that. PWND5

Collectively, results indicated that although participants with a neurodegenerative disorder engaged with ACP to retain agency, they also sensed the likely involvement of family in a shared decision-making process. Participants with a neurodegenerative disorder felt both protected by, and protective of, family members whom participants with a neurodegenerative disorder expected to retain a voice as advocates.

4.3.3 Summary: Participants with a Neurodegenerative Disorder's Rationale for Generating an ACP

In keeping with the purpose of ACP, the primary motivation of participants with a neurodegenerative disorder was to exercise agency and make clear their healthcare directions. They had been encouraged by stakeholders such as family, support groups, and clinicians to complete an Advance Health Directive to ensure healthcare was consistent with autonomous quality-of-life goals. All had chosen to complete the Advance Health Directive for its binding nature, suggesting a determination to influence care. Similarly to Willmott et al., (Willmott et al., 2013), participants sought to take responsibility, avoid unwanted interventions, and spare family from guilt. Interestingly, some participants recognised that their family would feel conflicted about the presence of an Advance Health Directive, an issue documented elsewhere (Batteux, Ferguson, & Tunney, 2020; Moore et al., 2019; Schenker et al., 2012; Shah, Farrow, & Robinson, 2009; Smith, Lo, & Sudore, 2013). Participants experienced a sense of empowerment by exercising their right to direct care. However, one person referred to rejecting all medical interventions which could conceivably result in unintended consequences such as poor symptom control (Willmott, White, Parker, et al., 2016; Willmott et al., 2013). Consistent with the crucial element of achieving agency (Johnson, Butow, Kerridge, & Tattersall, 2018), all hoped the Advance Health Directive would be taken seriously by doctors. Akin to other research which associated ACP with therapeutic benefit (Scott et al., 2022; Thomas, 2011), people with a neurodegenerative disorder who generated an ACP found the process a confronting yet rewarding time to reflect, discuss healthcare preferences with family, achieve "security" and "move on".

These results show that participants with a neurodegenerative disorder were committed to the benefits of ACP and that their expectations corresponded to the premise of ACP. However, what follows is the first of two published results articles that present the *human factors* experienced by bedside patient agents (family and clinicians) when matters for principals with a neurodegenerative disorder are to be decided.

4.4 Publication: Advance Care Plans and the Potentially Conflicting Interests of Bedside Patient Agents

This first results publication, Advance Care Plans and the Potentially Conflicting Interests of Bedside Patient Agents: A Thematic Analysis, was published by the Journal of Multidisciplinary Healthcare on August 6th, 2021. This section describes the diffusion of patients' power by doctors' temporal decision-making whilst discerning the presumed best interests of the patient and avoiding conflict with patient agents. The following graphic (Figure 4.2) offers readers an overview of the potentially conflicting interests of bedside agents that contribute layers of influence to doctors' responses to ACP.

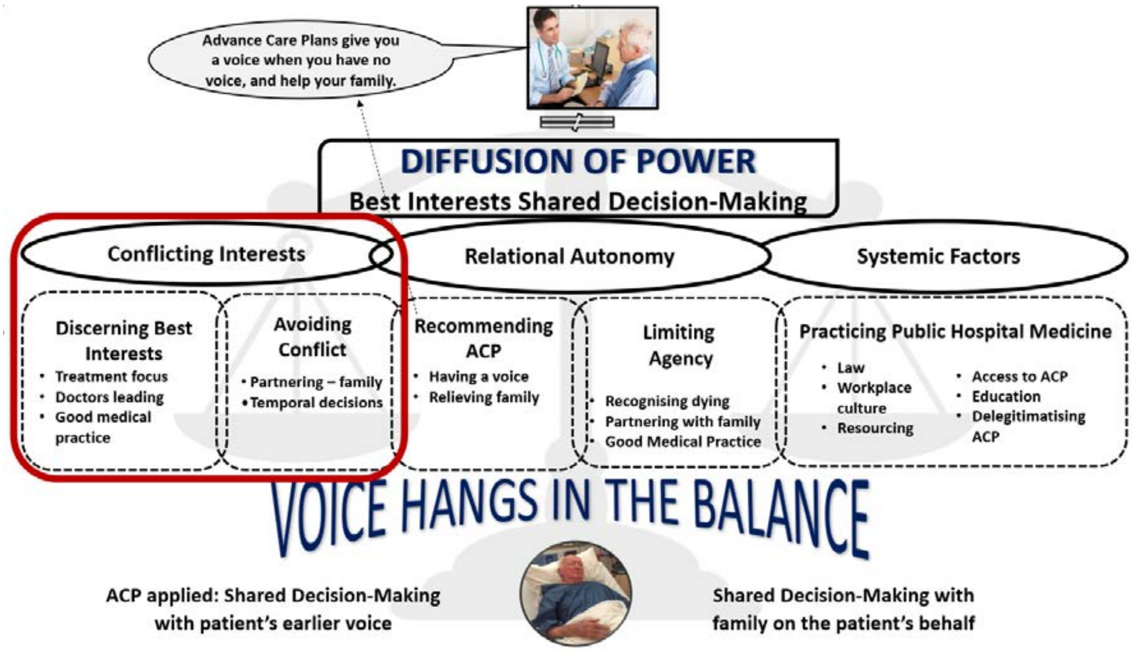
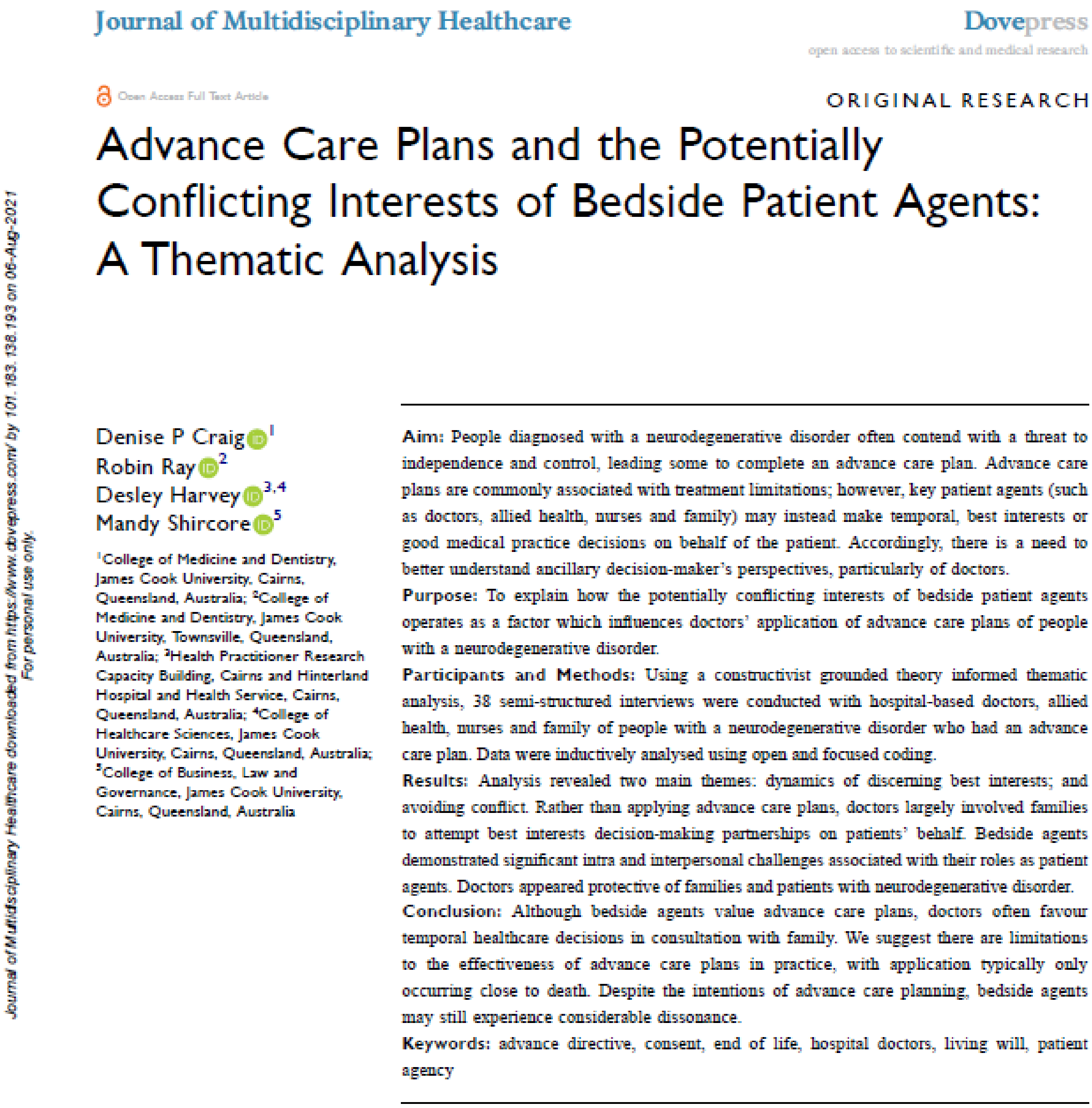


Figure 4.2: Diagrammatic representation of human factors [Part 1]: Conflicting interests of bedside patient agents.



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ORIGINAL RESEARCH

Advance Care Plans and the Potentially Conflicting Interests of Bedside Patient Agents: A Thematic Analysis

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Aim: People diagnosed with a neurodegenerative disorder often contend with a threat to independence and control, leading some to complete an advance care plan. Advance care plans are commonly associated with treatment limitations; however, key patient agents (such as doctors, allied health, nurses and family) may instead make temporal, best interests or good medical practice decisions on behalf of the patient. Accordingly, there is a need to better understand ancillary decision-maker's perspectives, particularly of doctors.

Purpose: To explain how the potentially conflicting interests of bedside patient agents operates as a factor which influences doctors' application of advance care plans of people with a neurodegenerative disorder.

Participants and Methods: Using a constructivist grounded theory informed thematic analysis, 38 semi-structured interviews were conducted with hospital-based doctors, allied health, nurses and family of people with a neurodegenerative disorder who had an advance care plan. Data were inductively analysed using open and focused coding.

Results: Analysis revealed two main themes: dynamics of discerning best interests; and avoiding conflict. Rather than applying advance care plans, doctors largely involved families to attempt best interests decision-making partnerships on patients' behalf. Bedside agents demonstrated significant intra and interpersonal challenges associated with their roles as patient agents. Doctors appeared protective of families and patients with neurodegenerative disorder.

Conclusion: Although bedside agents value advance care plans, doctors often favour temporal healthcare decisions in consultation with family. We suggest there are limitations to the effectiveness of advance care plans in practice, with application typically only occurring close to death. Despite the intentions of advance care planning, bedside agents may still experience considerable dissonance.

Keywords: advance directive, consent, end of life, hospital doctors, living will, patient agency

Figure 4.3: Cover page: Advance Care Plans and the Potentially Conflicting Interests of Bedside Patient Agents: A Thematic Analysis

4.4.1 Background

People with neurodegenerative disorders (PWND) such as dementia live with clear prospects of disabling cognitive decline (Regan, Preston, Eccles, & Simpson, 2019). Consequently, PWND often contend with a threat to independence and control (Low et al., 2018), leading some to exercise their agency by completing an Advance Care Plan (ACP). The genesis of formal advance care planning lies in complex medical, ethical, and legal debates associated with the potential juxtaposition of medical decision-making and patient autonomy (Russell, 2014). The mid-1900s saw an escalation of societal expectations that individuals should be allowed autonomy in healthcare decisions, which led to guardianship laws intended to preserve this right (Australian Health Ministers' Advisory Council, 2011). By the 1990s, legislation and structured ACPs had commenced in the USA where personal autonomy is an accepted cultural norm (Australian Health Ministers' Advisory Council, 2011). ACPs are now widely promoted around the world to both enhance patient autonomy and protect doctors from litigation (Wilkinson, 2018).

In Australia, advance care planning frameworks vary between states. Since the inception of advance care planning, legislative changes, and iterations of ACPs have occurred to facilitate communication of patient rights, preferences, or directions (Australian Health Ministers' Advisory Council, 2011). In the state of Queensland, legally binding Advance Health Directives [AHD] have been in use for almost two decades. In 2015 the Government of Queensland introduced a new, non-binding Statement of Choices form through which people may communicate important healthcare information intended as a guide to substitute decision-makers. In November 2020, the Queensland AHD (now Version 5) was amended to include values-based guidance statements as adjuncts to healthcare consent or refusal directions.

Accordingly, competent adults in Queensland have two formalised ACP options available: Statement of Choices and AHD. Adults have the right to express their wishes, values, and beliefs in a Statement of Choices and/or record binding healthcare directions within an AHD. By law, where a PWND has given directions within an AHD, matters related to the provision of care must be dealt with under the AHD. Both ACPs may be completed without medical *advice* despite requiring medical doctor *certification*. Collectively, these ACPs have been most associated with treatment limitation (Queensland Government, 2020), suggesting that failure to incorporate ACPs in decision-making may be associated with patients receiving unwanted interventions.

Under the *Powers of Attorney Act (1998)* and *Guardianship and Administration Act (2000),* where an AHD does not address the clinical issue at hand, a substitute decision-maker is required. Substitute decision-makers are tasked with making decisions in the patient's best interests, broadly meaning taking account of the patient's wishes and acting in a way least restrictive of the patient's rights. Yet, medical advice can be contradictory and people may be confronted by choices in which they have little or no expertise (Kaspersen, 2000). Consequently, for substitute decision-makers such as family, best interests decision-making can be a fraught proposition associated with emotional burden such as stress, guilt and doubt (Wendler & Rid, 2011). Not surprisingly, reliability of substitute decision-maker input appears variable, with discrepancies between substitute decision-maker and patient decisions well documented (Pope, 2012; Shah et al., 2009). Even in the most well intended judgements, decisions may reflect implicit bias and conflicting interests (Batteux et al., 2020; Schenker et al., 2012; Shah et al., 2009; Smith et al., 2013; Wendler & Rid, 2011). What is incumbent upon substitute decision-makers, however, is an authentic effort to incorporate what is known about the patient's wishes or directions, such as those recorded within an ACP.

Hospital-based clinicians such as doctors, allied health clinicians and nurses (AHC/N) are critical agents in patients' healthcare. All clinicians have a professional duty to act in the patients' best interests and respect patients' known views and wishes. Clinicians are ideally positioned to familiarise themselves with ACPs, raise awareness of ACP existence, and advocate for concordant care (Queensland Government, 2018). In so doing, the focus of the inpatients' hospitalisation may transcend the question of *what is wrong with the patient*, to *what matters most to the patient*. However, a recent scoping review of hospital doctors' application of ACP (Craig et al., 2020) to medical decision-making indicated that although doctors held largely positive attitudes towards ACPs, they prefer temporal decision-making and often do not read patients' ACPs.

To understand more about the reasons behind doctors' application of ACPs to treatment decisions of PWND, this study sought to hear the voices of bedside agents: doctors, AHC/N and family or friends of PWND with an ACP. Data collection occurred during the novel coronavirus disease 2019 (COVID-19) pandemic, at which time increased attention to ACPs and patient preferences appeared evident (Block et al., 2020; Curtis et al., 2020; Martin-Khan et al., 2020). We defined ACP as a patient-owned, written statement, articulating future healthcare wishes or directions applicable only during incapacity to consent. The Queensland AHD in effect during data collection was Version 4 and the Statement of Choices was Version

5.1. In line with study aims, AHD and Statement of Choices are specified only where relevant to distinguish legislated applicability.

4.4.2 Methods

4.4.2.1 Aims

The findings presented in this paper constitute part of a broader constructivist grounded theory research project exploring enablers and barriers to hospital doctors' application of ACPs of incapacitated PWND. Consistent with constructivist grounded theory methodology, the research team commenced this study with broad aims rather than specific objectives. This paper provides a thematic analysis explaining how the potentially conflicting interests of bedside patient agents operates as a factor which influences ACP application.

4.4.2.2 Study Design

An inductive thematic analysis informed by the constructivist grounded theory approach of Charmaz (Charmaz, 2014) was chosen for its capacity to help develop a new understanding of the underlying phenomena associated with this study. Grounded theory has been recommended for its suitability to explanations of phenomenon about which little is known (Birks & Mills, 2015; Wong et al., 2012). Constructivist grounded theory (Charmaz, 2014) methodology was used to inductively describe the experiences of doctors, AHC/N, family and friends regarding healthcare decision-making for an incompetent PWND with an ACP. The purpose of using constructivist grounded theory was to work towards the development of a theoretical framework for understanding the complex human experience of applying an ACP to life and death decisions on behalf of a PWND who sought to preserve their autonomy. The resulting theory will be published separately.

4.4.2.3 Ethical Approvals

Multisite approvals were granted by Townsville Hospital and Health Service Human Research Ethics Committee (54125) and James Cook University (H7930). Participant access to professional support if distress occurred was incorporated into approvals. This paper was informed by the Consolidated Criteria for Reporting Qualitative Research (COREQ), and data were maintained in accordance with the Declaration of Helsinki.

4.4.2.4 Participants and Recruitment

Three participant groups who had direct experience with treatment decisions for PWND who had an ACP during incapacity to consent were invited: hospital doctors, AHC/N, and family or friend advocates (henceforth ‘family’). Doctors were the primary focus of this study, with AHC/N and family participants theoretically sampled to achieve wider perspectives. All participants received written and oral information about the study and consented to interviews being digitally recorded and anonymised data published.

4.4.2.4.1 Doctors; Allied Health Clinicians; and NursesDoctors and AHC/N were recruited via health service newsletters, snowball referral and emails disseminated by heads of departments. All had treatment experience in the context of AHDs and a small number had experience in the context of a Statement of Choices. Purposive sampling was undertaken from units most associated with care at the end-of-life including palliative care, emergency, geriatrics, intensive care, medical oncology (White et al., 2016). In line with theoretical sampling techniques, some specialties (such as neurology, general medicine, psychiatry, respiratory and renal) and disciplines (such as social workers, speech pathologists, dietitians, and nurses) were invited to participate. Doctors from the respiratory and renal subspecialty declined participation. In this manuscript, AHC/N and doctors are referred to collectively as ‘clinicians’, however disciplines are separated for interpretation of data where necessary.

4.4.2.4.2 FamilyFamily responded to invitations during support group presentations, social media posts, or snowball referrals. Family members were invited to speak about their experience of hospitalisation of someone meeting the PWND criteria during illness and incapacity to directly consent.

4.4.2.5 Data Collection and Analysis

The authors developed a semi-structured interview guide based on professional experience and research, to flexibly-explore factors such as attitudes towards patient agency through ACPs, and barriers or enablers to applying the ACPs completed by PWND (see Figure 4.4). The guide was piloted across all groups, then amended iteratively as theoretical concepts emerged. Interviews were conducted across two hospital and health service districts by the first author [DC] and primary advisor [RR], face-to-face or via telephone or ‘MS TEAMS’ online software and ranged from 20 to 70 minutes (mean of 51.8 minutes).

Family patient agent guide.

Explore patient’s attitude towards future health care.

Background to patient completing an advance care plan.

Explore decisions patient made in advance care plan.

What was noticed about decision-making once patient was in hospital.

Any apparent role of advance care plan in treatment decisions.

How advocate would have liked decisions about care to have been managed.

Degree of advocacy for the advance care plan to be followed.

Effect the situation had on advocate.

Advice to others about completing an advance care plan.

Would advocate have one.

Any other thoughts not yet shared.

Clinician patient agent guide.

Explain experience treating people with a neurodegenerative disorder and advance care plan .

How advance care plans are included in decision-making.

When advance care plans are looked for.

Thoughts about differences between advance health directives and statement of choices.

Advance care plans as helpful or unhelpful. When/what circumstances.

Role of family when your patient has an advance care plan.

Use of health directive as a consent tool.

Confidence patients understood decisions made in advance care plan.

Explaining advance care plans to others.

Ways that advance care planning could be improved.

Attitudes towards own.

Figure 4.4: Example interview questions

Interviews were transcribed verbatim by either the first author (DC) or a professional transcription service. Early interviews were coded by two research team members (DC, RR) after which coding was compared and discussed. DC then coded all transcripts using a combination of open and in vivo codes, with QSR NVivo 12 software utilised to assist data management. In line with grounded theory, data and codes were constantly compared (Charmaz, 2014) and codes discussed and revised during regular research team (DC, RR, DH, MS) meetings, increasing confirmability of the data. As the analysis progressed, codes were collapsed into categories which captured recurring themes and sub-themes. DC wrote reflexive memos to explore and interpret understanding of categories and used diagrams to document relationships between themes and to develop an overarching conceptual framework. Data collection and analysis continued concurrently until the research team were satisfied that no new ideas were emerging, and data saturation had occurred.

4.4.3 Results

4.4.3.1 Participants

A total of 38 bedside agents participated between November 2019 and November 2020. Of the 38, 32 were clinicians representing a broad range of specialties and clinical expertise, all with ACP experience. Doctors, predominantly senior medical officers, were from the subspecialties of emergency, general medicine, intensive care, neurology, medical oncology, geriatrics and psychiatry. Nurses ranged from bedside to management and nurse practitioner level, and allied health clinicians were of a senior level. Six participants were family members of patients hospitalised with dementia, Motor Neurone Disease, stroke, Huntington's Disease and Cerebral Amyloid Angiopathy (see Table 4.2).

Table 4.2: Participant characteristics [Bedside Patient Agents]

Doctors	n 16	Senior Allied Health Clinicians/Nurses	n 16	Family	n 6
Cardiology	1	Dietitian	1	Patient ~ dementia	2
Emergency Department	2	Occupational Therapists	2	Patient ~ Motor Neurone Disease	1
General Medicine	3	Physiotherapist	1	Patient ~ Huntington's Disease	1
Geriatrics	5	Psychologist	1	Patient ~ Cerebral Amyloid Angiopathy and stroke	1
Intensive Care	1	Social Workers	4	Patient ~ stroke	1
Neurology	1	Speech Pathologist	1		
Oncology (medical)	1	Bedside registered nurses	4	Region	
Palliative Care	1	Nurse Unit Manager	1	North Queensland	4
Psychiatry	1	Nurse Practitioner	1	Greater Queensland	1
Seniority				Interstate	1
Registrar	1				
SMO	15				
Gender		Gender		Gender	
Females	6	Females	14	Females	4
Males	10	Males	2	Males	2
Age range		Age range		Age range	
30-39	6	30-39	5	50 - 59	2
40-49	4	40-49	6	60 - 69	3
>50	6	>50	5	>70	1
Years of experience		Years of experience			
5-10	3	5-10	5		
11-20	7	11-20	6		
> 20	6	> 20	5		

Data analysis revealed two main themes: dynamics of discerning best interests; and avoiding conflict. Collectively, these themes formed the basis of the core category: conflicting interests of bedside patient agents (see Table 4.3). Participants are identified by letters: AHC – Allied Health Clinicians, D – Doctor, F – Family, RN – Registered Nurse.

Table 4.3: Example of the coding process [Bedside Patient Agents]

Initial coding	Example Focused codes	Themes	Category
• Hospitals are where things get done to people • Doctors trained to treat and cure	Being treatment focused	Dynamics of discerning best interests	Conflicting interests
• Finding prognostication challenging • Limitations of medicine	Recognising limit of medicine		
• Perceiving self as expert • ‘Push-pull’ of advocacy • Feeling conflicted	Being patient agent		
• Prioritising good medical practice • Doctors’ responsibilities • Applying ACP to situation • Marrying medicine and law	Prioritising good medical practice		
• Feeling confronted • Feeling anxious • Communicating poorly • Seeing death as a failure	Feeling anxious and avoidant	Avoiding conflict	
• Protecting family • Treating family and patient as one • Wanting consensus decision-making • Wanting confidence in decision-making	Engaging family in temporal decisions		

Conflicting interests among bedside agents encapsulates the competing influences, such as cognitive biases which impact decision-making. Conflicting interests may occur when agents encounter cognitive discord between possible choices, such as: loving family advocating for the patient’s right to treatment refusal, yet not wanting the patient to die; or clinicians seeking to ascertain the best interests of patients and provide good medical care, yet the patient has refused life-sustaining treatment within an AHD.

4.4.3.2 Dynamics of Discerning Best Interests

Discerning the best interests of another person, in this case an incapacitated PWND who sought agency through ACP, is a complex ethical position for agents. All bedside agent groups spoke of the essential role that doctors play in contributing medical expertise and guidance to both patients and families. Doctors recognised their profession as predisposed towards active treatment and trained to solve medical problems. Remarkably, some doctors identified that medicine is often not holistic, or patient centred. Despite modern advances in medicine and technology, most of the doctors experienced difficulty prognosticating, including recognising end-of-life. When end-of-life is not recognised, the primary trigger to include the ACP in decision-making is diminished.

> Doctors are technicians, they're engineers, we're not scientists... So we're goal orientated, as doctors, we don't enter into things with open scientific enquiry. We're very outcome driven… we're actually taught in medical school that doctors are very bad at identifying looming death... and I have come unstuck from a patient saying "I don't think I'm going to live through this" and me going, "Oh, don't worry about it, you'll be fine, let's crack on with the rehab". And sure enough they have passed away from it. D3

> Sometimes there is a benefit in not knowing the patient as well, because a familiarity has its own problems. And we can get a little attached to long term patients and develop cognitive biases. It's highly individual-specific, highly experience-specific… but prognosticating is difficult… there's good evidence that prognostic, except for the last 24 hours of life, even palliative care specialists are pretty rubbish at estimating prognosis and time. D4

> So I think unless you've done time with palliative care, or ICU or even geriatrics, it can be quite challenging to actually recognise a dying patient. And people are very reluctant to diagnose patients with dying… When we are talking about someone… with extremely poor premorbid function and irreversible illness, stop doing lumbar puncture for these patients because that's not going to change their trajectory at all. D7

Most doctors indicated that doctors tend to be perfectionistic and want control over medical decision-making. Interestingly, one doctor explicitly connected doctors' perfectionism and desire for control with their vulnerability to feeling threatened when an AHD contradicts the doctor's treatment decision. This suggests the potential for conflicting interests associated with decision-making responsibility, with both doctors and PWND seeking some control over the PWND's healthcare.

> But the other issue with doctors is that, that sense of control and not wanting to make a mistake. And if the Advance Health Directive doesn't agree with them they'll panic and ignore it. Or it's just a – I don't think there'd be any issue if it mirrors what they want to do, what the treatment says to do. It's only ever going to be an issue when the patient's wishes are against what the doctors think should be done. D16

Doctors appeared to respect their responsibility to provide good medical care which, in their judgment, would be care that is in the patient's best interests. Accordingly, some valued their right to resist "futile", unreasonable treatments associated with some patients' AHDs which consented to death-delaying treatment. However, some doctors referred to judging good medical practice as a subjective process that challenges doctors. Therefore, interpretation of applicability of AHDs also varies between doctors, with some influenced by the AHD to provide intervention which other doctors would not provide.

> One does have to think of beneficence, not just autonomy, and make an overall judgement, what is the right thing for the patient, considering the spirit of the decision that they have conveyed [within an AHD]. D6

> Fortunately, in Australia we doctors have the latitude to provide the healthcare that they think is appropriate and in a way it doesn't matter what the patient's written in the Advance Health Directive… That being said, amongst my peers I fall at one extreme where there are some patients that I think I would not resuscitate whereas my closest peers would because the patient had expressed desire to be resuscitated. D11

> At the same time doctors have rights, too, hospitals have rights, too, so you can't compel me to do something that I think is futile or is against good medical practice. D3

Interestingly, most doctors appeared uncomfortable about their limited understanding of ACP related legislation, however most believed that applying good medical practice would afford them legal protection.

> The line where you do and you don't, that is very difficult, but that, you see, the legislation in Queensland and I know it's different elsewhere, but the legislation in Queensland clearly states it has to be consistent with good medical practice. Now if I've got someone who I can fix within a few hours and they're going to be better the next day and back to where they were, it's not consistent with good medical practice to let them die. D5

> I haven't specifically looked into Queensland law because I haven't had to… I think it's like a national umbrella for healthcare workers and doctors that medical judgement is very important… we're kind of 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 completely futile, or we're inflicting pain and torture on a person for no reason, no benefit… my understanding is that we're protected under that sort of circumstance. D15

One doctor acknowledged the impact of doctors' personal values systems on clinical judgements.

> So I think that there are biases between certain clinicians. I've seen biases from religious clinicians away from certain treatment pathways which don't adhere to their value systems. I've seen people completely the opposite because of just personality I guess or difference of opinion... I think we apply our value systems to those documents. D8

All doctors spoke of inherent complexities of healthcare and consequently they perceived ACPs in isolation as of little value. Commonly, doctors asserted that medical decisions should be led by doctors in association with known patient preferences, typically ascertained in consultation with family rather than the ACP. All groups agreed that family contribute valuable personal knowledge about the patient's situation and healthcare preferences. Most doctors appeared motivated to minimise family's discomfort, in part because family "will live on" with the experience of the PWND's death, potentially putting family's interests in conflict with the PWND's agency. Whilst a small number of doctors spoke of "trying" to prioritise patients' needs over those of family, doctors generally interpreted family inclusion as an essential element of good patient care, implying difficulty negotiating boundaries between patients and families.

> There's a list of, I think, the health directive is supposed to be the number one before all else, but in reality, [we use] next of kin... And sometimes it's a big negotiation between like whether or not they'd still be suitable for a [hospital unit] admission to give them a chance to turnaround versus not. D15

> I don't think you can treat patients independent from their families even though you want to at times. D16

> I think we've got to take great caution in not treating the family, treating the person and their wishes. But… Advance Health Directives are not clear cut quite often…. they cover a very

> finite set of circumstances and a finite set of treatments… they often don't capture the person's wishes and the person's life history. D4

Sympathetically, some doctors tried to shield families by becoming paternalistic (also referred to as empathetic) and making definitive recommendations.

> And you've got somebody who's unconscious and then it comes down to, I'm afraid, a certain doctor knows best paternalistic attitude…. I think paternalistic is the wrong word. I think it's being empathetic and respecting the fact that that patient couldn't possibly have envisaged this scenario, not being a doctor… discussion with the family has to be trust engendering, has to be accurate, honest and, in my view, should revolve around two things, which is prognosis and treatment and, secondly, the patient's wishes and then try to intermingle all those together to get an outcome which is appropriate for everybody. D5

Despite the overarching responsibility which doctors maintain for patient care, data revealed AHC/N contribute considerable power to influence the application of ACPs to treatment decisions. Clinician groups broadly endorsed AHC/N as the most likely clinicians to identify the existence of an ACP, bring it to the attention of doctors, and to advocate for enacting patients' documented wishes. When AHC/N perceived a conflict between prescribed medical care and a patient's ACP, some challenged doctors. Some doctors credited AHC/N with making it difficult for doctors to overrule an AHD. Data suggested the potential influence of AHC/N confidence, hierarchy or scope of practice and the possibility that these clinicians may be less constrained by their responsibilities than doctors. One nurse explicitly referred to the relative powerlessness of nurses, with a colleague reportedly ostracised by team members for raising a formal complaint when an AHD was not applied.

> The non-medical multidisciplinary team [MDT] are more strong champions for implementation of advance care directives than the doctors….. It's [MDT] very supportive until you want to do something other than what the ACD [Advance Care Directive] says, which is when you have to carry the whole team around with you. D6

> [When persisting with life-sustaining treatment against the patient's wishes] I would have very clear debates with the doctors, "Why are you doing this? What's this actually about?" AH2

> What ended up happening is the nurses took charge and didn't, [they] were advocating for their patients. So, they called Ryan's Rule [process to escalate concern]… that person who took it further and … Ryan's Ruled it, was then kind of ostracised by senior medical staff...

> But that was conflict of interest, conflict in beliefs, conflict of paperwork… it was everything all in one... we're the first persons to get blamed because we're the bottom of the food chain. RN1

Of the allied health clinicians, social workers were most often referred to as core patient advocates. Speech pathologists, dietitians, psychologists, physiotherapists, and occupational therapists described themselves, or were referred to by colleagues, as advocates who resist involvement in treatment considered counter to the PWND's ACP. All clinician groups indicated that AHC/N can develop rich insights about patients and families, enabling them to contribute considerable information which doctors agreed was advantageous.

> The main people who are champions for this are nurses and the social workers. The physios and OTs [Occupational Therapists], their interest in that is "This patient says I don't want treatment, why am I treating?" D6

> Before you develop a holistic opinion, you'd take it to the MDT... They'll tell you about their journey through the 24 hours because at the end of the day the doctors are not there, the nurses are with the patients far more than the doctors. And often the nurses are very good at, they have a lot of contact with families as well… physio will give you information…. that can help you prognosticate a bit… the occupational therapists. The social worker, and you know, dietitian and speechies can tell you about prognostic factors… But a lot of the times… it really comes back to the core of social work, nursing, and medicine. D4

Most clinicians perceived a potential conflict of interests associated with family's power and role as partners in decision-making. Some clinicians expressed that although family had been supportive of the concept of PWND's agency through ACP, when faced with the experience of applying it, families were emotionally conflicted.

> There's that dynamic of what the patient wants, and what the doctor thinks is reasonable, and then you've got the family. It's a bit of a dance really. RN2

> But often, when patients' family are driving it, that is because they have some belief in something that they want to make sure is adhered to. It is very difficult to wade through this problem that is not yours and not adulterate the decision with your own views, and purely say "This is what this person would have done". D6

> The Advance health directive does obviate a lot of problems because there's an inherent conflict… between families or next of kin, and the person's wishes. On one hand, we all want

> our loved ones to live forever and be happy and do all those sorts of things. You know, there's certainly, there's some… you know, we all have those motivations that we don't want to lose somebody. D4

Some clinicians were suspicious of family members' motives, perceiving families as biased and unable to separate their own needs or beliefs (often emotional or religious in nature) from the patient's.

> I've seen tension… between families and medical teams… we've had family, like a lot of argy bargy between family and particularly, I've worried that the family don't necessarily have the best interests of the patient at heart. I think in some situations it [ACP] can make things trickier for families in a time where their loved one is incapacitated… often people… are looking for a locus of control in a time where they really want control. I think that can actually be challenging. AH10

In a clear demonstration of the emotional conflict faced by families, these participants recalled considerable intra and interpersonal conflict between themselves and clinicians when presuming the PWND's AHD should be applied, and when advocating for the patient. In all cases, the PWND, via their AHD, requested a palliative approach to end-of-life if their condition was considered by the doctor to be terminal, incurable or irreversible. Accordingly, advocating for application of the AHD was associated with the expected death of the PWND, and considerable distress for some family members. Two participants remarked that subsequent symptoms of anxiety had persisted years after the PWND's death.

> We then had to negotiate with the medical people and that's where tensions came… [Doctor] came trying to encourage [PWND] to continue with the therapy that might save [PWND]... she even tried to argue the point… and I remember [Name] and I standing there in front her in effect trying to say as carefully and clearly as we could "the answer is no"… getting them to back down and then just stay out of it. They were no longer going to be part of the treatment, and just to stay away from us. F3

> That's a dreadful thing to have to do…I had to go to [Doctor] and say, "Well what about this advance healthcare directive….". it's like, you've got to go and precipitate the demise of your loved one, just [expletive] awful… I didn't know what the hell was going on… and find out two days later, "Oh we're not doing that because of some advance healthcare directive", off the nurse's aid in casual conversation… which was exactly why [PWND] got an advance healthcare directive… I know that at the time I was too uncomfortable, ashamed, guilty, grief-stricken, absolutely devastated, whatever, to tell our friends who visited [PWND] daily that I

> had just had to virtually insist that the doctors follow the directive and cease artificial feeding. Still haven't told them to this day. Instead I told them “The doctors have decided”, which is what should have happened but really did not. F1

> A couple of the younger doctors were nice. The older sort of treating doctors were just, you know “I know more than you do”. And you’d ask a question and they make you out to be a bit of a nong... I don’t like even going past the hospital at the moment. F2

4.4.3.3 Avoiding Conflict

An unexpected theme arising from most participants’ data across all groups, was that doctors often appear uncomfortable with, and avoidant of, conflict. As a profession trained to treat and solve medical problems, doctors appeared to experience intra-personal conflict when faced with a patient’s death. Doctors generally demonstrated high expectations of themselves as good doctors and appeared authentically committed to patient outcomes. Whilst doctors expressed agreement with their legal and ethical responsibilities as medical officers, they also appeared sensitive to expectations of them. Some doctors experienced considerable discomfort associated with patients dying, and some had endured emotional challenges discerning the philosophical boundary between prolonging life and prolonging death. Several doctors reasoned that death is broadly perceived as a failure of care, adding to their sense of failure or blame upon a patient’s death. Accordingly, transitioning patients from life-sustaining medical interventions to end-of-life care (potentially as a consequence of an ACP) was linked with inner conflict that required a significant, often uncomfortable, cognitive shift of focus.

> If you just say “for goodness sake, the family are really not able to make this decision and this person asked for this, this is what we need – we need to go by their wishes” they find that really hard. They don’t like conflict, doctors. AH6

> It’s like they didn’t want to be the ones that actively precipitated the end… and yet, in a way you’re the one who has to actively precipitate the end by sort of insisting that they follow the advance healthcare directive. So, it’s just, it’s a lot of mixed signals. F1

> What I find really challenging is going from a very aggressive healthcare approach to a philosophical ‘we’re not prolonging death’ approach... D7

> [Is death perceived as failure?] Definitely in medicine. Especially in the junior ranks. Look, I mean, when you were in your formative ages, you thought your job to become a doctor is to

> save lives. That’s what people say “you save lives”, right? All my life I have been saying to my patients “You will not die, don’t worry, I am there for you”. D6

> [Is death perceived as failure?] For me, it’s a real cognitive shift. And unless you're in that thought process to make that cognitive shift, it can be really hard. Because it’s philosophically opposed from a clinical perspective to really aggressively give medication to treat this, to treat that, to, “you know what, we’re actually not going to prolong your life. But, by doing that, we’re prolonging your death”. I say that to patients and patients’ families, perhaps not for their sake but perhaps for mine, to actually put me in the mood to make those decisions with them. D8

> Because we’re not just automatons, you know… do we keep this non-life-sustaining sub-cut fluid going or not? I mean put it in, take it out. But the emotional weight that was attached to removing that fluid was just awful. D9

Several clinicians described doctors appearing intimidated by outspoken patient advocates. Not surprisingly then, clinicians broadly endorsed that doctors typically seek to avoid conflict with families. Accordingly, despite a PWND tangibly seeking agency through an AHD, family members may be afforded considerable influence over treatment decisions, which may in fact reflect family’s needs and preferences.

> But if there’s family involved, we have to, quite often, go by the family wishes as opposed to the patient’s wishes. There can be a bit of conflict there because they [PWND], obviously wrote the healthcare directive when they were well and when they had capacity. D15

> There's a lot of different reasons why a doctor may not adhere to an Advance Health Directive and pressure from families is definitely in there. Because sometimes the patient may say no, I don’t want anything done but the families don’t agree with that. And when the patient hasn’t got capacity then they assume substituted decision-making whatever so it does get extremely tricky to honour the patient’s wishes. D16

> To some degree it's how much responsibility you’re prepared to take in a patient’s care… They're big life changes, yes. I think there’s – sometimes it is not feeling confident to weigh up all of those features and take a decision and be forthright about it because you may have to have conflict with family members and you may have to point out the futility that sometimes family members or patients don't want to accept. But that’s what drives a whole lot of madness in healthcare is always trying to pass the buck. D11

To avoid conflict, most doctors emphasised the importance of establishing a cooperative relationship with family to enhance decision agreement. Nonetheless, all participant groups concurred that doctors often have difficulty communicating adequately with PWND or families. Few doctors thought they had been sufficiently trained for end-of-life conversations, resulting in a common reliance on social workers when difficult conversations, such as end-of-life prognosis, were expected.

> So it just, it's again, comes back to investing up front. If you invest time, talk with the family, everyone is aware, on the same page… I think you have to portray or display yourself as someone who is genuine, who is acting in the patient's best interest. Once you've given them that confidence and they have started having faith in you I think things just happen a lot easier from there. D7

> Because people don't have the information to make the decisions…. nobody's actually told them "Oh, they're not going to get over this"… doctors don't know how to do it, and because doctors don't know how to really explain that, things are not going well. D10

> That's difficult and you probably need a few grey hairs to have that conversation a lot of the times. And it's just not possible if you're 23 to be trying to guide a conversation with highly emotional family members who just don't want to hear that because they're not going to take it from you. D11

> [How do the doctors manage end-of-life conversations?] Terribly. Terribly. Oh my God, the medical doctors, it's shameful, and that's quite often why I or a social worker would follow up with them [patients]. They've really pushed in [hospital unit] for the social worker to be present for every single discussion about end of life. AH4

> They're very medical minded and "We can fix it." …but let's not tell you about all those other things that might go wrong. So I quite like to be in those family meetings because I'm then able to prompt the family to ask those questions. I don't think the doctors do that well. They don't like to tell people that – you know, "Well you're going to die anyway". AH6

Several family members recognised that some doctors may experience emotional challenges associated with treatment limitations and a PWND's death. Only one provided an example of a positive experience of shared decision-making between family and doctor.

> The people that work there were fantastic and nurses were great, the doctors were good… I'm sure they meant well and wanted perhaps to give us a little longer with [PWND] among us. F1

> Well actually my brother-in-law is an orthopaedic surgeon and he said to me "They're [AHD] a toothless tiger." He said "If you're in bed and you've got an Advance Health Directive and your two daughters stood at the foot of the bed and they demanded that you be resuscitated and be given antibiotics, no doctor will waive this in front of them and say but your mother didn't want it". F6

> Look, there's always going to be messy situations. So in fact, the ones with the [hospital unit] people, I think were good. They were constructive. They didn't just back down immediately to anything that we said. In that sense they did their job properly to make sure that we understood. F3

The importance of leading temporal treatment plans with consent of families (as opposed to applying AHDs) reflected a means of avoiding potential conflict. Some doctors expressed that appeasing family can also be a source of discomfort, with some capitulating under pressure from family, or compromising treatment plans for a family's benefit. Some doctors feared and sought to avoid complaints from families, or legal action against them.

> And what we do is we just try and toe that line between making it a good experience for the EPOA [legally appointed substitute decision-maker] /significant other as well as respect the wishes of the patient. If it were something really startlingly obviously like the EPOA was saying you need to intubate them and we'd be less – probably a lot more forceful in our views. But, to be honest, the majority of cases are subtleties that we can happily allow them to have. We'll give them antibiotics for a week, or we'll give them fluids for a few days which is fine and as long as it comes under the banner of do no harm to the patient. When to play that, well, it's not a game but to do the dance I suppose. D9

> Like some of the stuff that we were having to do to like 80-year-old nannas that I just wanted to put a blanket on and put in a corner for some dignity, and yet their family want everything done… sometimes you also run into the problem that, yes, they want to go down a palliative pathway if they deteriorate but then when you talk to the family they're like "No, you have to keep them alive for the next three days till I get there"... it definitely plays into your mind like, if you've got a highly objective family, like it's hard to fight that because they're the ones that are going to put in the complaint and the litigation. D15

> Yes, I have pulled the “I am the doctor, I'll make a decision on some issues”. Because when there's a coronial it’s going to be my [responsibility], you know, I'm up there taking the rap. D16

4.4.4 Discussion

Exploring the perspectives of doctors, AHC/N and families of hospitalised PWND who expressed agency through ACP, revealed that these agents often experienced intra and interpersonal conflicting interests when acting as patient agents. This research appears to be the first to investigate the potentially conflicting interests between agents when a PWND who has an ACP no longer has capacity to consent to healthcare. Broadly, doctors held a strong preference for leading temporal best interests decisions in the context of the PWND’s known illness status, and they prioritised partnerships with families to meet collective needs. Families sought inclusion in temporal decision-making whilst simultaneously advocating for AHD application to respect the PWNDs treatment limiting directions, and in one case, to alleviate guilt. AHC/N maintained a unique position of influence to advocate for the PWND by promoting ACP application. Effectively, the agency of PWND may depend on the recursive relationship that exists between structures (such as hospital systems) and human agency (in this case clinicians and family) (Clark, Modgil, & Modgil, 1990; Giddens & Pierson, 1998) which can result in conflict as each of these actors retain considerable power when determining healthcare for PWND. Although well intended, temporal decision-making which favours family consent potentially conflicts with the rights of the PWND and raises questions about the utility of ACPs.

4.4.4.1 Dynamics of Discerning Best Interests

Given the complexity of healthcare and the relatively simplistic nature of ACPs, the realisation of agency through ACP is unavoidably impacted by a conflicting convergence of the hypothetical nature of ACPs and the responsibilities of bedside agents. Although PWND are encouraged to complete ACPs in their own best interests, when healthcare decisions were required, clinicians largely co-opted families to attempt best interests decision-making partnerships on patients’ behalf. PWND who develop an AHD have exercised a legislated right; hence, to overlook their agency by transferring power to family risks undermining a fundamental right of the patient.

Doctors in this study often presumed family's knowledge of the patient's intentions for ACP applicability and the appropriateness of including family in decision-making. Consistent with another study (Wendler & Rid, 2011), both clinicians and families perceived family as powerful patient agents, however family members were at times conflicted about their authority as substitute decision-makers. This situation gives rise to a potential imbalance of power associated with individual capacities such as communication skills, health literacy, self-confidence, and emotional investment in decisions, and therefore intra and interpersonal conflict when discerning patients' best interests (Shah et al., 2009; Smith et al., 2013).

Similarly to other studies (Bond & Lowton, 2011; Corke et al., 2009; Moore et al., 2019; White et al., 2017; Willmott et al., 2016; Willmott et al., 2013), doctors saw themselves as appropriate leaders of good medical practice, and advisors to healthcare decisions reflective of the PWND's best interests. Importantly, in situations where family reported healthcare dissatisfaction, they contended that the prescribed healthcare contradicted an AHD because doctors chose to overrule the patient's directive. This suggests philosophical inconsistencies in discerning best interests care. Although variable by subspecialty or individual's practice culture, doctors demonstrated tendencies towards life-sustaining treatment, as though they perceived sustaining life as synonymous with their role and patients' best interests. Through the AHD, the PWND had exercised their legislated power to give directions in what they believed to be their own best interests, yet our study revealed that doctors typically assumed clinical leadership over the PWND's best interests and prioritised temporal healthcare decisions.

Predictably, all clinician groups demonstrated high expectations of themselves and their colleagues as professional patient agents. Members of multidisciplinary teams made representation on patients' behalf which sometimes gave rise to conflicting opinions. Doctors' attitudes towards AHC/N input ranged from appreciative to feeling challenged. AHC/N attitudes towards their own contributions to treatment decisions ranged from self-doubting to confident. As noted by Olsson et al., (Olsson et al., 2020) doctors were typically identified as the key medical problem-solvers; however, this study also revealed that AHC/N and doctors associated doctors' responsibilities with the highest expectations of excellence and vulnerability to moral distress. It seems plausible then that confident AHC/N may feel empowered as patient agents, possibly because they are less constrained by the responsibilities of doctors. Collectively, clinicians from various disciplinary perspectives shouldered considerable ethical and professional standards obligations as agents for PWND who sought to influence their healthcare through ACP.

Fear of litigation has been associated with non-adherence to ACP in intensive care physicians (Gutierrez, 2012). Adding to this knowledge, numerous doctors in this study revealed their fear of misjudging situations, making critical clinical errors, and incurring litigation. Interestingly, despite significant advances in medicine and technology, or perhaps in part because of them, doctors conceded that prognostication is often challenging, a factor reported elsewhere (Nevin et al., 2020; Olsson et al., 2020). Difficulty recognising when a PWND is approaching death appeared closely aligned with delayed application of ACPs. Predictably, other research also associated doctors' recognition of patients' impending death with improved communication and end-of-life care (Houttekier et al., 2014), however, this often occurs close to death (Olsson et al., 2020). Late application of ACPs suggests the potential for provision of unwanted medical intervention and therefore revision of ACPs to establish PWND preferences should occur early, when treatment decisions might better reflect the patient's agency.

Disturbingly, some agents in our study found that their responsibilities as a PWND's agent triggered considerable inner conflict and or distress. Family members demonstrated both complementary and contradictory roles: they took responsibility for advocating for AHD adherence, whilst simultaneously asserting authority as substitute decision-makers. In reality, healthcare involves power imbalances, with exemplary communication of facts essential to achieve equitable empowerment of agents. Accordingly, when families in this study felt vulnerable to the authority held by the medical system, they exerted control and asserted their power to influence treatment decisions in line with their self-expectations.

However, roles remain unequal, with the capacity to advocate for application of AHDs compromised by inconsistent information sharing and uncertainty about the PWND's prognosis. Nevin et al. (Nevin et al., 2020) in their review described similar barriers to applying palliative care principles in acute care hospitals. They found prognostic uncertainties and end-of-life care were perceived as in conflict with acute care practice culture, leading some doctors to deflect and avoid difficult conversations. Similarly, this study identified a link between doctors' prognostication uncertainties and avoidance of timely transition from active treatment to AHD application. Further research may be needed to establish means of supporting doctors in this regard.

4.4.4.2 Avoiding Conflict

Consistent with social theory, doctors today shoulder considerable responsibilities and are forced as never before to justify their actions (Kaspersen, 2000). Patients and their families enjoy unprecedented access to healthcare information, and simultaneously, authority over healthcare consent. In response, it seems predictable that some doctors will develop fear-based, conflict avoidant behaviour patterns in the context of end-of-life healthcare consent. The degree to which doctors in this study appeared motivated to avoid conflict and extend their responsibilities beyond the care of the patient to incorporate families is noteworthy. Doctors appeared to have co-opted families, in part to mitigate potential reprisals but also on compassionate grounds. Doctors recognised that patient priorities must be respected, but they ascribed similar respect to the priorities of families, whom doctors noted would live on with memories of the PWND's healthcare and death. Unlike an ACP which remains a static document that cannot be probed; doctors and families have opportunities to interact and negotiate care. However, when negotiations do not meet their needs, doctors can become threatened by agents questioning care decisions. Clearly, modern doctors practice within complex, powerful healthcare systems and relationships, wherein patient agency through ACP is influenced by multiple agent pressures and thus stands as an ideal yet to be achieved.

Interestingly, White et al. (White et al., 2016) found Australian doctors were more motivated by ethical than legal considerations; however, when doctors doubted that a medical decision adhered to the law, family views were endorsed ahead of personal ethical principles. Accordingly, although justification of ACP non-application varies, doctors clearly exercise clinical judgement, leaving the door open to ethical reasoning. This study has highlighted doctors' protective attitude not only towards PWND, but also their families, reflecting doctors' sense of ethical responsibility which extends beyond their immediate patients. Further, these results may reflect treatment culture in a regional hospital context, which remains to be further explored.

4.4.5 Limitations

Whilst this study represents an important first step in the generation of a theory to explain factors associated with PWND's agency through ACP, the data were collected from a specific region and in relation to neurodegenerative illnesses. Although our research drew on the rich perspectives of 38 individuals, their views are not representative of all agents. It is possible that clinicians who participated were sympathetic to the concept of ACPs. Despite extensive recruitment efforts, family participation was low. Family participants held strong views about AHD application, suggesting people with alternative views may not have participated. It appears feasible that some family may not have realised their eligibility, or perhaps they did not feel strongly or wish to discuss their experience. Further, in some cases participants were known to, or colleagues of, the first author, which may have biased their responses. However, it is possible that this element represents a study strength by improving participants' reflexivity about their actions. Finally, efforts were made to engage doctors from other units and of junior status, however these potential participants declined invitations

4.4.6 Conclusion

This study provides insights into the potentially conflicting interests experienced by beside patient agents who seek to represent the best interests of PWND. Although bedside patient agents endeavour to respect patient choices, doctors feel conflicted about relying on ACP as sources of truth. Doctors do not appear conflicted by patient agency when doctors and families agree with the decisions within the ACP. Generally, doctors perceive that family cannot be excluded from a temporal decision-making partnership, elevating the needs of doctors and family beyond the agency of the PWND. Whilst not all ACPs are legally persuasive, doctors engage families and make decisions on behalf of PWND regardless of ACP legal status, thus placing bedside agents and patient agency in potential conflict. It appears that there are substantial limitations to the effectiveness of PWND's agency expressed through ACP, and that bedside agents can experience considerable intra and interpersonal conflict. The complex interplay between healthcare systems and the realisation of agency through ACP warrants further research.

Disclosure

The results from this publication are to be included in the doctoral thesis of Denise P Craig which will be uploaded to: James Cook University repository URL: https://researchonline.jcu.edu.au/. See reference (Craig, Ray, Harvey, & Shircore, 2021). The first author (DC) was financially assisted by the Far North Queensland Hospital Foundation Paul and Dina Kamsler Memorial Award, and the Tropical Australian Academic Health Centre Clinician Researcher Fellowship Scheme. Funders had no further role in the study. The authors have no conflicts to disclose.

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This article described the potential for substitute decision-makers to exercise power over incapacitated patients. When patients are relatively voiceless, doctors can partner with patient agents (such as families) to negotiate a shared agreement that doctors believe is in the best interests of patients and families. A shared agreement between bedside patient agents serves the needs of doctors by minimising the likelihood of uncomfortable social conflict and challenges to doctors’ authority. What the second article shows is doctors’ theoretical support for the primacy of patients’ autonomy, juxtaposed with the practicality of respecting the social context of patients’ lives. This social context of patient-family connectedness is referred to as relational autonomy. What follows then is the second of the publications which explains a contradiction between the claims made by clinicians about the benefits of ACP, and doctors’ power over incapacitated patients with an ACP in hospital practice.

4.5 Publication: Multidisciplinary Clinicians and the Relational Autonomy of Persons with Neurodegenerative Disorders and an Advance Care Plan: A Thematic Analysis

The following figure (Figure 4.5) demonstrates the correlation between the rationale of people with a neurodegenerative disorder for generating an ACP and the advice given to consumers by clinicians about the benefits of ACP. The figure offers an overview of the factors associated with doctors limiting patients' agency by taking a relational autonomy approach to decision-making.

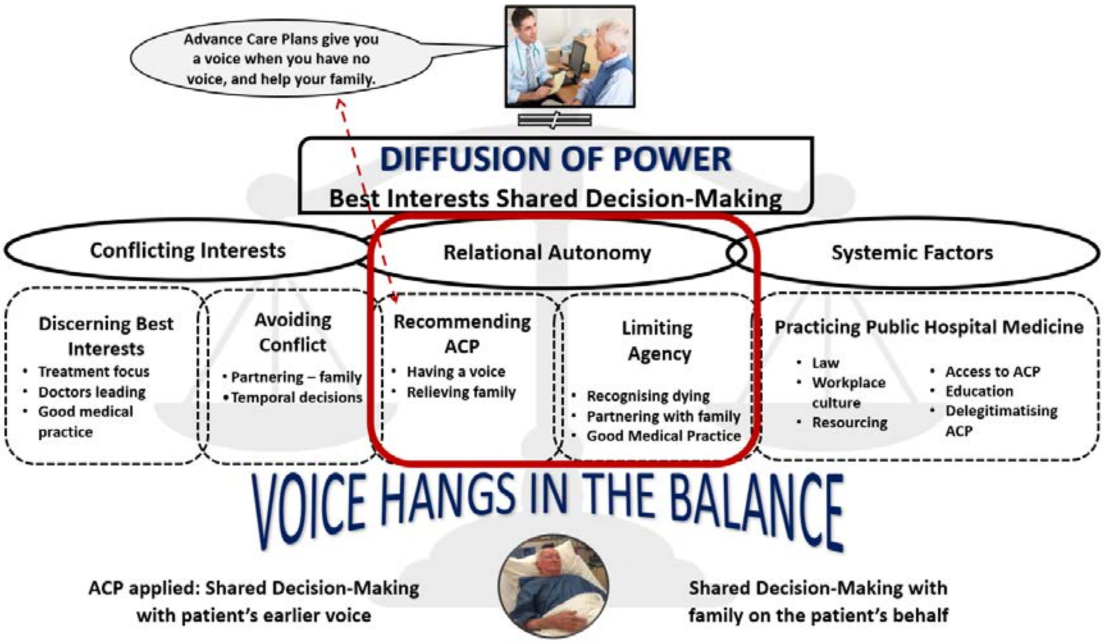

Figure 4.5: Diagrammatic representation of human factors [Part 2]: The relational autonomy approach taken by doctors

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ORIGINAL RESEARCH

Multidisciplinary Clinicians and the Relational Autonomy of Persons with Neurodegenerative Disorders and an Advance Care Plan: A Thematic Analysis

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Introduction: People diagnosed with neurodegenerative disorders often grapple with threats to their agency, prompting some to engage in advance care planning. Advance care plans are intended to protect autonomy by helping patients receive goal-consistent health-care. Accordingly, there is a need to better understand factors associated with hospital doctors' application of advance care plans to treatment decisions of this patient cohort.

Purpose: The purpose of this study was to explain the recommendations of multidisciplinary hospital-based clinicians about the benefits of advance care plans for people diagnosed with neurodegenerative disorders, and the elements that influence how doctors apply such plans.

Materials and Methods: Using a constructivist grounded theory informed thematic analysis, semi-structured interviews were conducted with purposively and theoretical sampled hospital-based clinicians: 16 doctors, six registered nurses and 10 allied health clinicians who self-reported having experience delivering healthcare to people with neurodegenerative disorders and an advance care plan. Allied health and nurse data helped to inform questions posed to doctors. Data were inductively analysed using open and focused coding.

Results: Analysis revealed two main themes: recommending agency through advance care plans; and limiting agency through advance care plans. These themes formed the basis of the core category: patient agency. All clinicians held positive attitudes towards advance care plans as a means to preserve patient voices and alleviate family of responsibility. However, the extent to which doctors shared decisions with family revealed a tension between individualistic agency associated with advance care plans and relational autonomy perceived by doctors as appropriate.

Conclusion: Although doctors expressed positive attitudes towards advance care plans, they typically practiced relational autonomy wherein they partner with family in contemporaneous healthcare decision on patients' behalf. Accordingly, the healthcare preferences of hospitalised, incompetent people with neurodegenerative disorders are balanced against judgements of both doctors and family.

Keywords: advance directive, allied health, end-of-life, hospital doctors, patient agency, registered nurses, relational autonomy

Figure 4.6: Cover page: Multidisciplinary Clinicians and the Relational Autonomy of Persons with Neurodegenerative Disorders and an Advance Care Plan: A Thematic Analysis.

4.5.1 Background

People with illnesses such as dementia, Parkinson’s Disease, Huntington’s Disease and Motor Neuron Disease (MND) live with the tangible prospects of disabling and progressive cognitive decline (Regan et al., 2019). In an ageing population, many people fear loss of autonomy and agency as a consequence of neurodegenerative disorder (Australian Health Ministers' Advisory Council, 2011; Awang, Mansor, Nai Peng, & Nik Osman, 2018). Internationally recognised dementia advocate Christine Bryden (Bryden, 2016, p.10) described her experience of dementia as a “journey of so many losses from diagnosis to death”. Consequently, people diagnosed with neurodegenerative disorders (PWND) often grapple with a threat to agency, loss of self-identity, independence, and control (Low et al., 2018).

Alongside accumulating losses, PWND are at high risk of hospitalisation in the last months of life, where end-of-life care, and death, can become impersonal and medicalised (Swerissen & Duckett; Watson & Thomas, 2018). Accordingly, PWND may choose to document their later life care preferences within an Advance Care Plan (ACP) to preserve agency (Australian Law Reform Commission). Agency is defined as an individual’s capacity to act independently and exercise free choice (Kabeer, 1999), albeit in the context of social influences that affect human behaviour (Giddens & Pierson, 1998). Grounded in a principle-based perspective (or ‘principlism’), ACPs offer a Western-styled, self-determination conception of autonomy (Robins-Browne et al., 2017; Wilson et al., 2014) intended to protect patients from paternalism (Gómez-Vírseda et al., 2019). Advance care planning represents a call to action, facilitated by structures within society, and it stands as a powerful, tangible act of agency for individuals who engage in the process.

The primary purpose of an ACP is to protect an individual’s autonomy and dignity by helping to ensure they receive healthcare which is consistent with their values, goals and preferences (Advance Care Planning Australia, 2020; Australian Health Ministers' Advisory Council, 2011; Sudore et al., 2017). Autonomy refers to a person’s capacity to act freely in accordance with a self-chosen plan (Beauchamp & Childress, 2001). An individual’s right to autonomy and maximal ownership of healthcare decisions is often reflected in modern codes of ethics (World Medical Association, 2018) and global policy (Ryan & McKeown, 2020). Further, the Medical Board of Australia has linked respecting a person’s rights to make their own decisions, including via ACP, with good medical practice (Medical Board of Australia, 2014). When working effectively, ACP support a person’s autonomy by representing the person who exercised agency whilst competent, in order to guide decisions whilst incompetent (Detering et al., 2010; Sudore et al., 2017).

Advance care planning has attracted much discourse surrounding the practical and moral shortcomings of future-focused healthcare decisions (Davies, 2002; Johnson et al., 2018; Witt, 2020). Contentions include inadequate instructions (Jimenez et al., 2018); conflicted or incapable surrogate decision-makers (Schenker et al., 2012; Smith et al., 2013); the potential of the person to have changed their mind, and limited capacity of the person to have anticipated the presenting circumstances (Mast, 2020). Further, once deemed incompetent, a person is unable to override their earlier decisions, thus binding the person to their earlier 'self'. Such a situation raises ethical concerns because of the threat to current autonomy (Davies, 2002). Additionally, individualistic interpretations of autonomy have been criticised for their failure to consider social contexts, with some ethicists instead proposing a 'relational autonomy' approach that includes socially embedded insights (Gómez-Vírseda et al., 2019). Not surprisingly then, a recent scoping review found hospital doctors globally have identified numerous apprehensions about the application of ACP in practice (Craig et al., 2020). Nevertheless, the novel coronavirus disease 2019 (COVID-19) pandemic has been associated with healthcare systems' renewed interest in ACP in an effort to better meet the needs of both patients and doctors (Funk, Moss, & Speis, 2020; Sinclair et al., 2020).

The first author (DC) of this study is a psychologist specialised in major neurocognitive disorder (often referred to as dementia). As a result, DC has held a clinical role assisting people living with dementia to better understand their legislated rights. However, both clinical and personal experience has shown that ACP application during hospitalisation has been inconsistent, and the factors associated with application were unclear. Consequently, attempted agency expressed through an ACP may be associated with ethical dilemmas impacting persons involved with caring at end-of-life. Collectively, arguments suggest that ACP may not reliably meet the needs of end-users: PWND, family or friends, and healthcare professionals.

In Queensland (Australia), legislation provides competent adults with the right to complete a statutory ACP, namely an Advance Health Directive (AHD). For an AHD to take effect, the person (known within the AHD as the principal) must be without 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 uncertain, or the doctor reasonably believes that circumstances have changed, and application would be inappropriate.

If an AHD refuses life-sustaining treatment, certain illness criteria must be met. (Please see Operation of AHD in supplemental information) Alternatively, competent adults may utilise a non-legally binding form (known as a Statement of Choices) to guide decision-makers about their healthcare wishes, values and beliefs.

For this research, an ACP was defined as a written statement articulating future healthcare preferences or directions, owned by the person and applicable only during incapacity to consent. It is important to note that in this manuscript, we refer to the overarching concept of ACP to indicate written documentation of a person's healthcare preferences. Where relevant to distinguish legislated applicability or to report specific findings arising from the data, ACP type (AHD or Statement of Choices) are differentiated. The Queensland AHD in effect during data collection was Version 4 and the Statement of Choices was Version 5.1. (Please see Supplemental Information).

4.5.2 Materials and Methods

4.5.2.1 Aims

This study constitutes part of a broader constructivist grounded theory research study exploring the factors which influence hospital doctors' application of the ACP of incapacitated PWND. Some aspects of the study, such as the potentially conflicting interests of bedside agents, are considered in more detail elsewhere (please see (Craig et al., 2021)) With the purpose and representation of ACP being to keep a person's autonomy central to medical decision-making, we set out to better understand: the attitudes of multidisciplinary healthcare professionals (referred to as 'clinicians') towards the usefulness of ACP; and the elements that influence how doctors apply ACP to treatment decisions for this group. This research represents an important step in understanding the factors associated with application of ACP to treatment decisions of hospitalised PWND, and ultimately, will help to inform a grounded theory. This paper offers a thematic analysis explaining what clinicians perceived as benefits of ACP, and the factors which have been associated with ACP application for this cohort across two regional health service areas in Queensland.

4.5.2.2 Study Design

An inductive thematic analysis approach, informed by the constructivist grounded theory principles of Kathy Charmaz (Charmaz, 2014) was used to explore and describe the perspectives hospital-based doctors, allied health clinicians and nurses in relation to the intended or actual role of ACP in healthcare decision-making. Grounded theory has become valued for its suitability to the explanation of complex and poorly understood medical-context phenomena (Wong et al., 2012). We used theoretical sampling and constructivist grounded theory analytic tools to probe participants' implicit meanings and actions to better understand the processes associated with making recommendations about completing an ACP, or treating a PWND during illness when an ACP might reasonably be expected to take effect. Constructivist grounded theory provided a trustworthy, inductive means through which to construct a theory 'grounded' in rich data.

4.5.2.3 Ethical Approvals

The National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council, 2018) underpinned all aspects of the study. Multisite approvals were granted by Townsville Hospital and Health Service Human Research Ethics Committee (54125) and James Cook University (H7930). Verbal and written informed consent from participants was approved by both ethics committees, and participants consented to publication of anonymised responses. Participant access to professional support if distress occurred was incorporated into approvals. This paper was informed by the Consolidated Criteria for Reporting Qualitative Research (COREQ) and data were maintained in accordance with the Declaration of Helsinki.

4.5.2.4 Participants and Recruitment

Two participant groups were identified using purposive and snowball sampling methods: 1) hospital doctors with experience in decision making with/for this cohort, and 2) allied health clinicians and nurses with experience delivering healthcare to the target cohort in situations where the person lacked decision-making capacity. Snowball sampling was defined as sampling that utilised existing or potential participants to identity other potential participants (Howie, 2010). Whilst doctors were the primary focus of this study, allied health clinicians and nurses were included because of their insights into the practices of doctors in the study context. Participants were recruited from two major regional hospitals and three small hospitals. All participants received written and oral information about the study and consented to interviews being digitally recorded and anonymised responses published. Due to geographical distance from the interviewer and several participants' stated preference to provide only verbal consent, four participants gave verbal consent which was obtained twice: once before and once after digital recording commenced. All other participants provided written consent. Anonymity was assured, and participants were assigned a pseudonym code. Participants were advised that under exceptional circumstances, disclosure of their data could be required by law. Participants were advised of the availability of referral to professional counselling if appropriate, however no onward referral was requested or deemed necessary.

All clinicians were recruited via health service newsletters, snowball referral and bulk emails disseminated by heads of departments. Purposive sampling from units most associated with care at the end-of-life included palliative care, emergency, geriatrics, intensive care, medical oncology, neurology and general medicine. In line with theoretical sampling techniques, some specialities (such as respiratory/renal medicine) and disciplines (such as social workers) were identified and invited to participate. Doctors from the respiratory/renal subspecialty declined participation.

In this manuscript, allied health clinicians, nurses and doctors are referred to inclusively as ‘clinicians’, with disciplines separated only where relevant to distinguish data sources or subject matter.

4.5.2.5 Data Collection and Analysis

Based on professional experience and research, the authors developed a semi-structured interview guide which was used flexibly to explore factors such the attitudes of clinicians towards the potential benefits of ACP, and the experiences of clinicians in relation to applying the ACP of PWND (see Figure 4.7). The interview guide was piloted across all groups, then changed iteratively in response to emerging theoretical concepts. Questions were adapted to reflect participant type. Clinicians were asked about their attitudes towards ACP and their utilisation of the ACP process. Interviews were conducted by the first author [DC] and primary advisor [RR], face-to-face or via telephone or ‘MS TEAMS’ online software and ranged from 20 to 70 minutes (mean of 51.9 minutes).

Clinician guide.

Explain experience treating people with a neurodegenerative disorder and advance care plan.

How are advance care plans are included in decision-making.

When are advance care plans looked for.

Thoughts about differences between advance health directives and statement of choices.

Advance care plans as helpful or unhelpful. When/what circumstances.

Role of family when your patient has an advance care plan.

Use of health directive as a consent tool.

Confidence patients understood decisions made in advance care plan.

Explaining advance care plans to others.

Ways that advance care planning could be improved.

Attitudes towards own

Figure 4.7: Example interview topics for clinicians

All interviews were transcribed verbatim by DC or a professional transcription service. To ensure credibility, each transcript was checked against the recorded interview and further observations and impressions were recorded in memos. DC coded all transcripts whilst another researcher (RR) coded a sample of transcripts, with coding then compared and discussed to enhance confirmability of the data. Coding was conducted line by line using a combination of open and in vivo coding and code books were developed. QSR NVivo 12 software was utilised for data management including organisation and retrieval of transcriptions, storing memos, coding and comparing data, and designing concept map iterations. In line with ensuring trustworthiness of grounded theory data, codes and data were constantly compared, discussed and revised as a research team (DC, RR, DH, MS) increasing confirmability of the data and minimising the potential for personal bias (Charmaz, 2014). As the analysis progressed, codes were collapsed into categories which captured recurring themes. Reflexive memos were used to explore and interpret our understanding of categories, and diagrams were used extensively to document relationships between themes and to develop an overarching conceptual framework. Data collection and analysis continued until the research team agreed that no new ideas were emerging, and data saturation had occurred.

4.5.3 Results

*4.5.3.1 Participants*A total of 32 people participated between November 2019 and November 2020. Participants represented a broad range of specialties and all self-reported experience treating PWND during incapacity in the context of ACP. Doctors were from subspecialties: emergency, general medicine, intensive care, neurology, medical oncology, geriatrics, and psychiatry. Nurses and allied health clinicians were senior clinicians from a broad range of hospital units (see Table 4.4).

Table 4.4: Participant characteristics [Clinicians]

Doctors	n 16	Senior Allied Health/Nurses	n 16
Cardiology	1	Dietitian	1
Emergency Department	2	Occupational Therapists	2
General Medicine	3	Physiotherapist	1
Geriatrics	5	Psychologist	1
Intensive Care	1	Social Workers	4
Neurology	1	Speech Pathologist	1
Oncology (medical)	1	Bedside registered nurses	4
Palliative Care	1	Nurse Unit Manager	1
Psychiatry	1	Nurse Practitioner	1
Seniority			
Registrar	1		
Senior Medical Officer	15		
Gender		Gender	
Females	6	Females	14
Males	10	Males	2
Age range (years)		Age range (years)	
30-39	6	30-39	5
40-49	4	40-49	6
>50	6	>50	5
Years of experience		Years of experience	
5-10	3	5-10	5
11-20	7	11-20	6
> 20	6	> 20	5

Data analysis revealed two main themes: recommending agency through ACP; and limiting agency through ACP. These themes formed the basis of the core category: patient agency (see Table 4.5) Participants are identified by letters: AHC – Allied Health Clinician, D – Doctor, RN – Registered Nurse.

Table 4.5: Example of the coding process [Clinicians]

Initial coding	Example Focused codes	Themes	Category
Patient choices Taking ownership Avoiding unwanted healthcare Peace of mind	Having a voice in future healthcare	Recommending agency through ACP	Patient agency
Alleviating substitute decision-makers Ensuring family understand wishes Family suffering	Relieving family of burden		
Shifting to end-of-life focus Prognosticating Triggering ACP consideration	Recognising PWND was dying	Limiting agency through ACP	
Interpreting ACP relevance Leading medical decisions Marrying law and medicine	Good medical practice		
Seeing family as experts Family having to live with decisions Wanting consensus decision-making ACP as a guide	'The dance' when partnering with family		

4.5.3.2 Recommending Agency through ACP

Clinicians were overwhelmingly supportive of the concept of advance care planning, particularly in the context of neurodegenerative illness or advancing age. Some spoke of ACP being an important means by which thought processes associated with end-of-life preferences of PWND and discussions with family are triggered. Doctors felt more confident discussing treatment limitations with families of PWND who had completed an ACP compared to those who did not have an ACP, suggesting the ACP process extends benefits beyond the PWND to both family and doctors.

When reflecting on their own potential agency as healthcare consumers, only three clinicians (allied health, nurse and doctor) had completed an AHD. Some clinicians stated they might complete an AHD when of advanced age or diagnosed with a chronic illness, whilst others indicated an intention to complete an AHD, but had not. Clinicians overwhelmingly perceived that their family were capable of making decisions and advocating on their behalf. This may reflect the socio-cultural status of highly educated and health literate clinicians with a practice culture favouring contemporaneous, shared decision-making with patient representatives. In relation to their patients, however, clinicians supported a PWND's agency through ACP, with two subthemes arising from the data: having a voice in future healthcare, and relieving family of burden.

4.5.3.2.1 Having a Voice in Future Healthcare:Clinicians considered that ACP provides a valuable means by which PWND could represent themselves when they otherwise could not. Clinicians maintained that PWND should be encouraged to engage in advance care planning to make known their healthcare directions so that healthcare could be aligned with their directions.

> It's a way of having a voice when you have no voice. RN2
>
> They may be in a position one day where they won't be able to make their wishes heard and if they can't be heard then it can cause a lot of distress for them and their family members. D9
>
> So it's up to you and what you want, and it's important that we have these documents… So I tell them that the best thing to do is an Advance Health Directive and I always say, "So you don't get something done to you that you don't want" that's the main thing…. advance care planning is really for when they are not able to tell us what they want... D2
>
> We explain to people that with the health directive, "When you can't make decisions, it makes decisions for you." RN3

Although people who generate an ACP are under no legal obligation to share their decisions or decision rationale with a third party (such as family), they are encouraged to do so within Queensland ACP templates and Australian ACP promotional materials (Advance Care Planning Australia, 2020; Queensland Government, 2019). Interestingly, clinicians appeared to associate much of the benefit of ACP with the likelihood that PWND would discuss their decisions with family. Accordingly, doctors expected that family would have a sound understanding of the PWND's healthcare priorities and therefore could speak on the PWND's behalf. Doctors then practiced what we describe as a relational autonomy approach to decision-making by engaging family to represent the voice of the PWND. Relational autonomy refers to complex and intersecting social connectedness and relationships between people (Mackenzie & Stoljar, 2000) who are invested in, and affected by, the life or death outcome of the PWND.

> It's actually pretty uncommon that the person who makes one hasn't discussed to some degree with the family members, close family members anyway, what they're going to put in there. … it is really hard for family members in a highly emotional situation to think clearly and try to put themselves in the shoes of their loved one because they're part of the picture in a different way.… D11

> If they [family] understand and know your wishes, they're more likely A). to follow them if you lose capacity and B). to be accepting because it's very distressing to find yourself having to make choices on someone's behalf when you don't know what their preferences are… family who know will often respect much more easily than those who don't. D1

> [When a PWND has an AHD] It means that they've thought about it, which is good, particularly if they've got a chronic condition which is lethal then that's very important that we get hold of that directive and to find out what their thoughts and feelings are, particularly if we haven't got good access to next of kin. Next of kin, of course, is very important indeed and they usually have been involved… and they can usually give us a glimmer as to what's in that directive but we like to see the directive as well…. None of these decisions are light, they're very carefully made decisions and they're always done with the relatives. D5

> It works out well if conversations have been had with the patient and with their family and very clear guidelines are written out beforehand. D9

In relation to generating an ACP, doctors typically recommended that people explicitly discuss their choices and preferences with their family. This advice reflected awareness that end-of-life is a relational process (Gómez-Vírseda et al., 2019; Wilson et al., 2014), impacting others (such as family and healthcare staff) who might also exercise agency in decision-making, potentially conflicting that of the patient (Craig et al., 2021).

> I think one of the most useful things for the family or the closest enduring relative or friend or whoever is in that substitute decision making role is, I think it's very important that they personally understand the wishes and preferably not just see the document, but be part of the conversation to frame it. D4

> In the end there's always the bad bit, and so if you accept that it's a finite life, you need to prepare for that and that means thinking about what's important to you, writing them down,

> communicating it to your family in case you lose capacity… and it's really important to share those things with your doctors and your family so you're more likely to get the outcomes you decide. D1
>
> I do explain it’s quite convoluted. It’d be good to chat to their family before or whilst doing it, so they’re aware and everyone’s happy and there’s no conflict when the time comes to put that into place. D2
>
> Just try to let them know that, look, this is something serious, they need to think about and need to let your family members know [about preferences for treatment]. D7

Despite asserting that ACP extends the patient’s voice, most doctors conceded they do not reliably refer to ACP. Additionally, some doctors expressed scepticism that a PWND’s agency via ACP would be valued by future treating doctors, with implications for advising people to complete an ACP. Therefore, variation in practice culture leaves patients vulnerable to individual preferences of treating doctors.

> [Interviewer: How confident are you that your doctor colleagues will follow an ACP?] Not super confident and I think that that’s just based on predetermined thought processes and depending on if their value systems really changes things. D8
>
> I am not confident at all that the effort that people put into trying to make sure that their wishes are known and adhered to, actually, that it is rewarded. I don’t believe that they’re always searched for and thought about…the ARP [Acute Resuscitation Plan] is often done by a statutory health attorney, and this person [PWND], themselves, did an AHD, and that’s not what’s been used to inform the ARP. D2
>
> So working in [UNIT], for instance, where everyone coming in will likely need surgery which has a lot of attendant risks, usually what they will do is they will have an informal chat with a statutory attorney for health matters, or the patient. They don't usually refer to an Advance Health Directive. D3

4.5.3.2.2 Relieving Family of Burden:Despite patient healthcare being the central purpose of medical decision-making, results revealed that doctors extend considerable empathy towards families, indicating a tendency to take a relational autonomy view when caring for patients.

Accordingly, clinicians perceived ACP as helpful because they alleviate family member's burden when making difficult decisions.

> I've witnessed that they have the comfort of knowing that their decisions are backed up by their relative [PWND]. It's never easy to say stop providing active management but at least they can say well that's what he wanted. D9

> It takes that responsibility away and it relieves the burden a little because your family knows this is your choice. AH8

Doctors recognised the emotional toll and long-term consequences felt by families involved in end-of-life decision partnerships. Therefore, ACP to lessen burden was endorsed. Although well intended, it was evident that doctors at times coerce individuals to engage in ACP, a process which ethically and legally must be voluntary. In so doing, the burden of decision-making is imposed on patients as a means of protecting family.

> I would usually use this phrase that "It is not fair for your daughter or your son to make these decisions …. So to be fair to everyone I think while you can, you probably should make it very clear what you want done" D7

> Mostly to point out that it's going to protect their family members from having to make really difficult decisions in really difficult moments. D11

Collectively, results revealed that doctors recognised the potential benefits of ACP, not only for establishing a person's healthcare priorities, but also as a mechanism for guiding and relieving family. Doctors also recognised and valued the importance of relationships that surround a dying person, thus involving these relationships in the decision process.

4.5.3.3 Limiting Agency through ACP

Perhaps not surprisingly, the critical limitation to agency through ACP was the necessity for doctors to agree with the directions expressed in the ACP. Most doctors explicitly prioritised family consent to healthcare, rather than defer to the statutory AHD. Doctors stated they may rely on an AHD if no family were present. ACP application data revealed three subthemes: recognising the PWND was dying; good medical practice; and 'the dance' with family.

4.5.3.3.1 Recognising the PWND Was DyingRecognising that the PWND was dying was broadly endorsed as the primary trigger for doctors to read and consider applying the person's

ACP. Clinicians commonly asserted that doctors are treatment focused and only apply an ACP when illness is irreversible and end stage (Browne et al., 2021; Richfield & Johnson, 2019). Despite the availability of tools designed to assist doctors to recognise dying in people with diseases such as Parkinson's Disease (Richfield & Johnson, 2019) and dementia (Browne et al., 2021), prognosticating end-stage neurodegenerative illness (in the absence of cancer) was considered to be particularly challenging because of unpredictable illness trajectory. Accordingly, doctors asserted they see fewer 'flags' to review ACP. Therefore, although the purpose of ACP is to give voice during periods of voicelessness, the inclusion of the person's voice may only occur after (potentially unwanted) medical intervention consistent with hospital doctors' treatment culture and their inability to recognise palliative phases of neurodegenerative illness until death is imminent.

> I wouldn't be doing it [reading ACP] the first time I see a patient because I'm supposed to be there to help them. I look more at the advance care planning when I start seeing that things are deteriorating, or when I see that …. it's pretty much at the end… Only when it's pretty clear that things are not going the right way, that's when they would apply it, only last resort. Health wants to have them [AHD] just for the very, very last minute, not for in between, not for beforehand, because we are here to help people. D10
>
> I think, again, the more unwell a patient is, the earlier we will look for that plan. D12
>
> The way I look at ACD [Advance Care Directive] implementation is different for cancer patients compared to all the other end stage diseases, which are equally bad, but for some reason, we are cancer focussed when it comes to death. So, cancer patients, they end up at an acute end emergency department, there are enough flags raised, "oh, this patient has cancer, has a prognosis of three months, there's an ACD, should we just comply with it", very easily. For non-cancer patients, so to some extent, because of the studies that cancer – the research that has gone on in cancer, we have life expectancy slightly more clearly delineated compared to advanced renal disease, or advanced dementia, where you don't really say "well, you are at this stage, your life expectancy is five years, two years, one year". Even people with a life expectancy of six months, we don't know if they have severe dementia. So there is no flag raised at the front end. D6
>
> You know, things like MS [Multiple Sclerosis] and motor neurone and all that, they can be going up and down and you don't know if this is it or if it's not… these neuro ones can be hard because you just don't know... Whereas cancer, you just look at the blood results and you can pretty well prognosticate pretty accurately. RN2

> There's a lot of grey in terms of the medical team may not know the prognosis or they may not know whether this is a curable or recoverable illness that the person has… I'll often feel troubled because I'll think they keep giving the patient all of this stuff and I'm pretty sure they're going to die in a month, a week or a couple of weeks but the medical team aren't saying that. They're saying, "No, no, no, we're aiming for curative intent..." So the dialogue is very much that the patient's not dying… but I kind of, like in my gut I'm kind of like… they're not going to survive, and then it's resulted in their last few weeks have been full of potentially unnecessary medical treatments and interventions. AH9

4.5.3.3.2 Good Medical Practice

Pursuant to the *Guardianship and Administration Act 2000* (Qld) and *Power of Attorney Act 1998* (Qld), doctors in Queensland are excused from applying AHD directions which they deem inconsistent with good medical practice. Not surprisingly then, most doctors stated they would only apply directions which they judged to be consistent with good medical practice and in the person's best interests. In evaluating good medical practice, doctors considered healthcare principles such as beneficence and nonmaleficence.

> I would definitely discuss it with the family and say "the advance document said this, we need to think about what's in their interest"… medicine has great capacity to prolong life, but doesn't always bring benefit or there comes a time when the benefits are outweighed by the harm... the issue words were good medical practice and I think that's a subjective thing. D1

> It's Advance Care Planning for your wishes but it has to be… consistent with accepted good medical practice... Now if it's a different matter like it's a neurodegenerative thing, someone's got a motor neurone disease and they come in with aspiration pneumonia and there's no possibility of them getting better and the health directive says "don't do anything", well we wouldn't do anything, that's fine because that's consistent with good medical practice and it's consistent with what they thought and it fits the scenario that they were likely talking to their GP about… The problem is, is when you've got an Advance Health Directive and no relative. And you've got somebody who's unconscious… in neurodegenerative disorders, you know, we would be very loath to, but in that particular situation where they were otherwise well… we'd probably intervene and just fix them overnight and say it was a simple problem and you're better now. D5

> It becomes very challenging when it goes against good medical practice - I use that as a specific legal term - and when family have a dissenting opinion… I think that there also needs to be, in some cases, discussion about good medical care and philosophical changes in care,

> particularly towards end-of-life. I've seen many people say that they want very invasive treatments when you know if they become critically unwell their likelihood of survival is very, very low. And it would be, to use an ethical term, it would probably be a futile medical treatment. And whether or not we actually should give them that option is a real – there's some nuance there that you need with some clinical experience I think. D8

> The treatments that are not really likely to be a great help and they're actually very burdensome, they cause pain or else they cause a high degree of monitoring or interaction with health staff that is just overall not going to provide a great benefit. And I make that judgement and then use whatever resources I have to try and go towards that direction. D11

> As a doctor in this country we are not obliged to provide medical treatment that is futile. D12

In practice, partnering with patients and families and traversing the boundaries between patient autonomy, best interests and good medical practice appears fraught. One doctor described dissonance resulting from the application of an AHD which contravened good medical practice. This case highlights the potential impact of individually autonomous directions that induce discomfort and perhaps unintended consequences for others, such as family and clinicians.

> I can tell you specifically about a particular religious group. [PWND's relative] had very bizarre healthcare ideas or theories or however you'd like to – and [PWND] ascribed to that particular healthcare belief system as well. And it was completely polar opposite to good medical practice. And we had an Advance Health Directive which, unfortunately, was very non-specific and from a different jurisdiction which made it quite complicated. But, in the end, we managed to navigate a pathway which was consistent with the patient's healthcare beliefs which was completely opposite of good medical practice. It wasn't particularly in the family's best interests either but, I feel, it was in – and everyone in the end came together and was accepting of that decision, I suppose, using the healthcare directive and what is known of her healthcare beliefs… Very challenging, very time consuming. We spent days and days on this case and even when you reflect back on it, I'm still not sure if I did the right thing either. And it's hard for a medical practitioner or even allied health who were involved in that decision-making as well, and family. So it's quite challenging. D8

4.5.3.3.3 'The Dance' with Family

Not surprisingly, both participant groups overwhelmingly considered family to be patient experts and therefore valuable PWND representatives. Interestingly and in contrast to individualistic agency associated with ACP, data showed a strong tendency of doctors to favour a consensus model of decision-making which reflected a relational autonomy reality. Although AHDs are intended to provide patient consent, most doctors asserted that it would be rare to apply an AHD without obtaining consent from family.

> We try a softly softly … approach, you know, go in and gauge their feelings on things… and then maybe the next day going back in and saying “how do you think they're doing? I notice that you're still wanting them to have fluids… you know, it’s clear that his wishes were this and how can we help you get there?” … it’s not black and white… We’ll give them antibiotics for a week or we’ll give them fluids for a few days… as long as it comes under the banner of do no harm to the patient. When to play that, well, it’s not a game but to do the dance I suppose. D9

> I fully understand that I probably don’t know that person particularly well either so I probably don’t know what is best for that particular patient either. So, sometimes from a family perspective, they’ve lived with them for 50 years, they’ve been caring for them for 30 and they know what their mum wants when they have lost capacity… I use their judgment because they know them. D8

> I don’t think we could say “It’s all there we’re going to follow the health directive, ignore you guys”. We still need to go back to them [family] and say “It’s not working” or “getting worse”, or “we should really stop”... you can’t ignore – you can’t bypass that. D14

> That can be quite annoying because, it’s like, well, they’ve got their wishes there, like it’s all written down. But… you still need the family onside and stuff when they’re in hospital. D15

Despite their relational autonomy approach, several doctors referred to tensions between effecting the wishes of the PWND and the practice of partnering with family. Data revealed challenges associated with relational autonomy, in part because family members may not be regularly or proximally involved with the PWND yet become involved at a critical juncture of healthcare. In essence, taking a relational autonomy approach can add complexity to decision-making.

> I think that you need to work with the patient, the document and the family member to come up with a plan which is okay. In terms of family, there's a whole bunch of considerations that need to be taken into account and I use the ‘relative in California’ type syndrome where it can be performed by someone who has no direct involvement in the patient’s care and might not actually be the best person to be making those decisions... So challenging, always challenging. D8

Interestingly, doctors were often aware of a legislated hierarchy of decision-making, yet they frequently referred to relying on a person recorded within medical records as a 'next of kin'. In Queensland, a person recorded as next of kin may, or may not, be the lawful decision-maker.

> The Health Directive is supposed to be the number one before all else, but in reality, next of kin, for us normally, is like a spouse would be number one. D15

> I don't think that they're referring to the official hierarchy of consent that we have. I mean, some states have a very explicit hierarchy of consent, Queensland not so much. I think it's really whoever presents themselves as being somebody who's in a close and continuing relationship. I think it's just whoever presents themselves as next of kin. Sometimes it's formalised, so if you get nursing home patients it will be next-of-kin is listed, sometimes it's whomever is listed in the existing hospital records. It's a bit ad hoc. D3

> [How is a substitute decision maker ascertained?] Sometimes on their care facility's pages of information they send they've got an EPOA or whatever, or it's just the next of kin and then you phone the next of kin and ask them. D12

Despite the potential power of life altering healthcare directions contained within an AHD, the written mode by which patients retain 'a voice' is controlled by others. Some doctors considered that AHD lacked nuance and therefore applicability to most situations. Several chose to read an AHD only in situations where medical options had been exhausted, or no family were available to provide information or to contest the PWND's decisions. In the absence of family, ACP provided a useful opportunity to learn about a patient's preferences. Consequently, absence of family reduced one possible barrier to ACP application, and therefore PWND agency. This factor has been addressed in detail separately (Craig et al., 2021).

> Healthcare Directives are quite often "if there's no quality of life" or "it's not reversible" or whatever, like it's quite broad in its terminology and stuff… if there is a Healthcare Directive [and] there is no family to contend it… we can translate that onto an ARP [Acute Resuscitation Form] form like saying that this is the patient's wishes. D15

Collectively, the extent to which doctors engaged family consent in a shared treatment plan revealed a tension between individualistic agency through ACP as provided for in law, and application requirements as perceived by doctors.

4.5.4 Discussion

This study provides insights into the attitudes of clinicians towards ACP as a mechanism for agency of PWND. Whilst there was considerable support for ACP, the realisation of agency of PWND was limited by family and doctors who asserted their own agency as contemporaneous decision-makers. We found evidence that agency through ACP was usually only actualised when curative options had been exhausted and the person was dying. Broadly, despite the PWND's attempt to exercise agency through an ACP, doctors' attitudes reflected a collective, relational autonomy reality. Specifically, the extent to which doctors engaged with their patients' ACP was associated with doctors' capacity to recognise approaching death, and further, the importance doctors placed on relational autonomy through shared decision-making with family.

4.5.4.1 Recommending Agency through ACP

In line with modern ethical practice principles, a common theme throughout this study was the importance doctors placed on respecting the healthcare priorities of their patients. As with another Queensland-based study (Willmott et al., 2013) clinicians overwhelmingly supported the concept of ACP as a means of individuals taking healthcare ownership. Further, ACP represented an important mechanism through which to reduce burden felt by family. Comparable with the findings of Leder et al, (Leder et al., 2015) some clinicians asserted that due to the emotional nature of a loved family member's death, ACP are often more valuable to family than to doctors. In this study, doctors recognised complex social and cultural underpinnings of their patients' autonomy, beyond that implied by individualistically oriented ACP.

The consistency with which doctors acknowledged the connection between patient and family revealed a tension between individualised autonomy as provided by Queensland law (through AHD), and the interconnected nature of relationships recognised by clinicians. As a measure of the importance placed on patients' significant relationships, doctors considered family should share in temporal treatment decisions. Therefore, family were assigned a partnership role, sometimes by interpreting ACP relevance in the given circumstances. Not surprisingly then, doctors generally recommended that the ACP process should include dialogue with family to facilitate decisional agreement. In essence, realisation of agency through ACP of PWND reflected a philosophical dispute between legislated individual-leaning agency and the practices of doctors which favoured a collective (or relational) agency approach.

4.5.4.2 Limiting Agency through ACP

Agency through ACP for PWND as inpatients is clearly complex. Despite advising consumers that ACP provide a voice for the voiceless, most doctors constrained this voice by not reading ACP unless treatment options were exhausted and death appeared imminent. Evidently, some doctors do not recognise (Browne et al., 2021), or acknowledge PWND deterioration, and application of ACP is delayed. In line with other studies (Moore et al., 2019; White, Willmott, Cartwright, et al., 2017; White, Willmott, Williams, et al., 2017; Willmott et al., 2013), doctors emphasised that ACP are only applicable when consistent with good medical practice and in the person's best interest. Best interest judgements, however, are often influenced by socially constructed norms (Giddens & Pierson, 1998) and potentially unconscious values associated with doctors' agency (Billings & Krakauer, 2011; Giddens & Pierson, 1998). Despite the legally persuasive AHD being established to apply the patient's voice to consent or treatment refusal, most doctors did not use them for this purpose. Instead, as stated above and in other research (Moore et al., 2019), doctors incorporated the voices of family in a medically led, shared decision model on the patient's behalf.

However well-intended stakeholder actions might be, this study suggests significant limitations to the agency of PWND, at least through ACP, in the hospital context. Doctors consistently presumed that families would have been involved with the person's ACP and that family are efficient sources of establishing patient preferences. Literature, however, cautions against the reliability of family as informants, with biased and variable capability well documented (Fritch, Petronio, Helft, & Torke, 2013; Kwak, Wallendal, Fritsch, Leo, & Hyde, 2014; Pope, 2012; Shah et al., 2009). Conversely, others have conceptualised family as ideally placed to enhance patient autonomy, typically through relational knowing associated with their shared history (Robins-Browne et al., 2017). Importantly, cultural variance of both clinician and patient may be associated with end-of-life care preferences (Frost et al., 2011) and attitudes towards the role of family at end-of-life (Bullock, 2011), making cultural sensitivity essential at this time. Doctors in this study adopted a temporal and relational autonomy approach to respecting the healthcare preferences of PWND.

Further important limitations to the individual autonomy model, as represented by ACP, seem relevant to this discussion. For example, Gomez-Virseda, De Maeseneer and Gastmans (Gómez-Vírseda et al., 2019) in their review pointed out that certain conditions are required for a decision (such as within ACP) to satisfy ethical autonomy criteria. These criteria include, but are not limited to, that decisions were made without interference (such as coercion) and that the person was sufficiently informed. Current ACP processes in Queensland do not adequately address these requirements. For example, there are minimal protections in place to ensure a person understands the implications of their decisions, and those who do engage in ACP are free to exclude medical advice. Additionally, some doctors in this study admitted pressuring patients to participate in ACP, potentially contravening ethical and legislated prohibition on coercion, and thus inadvertently jeopardising autonomy.

A major contention against individualistic autonomy is the argument that people exist as interconnected beings, as part of a broader social context, and therefore individualised autonomy disregards the social values and autonomy of others (Gómez-Vírseda et al., 2019; Wilson et al., 2014). An alternative interpretation of ethical decision making recognises the different and potentially competing interests to be balanced (Craig et al., 2021; Wilson et al., 2014). Shared decision-making partnerships between patients, families and clinicians are seen by some bioethicists as more appropriate to end-of-life decisions (Gómez-Vírseda et al., 2019; Wilson et al., 2014). However, people who complete an ACP to restrict involvement of their family, may be disempowered by doctors who presume the supremacy of collective decision-making, or who do not read the patients' 'voice' (expressed through ACP) in a timely manner.

Importantly, legislative and healthcare systems have acknowledged the right of persons to hold views, make choices, and take actions based on their values and beliefs (Australian Health Ministers' Advisory Council, 2011; Medical Board of Australia, 2014; Queensland Clinical Senate & Health Consumers Queensland; Queensland Government, 2016, 2018a, 2019; Royal Australian College of General Practitioners, 2012). However, for good medical practice to be maintained, respect for this right must extend beyond a supportive attitude to supportive actions (Beauchamp & Childress, 2001; Gutierrez, 2012). With ACP an institutionally sanctioned offer of choice, it is beholden upon stakeholders to respect an individual's agency by respecting their ACP. Failure to do so contributes to morally problematic false promises (Johnson et al., 2018). The extent to which an incompetent PWND's agency is either subjugated behind that of doctors and family, or enriched by relational autonomy, may be open to interpretation by the reader and PWND who are promised a voice through ACP.

4.5.5 Limitations

This study has some limitations. Firstly, we acknowledge that the study may lack cultural relevance to some groups within society who may offer alternative explanations for ACP application. Secondly, the data were collected from a specific region and with a focus on neurodegenerative disorders and relied on self-reported experience of clinicians. Accordingly, results are not intended to be generalised to other populations or all doctors. Thirdly, the first author was known to several of the participants which may have biased their responses. We consider it likely, however, that this factor provided a study strength by supporting participants to reflect about their attitudes and experiences. Fourth, despite efforts to engage doctors from other units and of junior status, the study did not achieve engagement from all sectors or doctor seniority. The study did, however, achieve good representation from senior doctors of varied age, gender, subspecialty, and years practicing. Finally, with data collection occurring during the novel coronavirus disease 2019 (COVID-19) pandemic, positive attitudes towards ACP may have predominated, reflecting a heightened interest in end-of-life care at that time.

4.5.6 Conclusion

In the context of our study, we have examined the attitudes of doctors towards patient agency through ACP and the restricted circumstances within which the ACP is likely be applied to healthcare. We found that doctors prioritised engagement with family for consent to treatment, usually without reviewing the ACP. In essence, doctors practice relational autonomy when they envisage that families understand the person's likely wishes, and collectively, doctors and family partner in contemporaneous healthcare decision on patients' behalf. Doctors' protective concern for family, and their tendency to prioritise active treatment, forms a limitation to realisation of patient agency through ACP. Accordingly, inpatient agency is balanced against judgements of both doctors and family. Further research may herald insights into the system factors which impact ACP application.

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4.6 Further Analysis

During the immersive process of refining thesis chapter drafts, I went on to reflect on two additional concepts associated with the application of ACP which were not explained within the two publications presented in this chapter. These are *social power*, and *wicked problems*, which I discuss here.

4.6.1 Social Power

Further analysis of the human factors evident in medical decision-making illuminated that it is the roles available to those with social power that become dominant and may appropriate the patient’s voice. I considered that the concept of social power in the data, specifically *power-over* (the ability to influence others), *power-to* (used to counter dominance), *power-within* (personal power), and *power-with* (sharing power to increase others’ power) (Laverack, 2004) required further exploration. Power-over relates to an individual's dominance at the expense of another, resulting in a win-lose (or zero-sum) outcome (Laverack, 2004). Power-over is often associated with status (Laverack, 2004), such as doctors who are recognised as illness experts with the authority to provide or limit patients' access to healthcare resources. In the context of my research, a consumer may seek power over a doctor by generating an Advance Health Directive, however, a doctor exercises power over the patient by discerning the applicability of the Advance Health Directive. Alternatively, consumers can also be understood to be exercising their *power-to*, which refers to resisting a dominant model, in this case, medical paternalism (Berger, 2005). Persons who generate an Advance Health Directive have responded to their potential voicelessness by exercising state-sanctioned power to resist unwanted healthcare (Berger, 2005). Similarly, family members exercise their power to advocate when they encourage the application of the Advance Health Directive. Given the variability and complexity of patients' circumstances (often described in this research as *grey*), the outcome of doctors' power over patients' Advance Health Directive could represent either a win/lose or win/win outcome. What is clear is that doctors' authority, status, and power over incapacitated patients provide opportunities for medical dominance over patients, with or without considering an existing ACP. Consider the following quote from a participating doctor:

> If you've got a patient who's in a nursing home but has just broken their hip, a hip fracture in an elderly person is devastating and the person is in severe pain… it's been a well-established practice in medicine… that we fix that hip. Unless the patient is going to die within 24 to 48 hours with another problem, maybe even at 72 you might, but again, that would be a judgement. We decide to fix that hip even though it's an invasive surgical procedure. Why? It's palliative. It's like you're giving a morphine infusion because it stops the pain… sure it's often lethal in these situations and yes, they may have severe dementia… as far as I'm concerned, if you're going to fix the hip and go through all that process we don't want them dying in recovery… and making it a coroner's case and making it hard for the families… we'll put them in ICU overnight. The next day they're fine… So we often like to suspend the Advance Health Directive if we're going to do that procedure because if they say "not for intensive care", well you know, if you're going to do the procedure, do it properly or not at all. D5

However, through ethical guidelines and law, modern medicine has made progress toward transforming doctors' paternalistic practice culture by requiring doctors to share decision-making (a *power-with* concept). For example, doctors are obliged to partner with patients and obtain informed consent to non-urgent healthcare. In practice*, power-with (*or a win/win, non-zero-sum outcome) medical decision-making is dependent on doctors' willingness (power within) to engage with other stakeholders. Doctors retain power over stakeholder engagement and therefore the degree to which their practice facilitates (or transforms) the power within others. In this research, doctors engaged both *power-over* and *power-with* strategies by controlling the extent to which they responded to patients' ACPs versus formulating a contemporaneous treatment plan in conjunction with the family. Interestingly, doctors' behaviour was often influenced by the power of multidisciplinary clinicians (allied health clinicians and nurses) who demonstrated their transformational *power within by* effectively negotiating with doctors on behalf of patients. Although doctors retain responsibility, authority, and power over the application of an ACP, in this research, their experience of exercising their power was balanced against the power of bedside patient agents. However, whilst enacting this power, bedside agents are faced with difficult and complex decision-making, or *wicked problems*, causing emotional anguish.

4.6.2 Wicked Problems

My thinking has evolved to conceptualise the application of ACPs as meeting several of Rittel and Webber's (1973) *wicked problem* criteria. Wicked problems defy clear problem statements and definitive resolutions (Rittel & Webber, 1973; Varpio, Aschenbrener, & Bates, 2017). They are social systems problems that are complex; plagued by ambiguity and uncertainty; bounded by constraints (such as political and technological); often involving multiple decision-makers with conflicting values; and with ramifications that confuse people (Buchanan, 1992; Horn, 2001). They have been described as *socially messy* problems (Horn, 2001) wherein stakeholders such as patients, their doctors, families and multidisciplinary clinicians can be expected to disagree in their interpretations of problems and the most appropriate solutions (Ritchey, 2013; Varpio et al., 2017). Importantly, for every wicked problem there is more than one possible explanation and perhaps solution, and every problem is a symptom of a higher-level problem (Buchanan, 1992; Rittel & Webber, 1973). Hospitals and their doctors are in place to treat illnesses, and ACPs are most often used to resist or limit the medical treatment which doctors might offer. The complex, irreversible and often emotional nature of applying an ACP which might become associated with a patient's death can thus plunge patient agents into a socially messy terrain of *wicked* human experiences. As expressed by one doctor:

> You see it time and time again, most doctors will act on anxiety, time pressures, feeling like they might make the wrong decision or let people down. That's very much the core of a lot of doctors' behaviours around Advance Health Directives. It's about anxiety. D16

Not surprisingly then, doctors often traverse shared decision-making in a way most agreeable to themselves, which results in ACPs remaining unread.

4.7 Human Factors Summary

In summary, within this chapter I have demonstrated that people with a neurodegenerative disorder and clinicians were congruent in their beliefs about the purpose of ACP. However, the application of ACP is associated with wicked problems which are influenced by *human factors* (namely social power) and thus, the patient's voice hangs in the balance. The human factors revealed in this research indicated that although doctors maintain considerable power over vulnerable patients, in turn, doctors are vulnerable to the power of bedside patient agents. This finding suggests the potential value of healthcare systems fostering an authentic *power-with,* multidisciplinary approach to partnering with incapacitated patients through ACP. Power, as represented within hospital doctors' practice, disproportionately results in medical paternalism, albeit amidst a shifting power dynamic that sees hospital doctors having to negotiate with others. Having acknowledged the dynamics of human factors that impact doctors' decision making, my research also exposed factors associated with working in the hospital environment that impacted on doctors' choices. The systemic influences on doctors' power and practice related to the application of ACP are discussed in the following chapter.

Chapter 5: Systemic Factors

5.1 Introduction

In Chapter Four, I provided evidence of human factors present in shared decision-making without a patient's direct, informed, temporal consent. Here, within Chapter Five, I consider the application of Advance Care Plans (ACPs) through the organisational lens of the public hospital system that doctors represent. Patients (*outsiders*) who enter a hospital for healthcare have entered the powerful organisational workplace of doctors (*insiders*). One reflection on this concept of *inpatient-outsider* versus *doctor-insider* power asymmetry can be found in a memo in which I wrote:

> The patient who has X medical condition/s and is now in an *institution* is therefore somewhat bound by the rules of the establishment. The patient is *stuck* in a position of being in someone else's domain where they can expect workplace cultural variability. Doctors are in their workplace, their *office*, and they've worked out a way of being and managing their pressures. For example, an ARP documents a decision, an agreement between parties, so in theory everyone can be all right. It's current. It's clear. It's simple to construct. It's encouraged. It ticks the boxes for working with patients/families. But it's a short-term view of treatment – it's not holistic. Is that what much of medicine has become? Right here, right now - very little big picture foresight going on – 'so, dear patient, my focus is on treating you and then out the door you go'. This seems better in small towns because they do see patients come back and they seem to take a bigger picture view. (July 2020)

What follows is my analysis of the *systemic factors* which contribute to doctors' non/application of their patient's ACP.

5.2 Background

Dying is not primarily a medical event (Watson & Thomas, 2018), yet death is increasingly medicalised and occurring within hospitals which are typically busy environments where doctors prioritise active treatment (Buchbinder & Harris, 2021; Gawande, 2014; Swerissen & Duckett, 2015). Sadly, end-of-life hospitalisation risks patients enduring a treatment burden (Shepherd, Waller, Sanson-Fisher, Clark, & Ball, 2021) that they sought to avoid through advance care planning (Nguyen et al., 2017; Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007). It is worth noting that the Royal Australian College of General Practitioners assigns such value to advance care planning that it refers to it as “the embodiment of person-centred healthcare” (Royal Australian College of General Practitioners, 2012). A recent review of Advance Care Plans (ACPs) held on Queensland Health’s electronic *ACP Tracker* revealed that ACPs uploaded there have been most associated with treatment limitations, indicating that Queenslanders in recent years have most often established an ACP to avoid unwanted medical interventions (Queensland Government, 2020c).

The law which governs withholding or withdrawing life-sustaining treatment in Queensland, namely the *Power of Attorney Act 1998* (Qld) and *Guardianship and Administration Act* 2000 (Qld), is complex (White et al., 2016; White et al., 2014; White, Willmott, Williams, et al., 2017; Willmott, White, Parker, et al., 2016). Research consistently demonstrates that Queensland doctors have significant gaps in their knowledge of the law as it relates to withholding or withdrawing life-sustaining treatment (Parker, Willmott, White, Williams, & Cartwright, 2015; White et al., 2016; Willmott, White, Close, et al., 2016; Willmott et al., 2011a). Doctors tend to take a medical approach to decision-making, regardless of the law (White, Willmott, Cartwright, et al., 2017). Despite this, Queensland Health does not systematically evaluate doctors’ knowledge of patients’ rights associated with withholding or withdrawing life-sustaining treatment or ACP, and professional development on the subject remains voluntarily. These findings indicate a shortcoming in governance that could foster the potential for doctors to delegitimise ACP, and therefore patient agency.

In 2011, the legitimisation of ACP in healthcare settings was bolstered by the Australian Commission on Safety and Quality in Health Care (the Commission) which was established to lead national improvements in safety and quality of healthcare (Australian Commission on Safety and Quality in Health Care, 2019). The Commission developed National Safety and Quality Health Service (NSQHS) standards to protect the public from harm and to improve the quality of health service provision (Australian Commission on Safety and Quality in Health Care, 2017). Importantly, the second edition of the NSQHS standards (in effect at the time of my research) specifically highlighted the role of hospitals in upholding patients’ rights to autonomy through ACP (Australian Commission on Safety and Quality in Health Care, 2017). As a result, to comply with NSQHS accreditation standards, health service organisations must meet ten essential elements which include the implementation of processes that support advance care planning as part of comprehensive care delivery. Further, health services are to develop policies and procedures to manage risks; share decision-making with patients or their representatives; and utilise systems that support clinicians’ awareness of patients’ goals and preferences (Australian Commission on Safety and Quality in Health Care, 2017). These standards signify an intention of the Commonwealth to improve opportunities for patients to have a voice through ACP; for their voice to be heard despite incapacity; and thus, for incompetent patients to retain power by contributing to shared decision-making.

Queensland's public health system is established as a federated health system through the Hospital and Health Boards Act 2011 (State of Queensland (Queensland Health), 2020). Under this governance model, hospital and health services have direct responsibility for the provision of public health services and are accountable for their performance through a Board to the Deputy Premier and Minister for Health and Ambulance Services (State of Queensland (Queensland Health), 2020). The Department of Health takes the role of manager of the State's health system with statutory responsibility for a range of functions including strategic planning and commissioning healthcare services from a range of providers including hospital and health services (State of Queensland (Queensland Health), 2020).

To its credit, Queensland Health, in its role as a systems manager, has provided infrastructure through its ACP Tracker (Tracker) which was developed specifically to enhance ACP processes. However, training in the use of the Tracker is not mandated and doctors may not be familiar with the application's capability. It is also worth noting that Queensland public hospital and health services are responsible for implementing their own ACP policies and procedures which increases the potential for variation in commitment to ACPs. To support doctors, in 2018 Queensland Health published guidelines that were intended to inform and encourage the inclusion of ACPs in routine practice. However, ACP implementation training was not mandated and attempts by clinicians to access ACPs remained voluntary. To complicate matters, access to ACPs requires cooperation from patients (as document owners, referred to as the *principal*) or their representatives. In some cases, representatives have conflicting interests (Batteux et al., 2020; Schenker et al., 2012; Shah et al., 2009; Smith et al., 2013; Wendler & Rid, 2011) which may impact their collaboration and advocacy for doctors' use of an existing ACP. Accordingly, ACP accessibility appears multifaceted and problematic.

Despite the contentions of leading ACP organisations such as Advance Care Planning Australia (Advance Care Planning Australia, 2020) that ACPs help to ensure patients' preferences are known and respected, Queensland Health has encouraged rather than mandated doctors' perusal and consideration of patients' existing ACP (Queensland Government, 2018a, 2018b; Queensland Health, 2020). At the same time, Queensland Health has promoted the use of Acute

Resuscitation Plans (ARPs), describing such plans as an important part of ACP processes for inpatients approaching their death (Queensland Health, 2020). Essentially, by completing ARPs, the health system partially meets its ACP obligations by providing a process through which patients (or representatives) and doctors discuss and plan the medical response to patients' organ failure. Accordingly, it stands to reason that a doctor may complete an ARP without reference to patients' prior ACP, wherein the voice of the now incapacitated patient is lost.

Given the emphasis on ACP by some sectors (Advance Care Planning Australia, 2018; Queensland Government, 2019) including the Commission (Australian Commission on Safety and Quality in Health Care, 2017), the role of Queensland Health in the application of ACP must be understood if patients' voices are to be heard. People who generate an ACP are exercising their lawful right to maintain a voice in healthcare. However, medical decision-making for incompetent inpatients is multifactorial and occurs within a large and complex organisation. This chapter explores the enablers and barriers inherent within the Queensland public hospital system to explain the systemic contributions influencing doctors' non/application of ACPs to treatment decisions of incapacitated persons with a neurodegenerative disorder.

To avoid repetition, the method section has been omitted from this chapter.

5.3 Results

Six interrelated themes were identified through the data analysis process. The first theme, law, provides the overarching background to the application of ACP to the decision-making of incapacitated people with a neurodegenerative disorder during hospitalisation. The remaining themes of education, resourcing, access to ACP, workplace culture, and delegitimatising ACP, all discuss how systemic factors play a role in the application of ACP. Figure 5.1 diagrammatically represents the systemic influences on the application of ACP in public hospital practice (see Appendix I for example coding tree). 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, which I refer to as *power*, is diffused by the best interests shared decision-making systemic power present within public hospital practice. The patient's voice hangs in the balance whilst decisions are made by others.

Within the following data, participant groups are identified by letters: AHC – Allied Health Clinician, D – Doctor, F – Family, PWND – Person With a Neurodegenerative Disorder, RN – Registered Nurse, and a participant number.

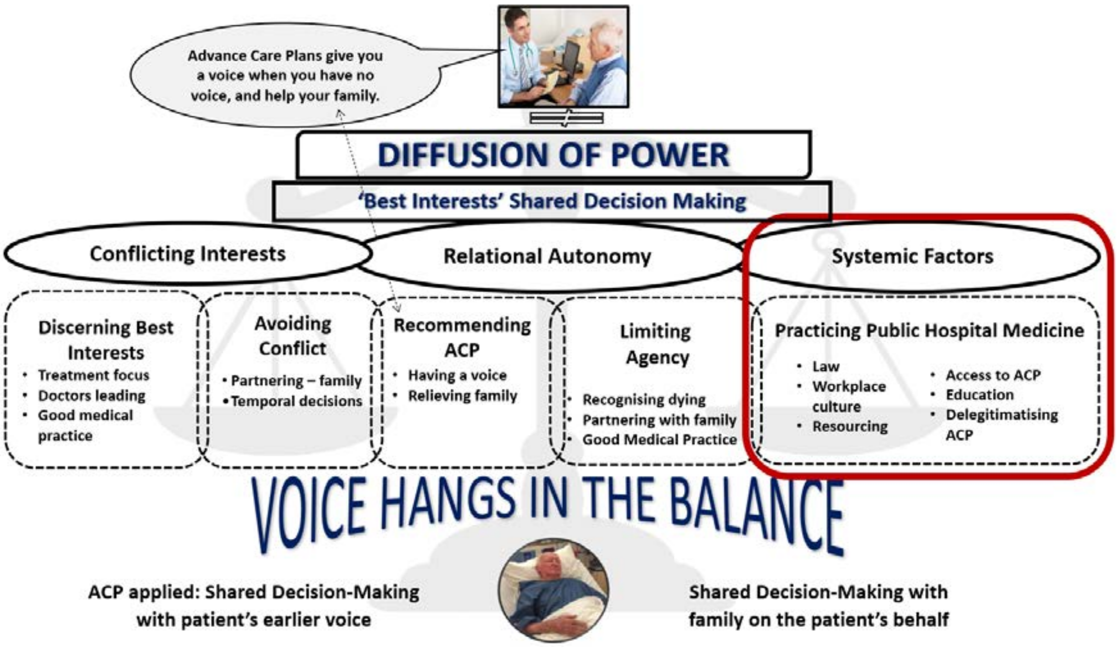

Figure 5.1: Diagrammatic representation of the systems factor themes

5.3.1 Law: Practicing Medicine within a Legal Construct

Doctors in this research 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 appeared to manage competing responsibilities by prioritising their interpretation of what constitutes the practice of ethical medicine.

> These are legal constructs, they're not medical constructs, so we're trying to apply medicine to what is a legal construct, and they don't always mesh particularly well. 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 necessarily understand it either. I mean, for instance, with this withdrawing of care and things like that, 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 and pressure groups and so, consequently, the law is mishmash, which is incomprehensible, unfortunately, because of all the different scenarios that can come up from it which have never been envisaged by the people that did it… that can be quite problematic. D5

Some doctors were sympathetic to the complex task of legislating healthcare, and they recognised difficulties associated with achieving alignment of medicine and law.

> I've worked within the context of what is there from a framework point of view. I do certainly empathise with the level of grey that these discussions, these laws have. But you can either go too far and it's too prescriptive and then no one will fit into the box, or you can have really big boxes and then it will sort of fit everyone. And so I understand that there's a bit of balance there and I really think that's our job as clinicians and leaders and holistic care providers to really navigate that for a patient I suppose. So I try… I don't have a problem with it I don't think. D8

> I don't know how much I want it to be legislated because the law doesn't fit with medical decision sometimes… I don't think we're ever going to have a very clear guideline that makes all the complicated cases easy. I think that the difficult cases are always going to be difficult and there are always going to be some that don't fit in with the regular pathways, even if we've got really tight laws. D16

However, one senior nurse spoke of doctors engaging the legal system to avoid patients' treatment refusal.

> The problem with the legal approach is that it has to fit all. It's not a subtle instrument and it doesn't take account of the person…. the legal model tries to do no harm, but in the process, does not address the outlier as well… But we [in healthcare] are moving through to more respect for the individual. However, once again talking of those outliers, for the person where the care-providers would see that that doesn't fit with their version of interventional healthcare, they would still find that difficult and I think that they would pursue a legal model… whether or not the patient thought it was burdensome. Our legal model, whilst it's trying to be safe, results in patients getting care that they don't want, that they find intrusive, and that worries me because that tells me that the care-providers don't know enough to respect the individual, and that healthcare still visits upon some patients burdensome care. That, in some cases, even gets to the point where they try and fight not to have it. RN6

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

> I haven't gone and read the laws themselves but part of the education that I was referring to very clearly said that 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 and that I find that reassuring enough. The courts have always supported doctors' decisions about limitations of care, which is very reassuring. I'm glad it's like that. D11

> I haven't specifically looked into Queensland Law because I haven't had to come across it specifically because … I think, it's like a national umbrella for healthcare workers and doctors that medical judgement is very important. And so like I don't, we're kind of 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 completely futile, or we're inflicting pain and torture on a person for no reason, no benefit. My understanding is that we're protected under that sort of circumstance and so, I don't think, yeah, I haven't had a run in with the law yet. D15

Most doctors revealed gaps in their knowledge of ACP legislation. They associated their limited understanding of the law with the complexity of the law and cited a need for law reform.

> Queensland Health has some good policies to read but at the end of the day the law's too grey and far too ambivalent in a lot of areas… There're so many grey areas, 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. And I mean, that's the problem with the law in that everyone goes on about ignorance to the law is no excuse and all the sort of stuff but, nevertheless, the law is a university degree, so you expect people to understand it despite not going to university. So there's this disconnect between reality and their own thoughts on ignorance of the law is no excuse is a catch phrase which comes out all the time from the coroner, which is just plain stupid. I just think that they feel that the laws should be reviewed and be … and maybe made simpler… particularly the laws on withdrawing care and things like that are very, very complicated. D5

5.3.2 Education as It Relates to Law and End-of-life

State-based laws and non-specific education programs leave doctors at risk of significant gaps in their knowledge of Queensland legislation. Overall, doctors appeared inadequately prepared for Queensland's complex legal framework.

> So, it's very, once again, it's [legal education] very limited. Medical school, there's … we did do a fair bit… they do a reasonable bit these days, but you've also got to do 50 million other

> things… some of it’s part of your training, the problem is, for instance, your speciality exams are nation-wide, and laws are state-based, so, there’s not a lot of good … it makes it very difficult to create a framework for assessment. D4

> I trained at [Name] University and in medical school… [had a] one-hour lecture every week for 12 weeks and then you got a test on it. It was very factual, “this is the law”. There wasn’t a great deal done on ethical decision-making. You talk about non-maleficence and beneficence and autonomy and justice as your four basic principles and that was about it really. D8

> When I was going through medical school, which admittedly is a long time ago, we really had no [legal education], nothing, zero. It never even was discussed... and we still have problems now because… legislations are very different in Queensland compared to Ireland or America. It’s an unusual piece of legislation... 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 realise that the law is different here… [How well is law taught to doctors now?] Poorly. I think medical school particularly. Education is very important… there should be a complete subject of law. D5

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 or, you know, remember that last case where we had this and we couldn’t do that because of that section of the law or whatever. But there's variations in practice. You know, one doctor won't do exactly the same as the next doctor which is very challenging. D8

> We quite often do these sessions and we do incorporate some of these things and there’s a lot of discussion on the ward and education of juniors. But for the difficult situations, I’ve learnt a bit and talked a bit with the legal… but it’s problematic. D3

> 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

Interestingly, one doctor recommended that education and professional development should be enlisted to help normalise the subject of end-of-life. This quote highlights a workplace culture of death denial and the potential need for a covert approach to the subject.

> When we train people, they need to cover that [end-of-life] component as a standard practice... [end-of-life] needs to be part of the curriculums but integrated into active treatments and not separate, like palliative care guys [give] a separate lecture. So every disease, every disease setting, medical, nursing, allied health, they all need to have end-of-life management and palliative care as one of the management options in med school, or taught in med school, nursing schools and allied health schools. And then in the hospital sector, end-of-life planning has to be one of the management plans for all patients... If palliative care is incorporated into every topic then suddenly… every doctor is trained to recognize the continuum… If you said today is an update on Parkinson's Disease, say you have 50 people going, then the lecturer then says, "I'm going to talk about the active treatment, and then, when things get worse, palliative care and end-of-life care." So you've got 50 of them now forced to hear that message. D14

Similarly, doctors recognised the need for targeted end-of-life education and the implications of ACP, not just in their discipline but in the community in general.

> [What would you recommend?] Teaching end-of-life and quality of life at university. Bombarding the current professionals with the knowledge… so that they understand how society is actually asking us to be a bit more aware of this. And society needs to understand that we're not going to live forever… even though society is wanting it [ACP], it needs to learn what it's actually wanting, because I don't think a lot of people realise what it means to apply an Advance Health Directive. D10

5.3.3 Workplace Culture

Another persistent theme was the influence of workplace culture as a factor in the application of ACP, with two subthemes emerging from the data: socialisation of doctors; and deferring to ARP.

5.3.3.1 Socialisation of Doctors

Hospital doctors' workplace culture typically prioritises diagnosing and actively treating patients in their care. Accordingly, doctors in this research often focused on a medical model of patient care which did not incorporate timely consideration of ACP.

> Once you go in [to medicine], you're kind of trained to love people. Trained to be empathetic. It's all training, you know, it's not like naturally you are a kind, generous person. It's just you are trained now… it will happen over time, but there will be people, if the training hasn't been balanced, then the doctors might be more treatment based... 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 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

> Whether it's orthopaedics, it's general surgical, medical, acute medical, it's all the same picture as, "You've come into hospital, this is your diagnosis, this is what the treatment is for that diagnosis and we're going to put it in place unless we hear otherwise". AH3

Clinicians also recognised and acknowledged the variability of organisations, training, and subspecialties in influencing doctors' socialisation towards, or away from, ACP application.

> Obviously there's disciplines with familiarity with Advance Care Directives, so palliative care, geriatric medicine, general medicine I would say, as well. There are surgical specialities… I think it's something that they're peripherally aware of and it's more just around the pragmatics of here's a person we have to take to theatre and there are attendant risks. D3

> [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, haematology… they often do far more heroic things because a lot of the times their patients do have big bounces, do big improvements. 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 orthopaedic team, it won't be given the same priority as if you're on a general medicine [ward]… D4

> My discomfort is probably more around working with medical fraternity and how they're going to react [to applying an ACP] and whether or not they're going to get in the way… when you look around the hospital and you look at the way people die, it's not system-dependent,

> it's doctor-dependent and team dependent because if you get the right person at the right time, you'll get a good death. AH7

However, doctors appeared to prefer learning from more senior doctors, implying a form of closed (*insider-insider)* workplace culture.

> It doesn’t necessarily help if you have outside people coming in to give lectures. If you had senior doctors talking, they’d be more receptive, if that makes sense. So, it’s education but also a cultural change as well. D16

Interestingly, data from larger hospital systems were associated with doctors being subspeciality and episodic illness oriented, thus socialising them away from holistic care.

> I think rural doctors actually end up having to do it [exercise holistic perspective] quite frequently because tertiary hospitals tend to be so sub-specialised that it's pretty hard to get a sub-specialist to address the whole person and say “OK well, sure I can fix this kidney but is that going to be a good thing overall for the patient”. D11

> Often when people are having those sorts of things [ACP] done in hospital, particularly, ARPs, you’re basing the information you give and what’s happening on this very discrete event. And if it’s been a heart attack, you might focus on their heart and what’s just happened and what things are like now versus looking at their whole situation. D2

Additionally, system complexities associated with professional boundaries were apparent in this data when multiple medical specialists were involved in a person’s care. This factor was coupled with unclear leadership of decision-making which subsequently can undermine the application of an ACP.

> Some people didn't feel that it was their role because they were very much disease centred and they'd come in to talk about the disease… or they may not have been clear about their role because they weren't clear as to who was actually responsible for the patient, they didn't want to usurp someone else’s role. If you’re seeing three and four specialists, who is the doctor who is taking overall command? I remember once I came to a meeting where this person is seeing a haematologist, a medical oncologist, got some imaging done, and seeing a surgeon and a respiratory physician and having been admitted under a general physician… each person just treats their disease and no one actually coordinates it all... the technician doctor just does his or her technician thing, doesn't think about the whole of the patient's interest. D1

The cultural focus on the diagnosis rather than the person led families to experience depersonalization of the person with neurodegenerative disease.

> There was a friend of ours who's an anaesthetist at the hospital… He'd come down every day and suck [Name] out. I didn't have to ask for it. And he said to [Name] one day, "You realise you'll just be the bloke with MND, you're not a person in here. You're just another – bed 22". F2

> In a sense they were all compartmentalised. They were only looking at him from their speciality. They were not actually looking at the whole situation… they were only seeing what their treatment might do for his body, not part of the whole picture. F3

On a more positive note, two nurses described practice culture as changing away from the medical *appropriation of patients' bodies* (Frank, 1996, 2009), towards greater respect for partnerships with patients.

> I think it's a culture change, a big shift in culture. I think as a health system, we had a way where we thought we owned people's bodies and what should be done with them, whereas now I see it as a shift to a partnership... Like, "how can we help you?" RN2

> I think that we've come a long way in healthcare. Religious beliefs of the care-providers, cultural structures within the healthcare system, used to just get in the way. And they got in the way with permission of society. Now I think that, certainly in my experience, there is a greater respect for difference. We're not there yet though. We still bring with us a Judeo-Christian first-world approach. And for those people who have a different perspective than that, I'm sure, they still have issues within the system. But we are moving through to more respect for the individual. RN6

Despite apparent developments in shared decision-making, some doctors resented losing medical power to non-medical substitute decision-makers. In so doing, doctors demonstrated a tendency towards the healthcare system's appropriation of knowledge.

> I think therefore, the decisions are being made at a point where people are in a least best, potentially the least best position to make these decisions. And I think there are a lot of problems with the substitute decision-making situation. I think you need a licence to drive a car, you need a licence to have a dog… But there's no, there's very little governance, there's very little training in the substitute decision-making both in terms of a legal and an ethical framework to guide people. One minute they're a child and the next minute they're supposed to make life and death decisions about their parents unexpectedly. D4

> I'm not just talking about ACD, I'm talking about decision-making in general. Weightage given to family members or decision makers is extremely high and very binding in Queensland... In [country], the final arbitrator of a decision is the doctor, and the patient's family may have their view, but a doctor can confidently say "that's not the right thing for the patient" and is not bound by the decision of the family. But here, I mean, essentially, they hold extraordinary powers. D6

5.3.3.2 Deferring to ARP

The second workplace culture subtheme indicated that doctors overwhelmingly conceptualised the ARP as the ACP type of most relevance to hospital care. Directions provided within an Advance Health Directive were considered potentially useful when completing an ARP, however ARP take precedence over other ACP during hospitalisation.

> 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 that I can see clearly, this is what they've documented that they want, and this is what they don't want… very black and white. I know exactly what I need to do. D12

> The ARP is complementary in hospitals. So, it's very important to clarify, to utilise any Advance Health Directive that exists to guide the discussion about the Acute Resuscitation Plan. I think those, the terminology is correct, that *advanced* indicates that this is a long-term view of their health, and *acute* means you're in hospital, something might really go wrong, what do you want them to do? D13

> One of the things I say to people is when you come into hospital, they might get you to look through this piece of paper that covers you in hospital, and then the Advance Health Directive covers you whether you're at your GP, in the community, in an ambulance. AH4

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

> The problem with the ARP now is 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 up priority, in a way, which is usually registrars do that because they know it's "you need to do this, you need to do this, you need to do this" because it's part of protocol. D10

> Most of the time people will look for at least an Acute Resuscitation Plan, at least, if they've had previous admissions… I'd have to check the Queensland Health policy, but obviously an Advance Health Directive trumps. 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 Queensland Health patient… it's a limitations of treatment plan. D3

Doctors conceptualised ARP as the most succinct and recognisable format for inpatients' acute resuscitation planning.

> Speaking from personal experience the priority has always been knowing what the patient's resuscitation status is… the first priority through the acute take, depending on how sick a patient is, it's always about making sure that there's an Acute Resuscitation Plan in place and the rest can be sorted out the next day or later in the admission. But I must be very honest to say that I don't think a lot of those people will be spending time to try to follow it up further. I think once we've seen an ARP documented for us it will be like, OK, well, ARP's in place. I think that's good enough. D7

> I find quite often with the nursing home patients with dementia and stuff they'll come in from the nursing home with their Advance Health Directive, and it is useful for us to know that that's what their wishes are but I do find that the hospital doesn't always acknowledge it or follow it unless it's specifically translated onto the ARP document because they want that ARP document in the hospital. D15

> We would be more looking towards the ARP side of things as well. "What do you want in the event of cardiorespiratory arrest?" For most other people that come in with an acute event… we will go through an Acute Resuscitation Plan with them and that will be the biggest guide. D13

Despite the binding nature of Advance Health Directives, doctors appropriate the patient's voice by consulting substitute decision-maker/s when generating an ARP. Accordingly, subsequent decisions documented within both Advance Health Directive and ARP may be inconsistent.

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

However, one doctor identified a preference for relying on the Advance Health Directive, on legal grounds.

> The ARPs are problematic; again, ARPs were introduced really without really comprehensive sort of legal opinion in my view and I think that they are somewhat problematic, ARPs. And it's much better to have an Advance Health Directive, much better. And then the ARP must reflect the Advance Health Directive. It must, with very few exceptions. Sometimes there will be exceptions simply because the Advance Health Directive is not consistent with good medical practice. D5

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 Advance Health Directive.

> That [Advance Health Directive] 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 Advance Resuscitation Plan… The Advance 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 contemporisation of it as well… If we've made an Advance Resuscitation Plan here, I don't tend to encourage people to go and get that exhaustive document done because I feel like it's protected us. 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… so I think certainly in larger hospitals there's a lot of ARPs that are created that are completely useless, that should never have been written because they don't, 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

> I think, in general, ARPs are done incredibly poorly. What I see frequently, particularly from junior doctors, is a menu type system of these are the things we can do, you can pick and choose as you want. And I don't think that that's a hand-in-glove approach to good medical

> care. I think we're obliged to review them every year, for ARPs anyway, that's actually often missed locally. So in the hospital, we just go "There's an ARP, it says do not resuscitate" and so that's fine but we don't look at the need to review it. D8

Further, ARP processes are not transparent, leaving the receiving clinicians potentially blinded to decision-making processes. Despite this, clinicians must judge the appropriateness of applying the ARP to the given situation.

> It depends who has filled it in and you obviously don't know the level of discussion that went into it, but – so generally, if I look at it and I think "Well, that's appropriate for this patient, I think I would agree with that", or if the patient has expressed their own wishes on the back, then I think "Great, I'm fully confident with that. I can go with that." D12

5.3.4 Delegitimising ACP

*5.3.4.1 Assigning Responsibility to General Practitioners (GPs)*Data revealed a clear and potentially problematic disconnection between the perceived roles of GPs and hospital doctors in ACP development. Hospital doctors considered that GPs were best placed to engage patients in holistic advance care planning, despite simultaneous uncertainty about the resource capability of GPs.

> I just say… talk with your doctor… having a good general practitioner or having a doctor that knows them very well and who can bring together all aspects of that patient's care… it's not in our scope to be able to sit down with a patient for an hour's discussion… I have no idea what's set up in the community in order to do that. Whether or not it's in the capacity of GPs to - part of their nurse-led clinics for people who come into a certain age and demographic as part of the healthcare plan. Sit down and say "right, we're going to discuss this". D9

> I think that's the role of the GP, promoting it, helping people understand it, having that non-confrontational community based [discussion process], when someone is well and at their best and able to, really, give it some good thought, rather than feeling under pressure in a hospital environment, where they're probably not that well. I think that's the role of the GP as well, [to review ACPs] making sure that it is still relevant and it's still current. D2

> GPs have a difficult financial conflict of interest, often. It's hard to do these things in 15-minute medicine, or 10-minute medicine… There's no special billing item that allows them to really sit down for an hour or two and actually work out what the story is and what the processes are. D4

However, some clinicians directly referenced the phenomena of disconnected primary and hospital healthcare. Data suggested that patients' family members and GPs, as well as hospital doctors, can have a limited understanding of the applicability of the Advance Health Directive.

> They [family] said "oh well that was ages ago, with her GP, does that mean that this [Advance Health Directive] takes into account now?" They thought that was because it was to be done with the GP only, not in this emergency situation… Even her family thought that that was just a GP thing, it wasn't actually to affect the current situation that was in front of us. AH1

> There's such a disconnect between community medicine and hospital medicine, you know; what goes on out in the community, signing an Advance Health Directive, has really very little bearing about what happens in the inpatient units. And also, you know, vice versa, the hospital doctors don't realise what it's – if they've been in a hospital all the time they don't realise what it's like to be out there in general practice world managing these very complicated patients and trying to keep them – so part of the problem here is the disconnect I think. D16

5.3.4.2 Distrusting ACP Processes

In an apparent vulnerability to the lack of transparency inherent in ACP documents, data revealed a pervasive lack of trust in the ACP process. Despite asserting that ACPs are best completed with GPs, some doctors expressed concerns about GPs' limited knowledge of complex conditions, with several idealising the inclusion of specialist advice when developing ACPs. However, most doctors argued that hospital-based specialists are not resourced to contribute to ACP development.

> It would be useful if any of the GPs have done a term in ICU during their residency to have seen things because I think a lot of it comes from experience and seeing what those interventions actually mean for people. I'm sure a module…. where the statistics of survival from CPR and some of the outcomes… [then] present to people "look, you've entered this age bracket, this is the reality, if this happens you could put the risks of what you might want in a directive". But I don't think there is an ideal system because I think it's something that always will get reviewed when they come into hospital. D15

> 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. For example, in this patient, the palliative care specialist and the oncologist should be involved in the education of the patient before such a decision was made, rather than a generalist who doesn't have the same depth of knowledge. And number two, a very clear

> description of all possibilities that can happen to them, and then saying yes or no, and for that you need a specialist. A specialist can help give them all kind of probable problems they can face in future, based on their condition. D6

Doctors also acknowledged that comprehensive communication between hospital specialists and GPs is variable. Accordingly, a person's capacity to complete a well-informed ACP may depend on the type of communication between GPs and specialists.

> You need the relevant specialist to be able 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 do well and we don't always – so if I'm prompted directly by an insurance agency or a GP to give an idea of prognosis I will reluctantly do so. Because – but I guess the point is that I don't always say it in the clinical letter unless they really want to know about it.... D9

> The problem is, is you can't cover everything, and the AHD can't be super complex, and we don't have enough sets of hands to sit down with every patient and their families and go through it. So, we're resource poor in that area. But if you're talking about an ideal setting, I do think having the GP… and it would be a multistep process, initial discussion, then feedback from people. The specialists from their major comorbidity areas that know them and then collate that information, re-discuss, finalise and come up with a, come up with something that's relatively easy to understand and straightforward, that's not 100 pages. D13

Doctors cited their concerns about ACP processes as a powerful reason for their reluctance to accept an Advance Health Directive as lawful informed consent.

> The problem is, there are occasional scenarios they couldn't have possibly envisaged… you've got an Advance Health Directive… and you're not sure whether the scenario has been discussed… Every time I've gone against Health Directives it's been accepted by them in the next day or two when they've got better. The Advance Health Directive is something which has been done with the GP, again, nothing wrong with that except that not every scenario will have been discussed, whereas we can discuss the present scenario with the live person [substitute decision-maker], which is much better. D5

> If I had an AHD that was 20, 10, five years old, again, comparing that with their wishes now I think is really important. But then, in terms of legality, I'd probably actually seek advice there because it's complex… When you look at the Advance Health Directive it's all so very specific. So it doesn't cover a lot of clinical scenarios in that it is a yes or a no scenario. And almost always a patient has ticked all of the yes's or all of the no's. So I'm not sure that there

> is a completely informed consent when filling out that document… Trust is really hard, you need to be able to trust that assessment. And, I don't know, I personally put stock in quite a few clinicians more than I might some others because of personal judgments, that kind of thing. D8

> If we're working down from the most powerful document the Advance Health Directive, the wording can be misleading in terms of things like having antibiotics and not, you tick a box, not necessarily understood in terms of outcomes, and the same with fluids and hydration. I mean hydration generally and nutrition and so on, that requires a bit of explanation. I think often the person's goals are clear but they're not sure what impact the medical interventions will have on those goals. D1

Interestingly, one doctor described having limited trust in Queensland's ACP witnessing processes and the potential ulterior motives of stakeholders.

> You have to trust your colleagues because you've got to be very careful about raising these questions, both politically, legally, and ethically. You wonder about some of the GPs and the EPOAs and all those sorts of things, there's a lot of questions around the regulation of this space… how on earth is a JP qualified to make capacity decisions, similarly lawyers… There're ones that you wonder about whether they had the capacity and the ability to do them. And there's ones that you wonder about the security of the current system where signatures look a bit strange, and you wonder about the timing and the setting of putting them in a context of their overall illness picture. D4

Alternatively, another doctor (who had experience as a GP) showed a tendency towards assuming diligence of the Advance Health Directive establishment process.

> When I was working in GP practice and I sat down with my patient we would sit there for 30, 40 minutes going through each individual thing and say this is actually what you're discussing, this is what you're saying you don't or do want. So my assumption that I have is that that's been done for everyone. D8

Another systemic weakness in ACP processes is the potential for a person to record binding decisions within an Advance Health Directive and not revise the Advance Health Directive despite changes in healthcare wishes. In the absence of a systemic trigger to review ACPs, responsibility for revisions resides with the ACP Principal (such as a person with a neurodegenerative disorder), and Advance Health Directives remain legally applicable despite the passage of time and/or a change of mind. Doctors argued that systemic changes to review processes should be implemented.

> I did sort of limit it to not to have much treatment but at that stage when I filled it in, I had gone down quite rapidly. Now that I actually picked up a big bit and plateaued out in the ten years, there's some things that probably don't mean as much to me because I did it in 2010 when I thought I was dying… I'd like them to go through it and to ask any questions that they have problems with, and for me to be able to respond if I can, and then they can give me their feedback, and then we can have another talk about whether I want to change anything. PWND2

> Particularly in the setting of something we know will be progressive, but for all people, there should be scheduled revisits… keeping it up to date as part of your [GP] health check. You don't put people on blood pressure tablets and go, "OK, well, that's good, we're done". You continually check their blood pressure. You adjust things as required. Advance care planning should be no different. D2

> If there's some capacity to get it uploaded onto the e-Health Record that would be really useful. But it's also something that needs to be reviewed like regularly so that we can trust that the information on there is correct. D15

In an interesting twist, despite a degree of ambivalence towards Advance Health Directives in non-urgent situations, one doctor has relied on Advance Health Directives when deciding whether life-sustaining treatment should be provided or withheld in emergent situations. However, when asked about a personal preference for either an Advance Health Directive or a Statement of Choices, this doctor's response highlighted tensions between succinct directions and adjunct explanatory detail, and the responsible doctors' uncertainty about the principal's awareness of the likely outcome of directions and therefore whether the ACP includes informed consent.

> Health directive. I think it's highly dependent on who's filling it out, how much detail they put in it, but also in a crunch, when you need to know whether you need to do CPR or not, in the middle of the night at 2 am you need a tick box… you've never met the patient, you're completely dependent on what you're told on the phone… there does need to be the ability to have dichotomous decisions... terminal illness, having a terminal cancer, that is very different than having a cardiac arrest which … the AHD… talks about processes, it doesn't talk about outcomes or potential outcomes. D4

5.3.5 Resourcing: Constraints of Limited Resourcing

All clinician groups referred to limited resources and variable treatment priorities as factors that reduce engagement with ACPs. Clinicians associated Key Performance Indicators [KPI] with pressure to create efficiencies and therefore reduced availability of time spent with patients.

> The medical teams really, I mean, they're the biggest cohort. They have about 40 per cent to 50 per cent of all the admissions in the hospital at any one time. They're averaging 200 admissions a day so there is that time factor. I don't think ED do it [access ACP] well at all because that's not their purpose, right. They don't dig deeper. It's just what's the main point, how do I get you out of here? When they go on to MAU [Medical Assessment Unit], it's a bit more, they've got a little bit more flexibility there, but the doctors are like "We've got 48 hours, sort it out in the community". AH4

> When a patient presents to the Emergency Department, there is a very big push [KPI] to quickly get the patient out of the department and up to a ward area. RN5

One doctor connected the outcome of under-resourcing with fear-based clinical responses.

> I think it's, for most of the doctors, a lot of their decisions, I think, are made on anxiety and they feel that they – one, 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

Despite these barriers, doctors recognised the importance of spending the time necessary with patients.

> For me I think if we had the time or to have allocated more resources it would be good to know what their [person with a neurodegenerative disorder] wishes would be. D7

> I think that the greatest barrier that we have that we're coming across in contemporary medicine is the constant drive to create efficiencies and to have, to put people in, non-medical people into roles like this… But with the constant sort of drive to move along five minutes, you know, efficiency, efficiency, efficiency, that is the part that we're losing, and that is where we are creating issues for ourselves in other areas such as this [ACP]. D13

> They said it's an acute situation, we can override it... that's really playing God, and some people, and some doctors play God… If someone had sat down and listened a little bit more

> and investigated a little bit more, they would've realised that the [symptoms] were because she had a severe Alzheimer’s Disease.... D10

For some doctors, the inclusion of ACP in treatment decisions was related not only to time constraints but also to the extent to which doctors trusted the judgement of other clinicians.

> I don’t think that we often spend enough time with our patients from a medical officer point of view… It’s hard. We do need to have a high level of respect for the clinicians that are seeing the patient. Trust is really hard, you need to be able to trust that assessment and I don’t know, I personally put stock in quite a few clinicians more than I might some others. D8

> It comes down to factors such as time pressure, and the fact that in a, particularly in a public hospital, as a consultant, you’re rounding … you’re not necessarily seeing the patient every day... if you’re there every day then your juniors aren’t getting experience… the frequency of your reviews and the intensity of your reviews will change based on… the trust level and the capabilities of your team. D4

5.3.6 Accessibility of ACP

A persistent theme throughout most data was timely access to ACP. Results clustered into two thematical categories: accessing ACP is voluntary, and; being ill-equipped to access ACP.

5.3.6.1 Accessing ACP Is Voluntary

Proactively seeking access to ACP is a discretionary and voluntary undertaking. Clinicians have numerous (potentially competing) responsibilities, and consequently, prioritising access to ACP is clinician dependent.

> Well it’s not mandatory, and there’s so much mandatory stuff now with people, like you’ve got to do a falls assessment, and a smoking assessment, and a this assessment, and a that assessment… it all takes time, and so in a busy medical system, people don’t have time for it… it is on the checklist to ask… and it’s up to the individual [clinician] to explore it further. RN2

> If I have a very unwell person and I start rifling through their notes to try and find out what’s going on in their medical history and I notice that there’s an Advance Health Directive. I’ll open that and have a look provided I have time because in my opinion that has been recorded by the patient at a time in their life when they’ve been able to think quite carefully about what they would want in that situation. D11

> Doctors don't have time to look at it, you've got other allied health clinicians trying to look to see if it exists and they don't look all the time, unless you've got integrity or, you know, the willingness to go in and scoop more into it, it gets dismissed. AH1

In situations where doctors seek access to their patient's community-generated ACP, doctors are dependent on the ACP being provided to them.

> It has to come in with the patient. The nursing home patients normally will send them through or hopefully have, if they're a frequent presenter they'll hopefully have one on file or will have done an ARP and we've got it in our system. But if it's someone from the community that hasn't really engaged with the hospital a lot and then has a crisis, if they're from home or whatever and we don't have access to it, we don't have access to it. I don't know if with the new e-Health records whether or not they're getting uploaded. I haven't actually seen any online. So essentially, they have to have already had contact with the hospital previously in order for us to access that information. D15

> 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 with, you know, for the paramedics, it doesn't always happen here. D3

One doctor perceived that Queensland Health could encourage ACP completion and improve ACP accessibility by employing hospital-based Advance Care Planners.

> Thinking back when I was at [Hospital], what seemed to work well… was for every patient that came into hospital there was one person who was designated to advance healthcare planning. So they would visit everyone if they hadn't already had the discussion and they'd sit down and they'd go through, not necessarily the nitty-gritty of end-of-life, but introduce to them the idea of EPOA and Advance Healthcare Directive. And I thought that that worked really well because then you'd see the knock-on effects that then when these patients came in for a second admission, it was all there. D9

5.3.6.2 Being Ill-equipped to Access ACP

Despite Queensland Health establishing an *ACP Tracker* to maintain records in a streamlined manner, clinicians demonstrated an inability to use the platform effectively. Most had been unable to locate ACP in electronic medical records and were not familiar with the ACP Tracker.

> I think that the advance care planning documentation is poorly filed, for want of a better word. It's not in a consistent place in terms of our records, particularly, our electronic records...

> We’ve got the advance care planning Tracker on The Viewer 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, no one has uploaded it, no one’s done anything further than that. And then, occasionally, they’re sprinkled through the documentation, and, sometimes, they’re under legal, and they’re just in various [places]. D2

> It can be quite tricky to trace that [ACP within IEMR] because you actually have to broaden the search criteria to include time and year from a few years back because if you don't actually broaden it then you won’t find anything on IEMR. D7

> Our electronic system is not well set up for displaying them to us, and I think that’s a real problem for our clients. It’s getting a bit better, but it is flawed... We use First Net, which gives us access to the electronic notes system. The problem is that the electronic notes system has essentially become a series of text files so they have to be labelled correctly… The Viewer is of limited value. The only real use for The Viewer and My Health is what medication the patient's on… I can’t say I’ve ever seen a reference in The Viewer to any cessation or limitation of care. RN6

Clinicians recognised deficits in their understanding of efficient processes, with some identifying an absence of training as a key factor.

> I've never entered data [into the ACP Tracker], I don't know if I've even had any training on how you're meant to do that. D3

> I’ve never seen one scanned into The Viewer. To be honest, I don’t access The Viewer much so that could happen. I haven’t looked there, but if it’s [AHD] scanned into IEMR then that would be useful. I look in IEMR, I ask the patient or family members or the care facility, but I think it’s just an awareness thing probably for me, like I wouldn’t even have thought that’s where I need to look for it. D12

> I haven’t had a lot of formal teaching regarding it [accessing ACP]. There's not much practice at all, it’s all fly by the seat of your pants. D8

As a means of avoiding barriers to retrieving ACP from hospital records, one nurse concluded that ACP should be retained with the patient in hard copy to ensure timely access by treating teams.

> The problem is in an emergency situation… whereby you start CPR and everyone’s up in arms going, “Do they have an ARP? Do they have their advance care plan?” And you’re

> sitting there on a stupid computer for about five, 10 minutes whilst you're doing CPR trying to find a piece of paper to tell you what you're allowed, can and can't do, clicking a whole heap of buttons and hoping you end up in the right spot. Digging up this paperwork is nearly impossible within your IEMR system. Before it used to be on the front of the chart… it should be clearly displayed at all times wherever that patient is… if that patient had gone downstairs for an x-ray, they've got no idea, which also has happened and as …a response team, we've been in medical imaging and known nothing about the patient, actually revived someone and went, "Oops. We weren't meant to do that." That's why I think that it needs to be there, ready, accessible, like there's no turning on computers or batteries dying. RN1

5.4 Summary

The results in this chapter offer insights into six interconnected systemic contributors to the application of ACP of hospitalised, incompetent persons with a neurodegenerative disorder: law, education, workplace culture, delegitimising ACP, resourcing, and ACP accessibility. Overall, three main conclusions can be drawn from the analysis. Firstly, underpinning the application of ACP in Queensland is complex legislation (*Powers of Attorney Act 1998* and *Guardianship and Administration Act 2000*) which doctors often did not understand and which they argued is problematic in clinical application. Related to this factor, there exists a failure of Queensland Health to mandate education and training to ensure doctors understand the law as it applies to ACP. Secondly, despite the premise that ACP gives patients *a voice when they have no voice*, doctors' practice culture reflected a tendency to diffuse the power inherent in ACP by claiming medical superiority in hospital-based, temporal, good medical practice decision-making, thus controlling the *hearing* of patients' voices. Thirdly, systemic pressure to achieve efficiencies within public hospitals has contributed to doctors' failure to incorporate the ACP of persons with a neurodegenerative disorder, in part because of poor ACP accessibility and the relative ease of deferring to an ARP. Therefore, the limited resources of Queensland's public healthcare system have contributed to a practice culture that has delegitimised patient-owned ACP. Consequently, the healthcare system exerts considerable influence over the degree to which ACPs are included in decision-making, thus placing the voices of persons with a neurodegenerative disorder in the balance.

Chapter 6: Systematic Factors Discussion

6.1 Introduction

In Chapter Five, I presented results that indicated six key systemic influences on doctors' adherence to the Advance Care Plans (ACPs) of patients with a neurodegenerative disorder. Here in Chapter Six, these factors are discussed and linked to doctors' *power over* patients and the *wicked* nature of decision-making for incompetent patients. As explained in Chapter Five, the following six systemic factor themes are interrelated.

6.2 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. My research revealed significant tensions between Queensland's legislation and the practice of medicine in Queensland public hospitals. Doctors' difficulties applying the *Powers of Attorney Act 1998* (Qld) and *Guardianship and Administration Act 2000* (Qld) to clinical scenarios has been well documented by others (Cartwright et al., 2016; Parker, 2010; Parker et al., 2015; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White et al., 2014; White, Willmott, Williams, et al., 2017; Willmott, White, Close, et al., 2016; Willmott, White, Gallois, et al., 2016; Willmott, White, Parker, et al., 2016; Willmott et al., 2013). Corresponding with the findings of White et al., (White, Willmott, Cartwright, et al., 2017) doctors in this research spoke of experiencing clinical challenges when interpreting the legislation as it applies to ACP and consequently, some asserted that legislation is not fit for purpose and should be modified. To work within a legal framework that they do not fully understand, doctors have prioritised their ethical responsibility towards good medical practice. This is not surprising, with good medical practice consistently endorsed within Queensland Health's clinical guidelines (Queensland Government, 2018b), the Australian Medical Board's Code of Conduct for Doctors in Australia (Medical Board of Australia, 2014), legislation (*Powers of Attorney Act 1998* (Qld) and *Guardianship and Administration Act 2000* (Qld)) and research (White, Willmott, Williams, et al., 2017). Further, under the legislation, doctors are excused from applying a Queensland Advance Health Directive if they reasonably believe the direction is inconsistent with good medical practice. In practice, doctors exercise their power over patients' voices by discerning the applicability of ACP and privileging the contemporary voices of patients' families.

As doctors described it, law and medicine reflect separate disciplines, and each has a limited understanding of the other. Accordingly, some doctors hoped, whilst others confidently argued, that good medical practice fulfils doctors' medico-legal responsibilities, a belief which appeared to undermine their perceived need to understand the legislation. This stands in contrast to the perspective of White et al. (White et al., 2016) who argued that practising within the law should be seen as a part of good medical practice. Accordingly, my research supports and extends the conclusions of Moore et al. (Moore et al., 2019), White et al., (White, Willmott, Williams, et al., 2017) and Wong et al. (Wong et al., 2012) who proposed that doctors prioritise ethical and clinical factors above legal obligations when making decisions for patients. Good intentions aside, failure to understand or apply the law as it relates to withholding or withdrawing life-sustaining treatment is problematic in that it undermines guardianship legislation which is intended to preserve patients' rights (Australian Health Ministers' Advisory Council, 2011). Further, ignorance of the law is no protection against civil liability, disciplinary actions or coronial proceedings (Queensland State Coroner; White et al., 2014). Doctors in the present research concurred with the argument by Willmott et al., (Willmott, White, Parker, & Cartwright, 2011b) that the law governing the withholding or withdrawing of life-sustaining treatment in Queensland is complex, counterintuitive, and sometimes inconsistent with good medical practice. Not surprisingly then, other scholars (White et al., 2014; Willmott et al., 2011b) have called for reform to simplify the law and reduce some of the barriers to mastery that are experienced by doctors (Willmott et al., 2011b). Navigating complex medicolegal, potentially end-of-life decision-making in the absence of clear and informed consent from patients thus constitutes a *wicked problem* (Buchanan, 1992; Rittel & Webber, 1973). Essentially, practising within a legal construct that doctors grapple with applying has further primed them to attempt best interests decisions on behalf of the patient with a neurodegenerative disorder. Doctors typically partner with families in preference to directly applying the patient's voice, expressed within an ACP.

Doctors' capacity to discern good medical practice, and their professional role in leading clinical decision-making on behalf of patients, has provided them with considerable agency within an asymmetrical power dynamic. As identified by other scholars (Bond & Lowton, 2011; Corke et al., 2009; Moore et al., 2019; White, Willmott, Williams, et al., 2017; Willmott, White, Parker, et al., 2016; Willmott et al., 2013), doctors from my research believed they held the superior medical knowledge required for complex healthcare, and they, not consumers, have been trained to lead medical decisions. To this end, 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 making binding (yet potentially uninformed) directions through an Advance Health Directive. Tensions between the law (represented within an Advance Health Directive) and doctors' concerns about the rigour of ACP processes and subsequent decisions have also been found by others (Moore et al., 2019).

Interestingly, doctors also recognised that legislation provides an overall framework within which they felt largely protected. This conviction was employed to their advantage when they assumed that in the event of legal 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. Willmott et al. (Willmott, White, Close, et al., 2016) found a similar attitude, with 44 of the 96 Queensland doctors in their qualitative research asserting that law does not have an impact on practice, and 36 doctors perceived that good medical practice was appropriate healthcare, regardless of the law. Similarly, Moore et al. (Moore et al., 2019) in their qualitative research of 21 Victorian doctors found that doctors generally held minimal concerns about potential legal consequences, provided treatment decisions were reasonably judged to be in the patients' best interests. This 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" (Willmott, White, Smith, & Wilkinson, 2014, p. 7). Collectively, public hospital systems maintain medical dominance in decision-making and doctors believe they are protected whilst practising ethical medicine. Despite the legal framework intended to safeguard the rights of all parties, doctors are influential, and they prioritise medicine that may well contradict the rights of patients.

These findings extend current literature by revealing that doctors within the North Queensland region have used their interpretation of the law to justify the extent to which they share decision-making with a person with a neurodegenerative disorder's earlier voice. Potentially appropriating another's voice this way occurs when one person assumes power over another, in this case, by doctors applying medical authority over a person with a neurodegenerative disorder's decision-making on the grounds of good medical practice. The historical and political privileging of medicine assumes the supremacy of one form of knowledge and consigns "patienthood within a hierarchy of power relationships" (Tang & Anderson, 1999, p. 84). Persons with a neurodegenerative disorder who constructed an ACP to achieve a lawful voice in their future healthcare despite incapacity may therefore be disempowered by a medical system that confers substantial power on doctors. Despite the power inherent in the Advance

Health Directive, the earlier voice of a now incapacitated person is thus usurped by a workplace culture that privileges medicine over law and diffuses patients' power by exercising authority over treatment decisions.

6.3 Education as It Relates to Law and End-of-life.

A key contributor to doctors' limited understanding of Queensland's legislation appears to reside in both undergraduate and postgraduate education structures. Legal education was described by most doctors as generic or not delivered at all, with only one doctor defining post-graduate legal training as adequate. This limitation to jurisdictional education leaves doctors (and therefore patients) vulnerable to peculiarities within a nationally fragmented legal system and accords with the submissions of Parker et al., (Parker, 2018) and Willmott et al., (Willmott, White, Parker, et al., 2016), that medical law education and training of doctors in Australia is uneven. Surprisingly, despite the passage of two decades since the inception of the *Powers of Attorney Act 1998* (Qld) and *Guardianship and Administration Act 2000* (Qld) and recognition by Queensland Health that end-of-life decision-making is complex (Queensland Government, 2018b), medico-legal education is not part of mandatory training for any discipline within Queensland Health. Similarly, orientation programs for doctors in the research sites did not include this important topic, leading some participants to respond to a clinical situation by reading the legislation, speaking with peers, or consulting an organisational lawyer. Given the degree to which literature has highlighted doctors' difficulties navigating Queensland's legislation (Parker, 2010, 2018; Parker et al., 2015; White et al., 2016; White, Willmott, Cartwright, et al., 2017; White et al., 2014; White, Willmott, Williams, et al., 2017; Willmott, White, Parker, et al., 2016; Willmott et al., 2013), and the stated inadequacy of Australia's unsystematic undergraduate and postgraduate legal education (Parker et al., 2015; White et al., 2021), lack of training by Queensland Health to all hospital doctors represents a significant systemic failure to ensure patients' rights are understood, especially in situations where gradual or total loss of decision-making capacity obscures the patients voice.

A second shortcoming in the education and training of doctors involved the subject of illness prognosis and doctors' ability to recognise their patients' approaching death. Research results indicated that both tertiary and workplace education and training have prioritised medical interventions above recognising a patient's dying trajectory (a shortcoming referred to by others (Willmott, White, Gallois, et al., 2016)) and difficulty prognosticating dying was closely associated with the non-application of ACP (Matlock et al., 2014). Given the inevitability of death, this result was surprising, yet systematic medical training related to end-of-life has historically been poor (Gawande, 2014; Sutherland, 2019). However, the analysis also revealed that doctors perceived clinical experience gained over time is the most effective form of training (an issue found by others (Gibbins, McCoubrie, & Forbes, 2011)), with in situ leadership and education by senior doctors preferable to theoretical education (Gibbins et al., 2011). Hence one doctor recommended that all illness topics delivered within workplace professional development sessions should take the opportunity to educate doctors about the limits of medicine by incorporating end-of-life modules that include shared decision-making, yet this does not typically occur. Others have argued for improvements in systematic support for doctors by standardising end-of-life training and redesigning medical school curriculum (Horowitz, Gramling, & Quill, 2014; Sutherland, 2019), notably concerning the law (Parker, 2018). Participants' resistance to end-of-life education appeared to be associated with medical culture, yet under accreditation standards, Queensland Health bears responsibility for implementing a systematic approach to education and training of doctors throughout their careers to address such a critical knowledge gap (Australian Commission on Safety and Quality in Health Care, 2014a, Section 5.01).

6.4 Workplace Culture

One clear theme that permeated the findings in this research was the underlying treatment focussed workplace culture of hospitals which associated death with failure. Predictably, the dominant practice culture of doctors reflected a longstanding death-avoidant medical model: doctors assumed that patients attend hospitals for treatment, and doctors insisted that they are trained and legally responsible for ethical decision-making in the best interests of patients. Doctors felt legally and morally justified exercising medical control over the best interests decisions of incapacitated patients with a neurodegenerative disorder, thus moderating patents' power by discerning the applicability of ACPs (see also Chapter Four). Somewhat problematically, ACPs were seen as an attempt by patients to hypothetically (and potentially naïvely) limit treatment, which if applied, may lead to an uncomfortable outcome for the healthcare system: an untimely or preventable death during hospitalisation.

Although it was clear that doctors sought to respect the wishes of their patients, doctors also perceived death to be broadly interpreted as a failure of medicine and therefore a failure of hospital care. The *death as a failure* mindset of doctors (Gibbins et al., 2011), and society more broadly, may well have been maintained by the healthcare sectors' decades-long "name-blameshame" culture (Duckett, Collins, Kamp, & Walker, 2008, p. 616). Internationally, public reporting of healthcare outcomes is well established, and more recently, Australia has followed suit (Duckett et al., 2008). In the aftermath of the 2005 Bundaberg Hospital scandal, Queensland's quality and safety management processes saw a new emphasis on transparency and a legislated requirement that hospitals publish annual performance reports (Duckett et al., 2008). Quality indicators selected for regular monitoring included in-hospital mortality for acute myocardial infarction, stroke, fractured neck of femur and pneumonia (Australian Commission on Safety and Quality in Health Care, 2014b). One purpose of reporting hospital mortality was the early recognition of suboptimal healthcare, followed by a remedial response to it (Australian Commission on Safety and Quality in Health Care, 2014b; Duckett et al., 2008). However appropriate quality indicators may be, emphasis on mortality rates in public hospitals and reference to "favourable trends seen (overall) for all measures of mortality" (Australian Institute of Health and Welfare, 2016, p. 6) does little to normalise death as a natural outcome of old age or the end stage of chronic illness (Trankle et al., 2020) such as a neurodegenerative disorder.

The law is arguably one of the most powerful frameworks governing end-of-life care in hospitals (White, Willmott, Williams, et al., 2017). Accordingly, under Queensland's legal framework, Advance Health Directives should be applied consistently, yet findings in this research suggest this is not the case. Instead, corresponding with the findings of Willmott et al., (Willmott et al., 2013) there existed a tension between patient-owned ACP (particularly the Advance Health Directive which offers considerable power to patients despite incapacity) and doctors' clinical priorities to deliver good care. Importantly, doctors asserted their right to discern the applicability of ACP during hospitalisation, largely by establishing the patient's illness status (including decision-making capacity) and consulting with family in a relational autonomy approach to shared decision-making. This research has therefore extended the findings of other scholars (Arruda et al., 2020; Johnson et al., 2018; Willmott et al., 2013) by identifying this practice specifically concerning hospitalised patients with a neurodegenerative disorder. Consequently, despite the Advance Health Directive being offered in law as a means of patients retaining power in healthcare decisions, the hospital system, through its doctors, maintains control over ACP application.

The tensions associated with the application of ACP in this research context appeared to be moderated by organisational dynamics, with workplace culture in larger hospitals typically being subspecialty focused. Inpatient treatment was described as fragmented by episodic care delivered by disconnected teams with differing responsibilities (referred to by clinicians as SILOs), further eroding the application of ACP in part because of a lack of consistent, longitudinal, medical leadership. Disconnected care was coupled with doctors taking a short-term view to care; of treating patients with a neurodegenerative disorder in terms of the presenting illness in preparation for discharging the patient; and difficulty recognising the signs of approaching death in a timely manner. Perhaps reflective of busy modern hospitals more broadly, these insights mirrored the perspective of Australian doctors Rachelle Buchbinder and Ian Harris who contended:

> "One of the problems is that there is uncertainty among doctors regarding the role of some treatments, which often leads to a "give it a go" mentality. The lack of guidelines or protocols for treating dying or very sick patients doesn't help. The problem is made even worse in situations where the dying person is unconscious or unable to discuss treatment options due to dementia. The tendency in those cases is to try anything to save or extend life, with little regard to quality of life". (Buchbinder & Harris, 2021, p. 161)

Conversely, medical practice in the rural sites signalled a tendency of the smaller hospitals' generalist doctors: to provide continuity of care to patients; to have more familiarity with patients' wishes; and a greater probability that they would apply an ACP.

6.5 Delegitimising ACP

Another pervasive theme was the extent to which doctors have delegitimised patient-owned ACP. Analysis revealed that doctors have disconnected hospital and primary care roles and assigned GPs with primary responsibility for managing ACPs. This disconnect correlated with the general attitude of clinicians that ACP is most relevant to community healthcare, despite hospitalisation risking a high treatment burden (Shepherd et al., 2021) which the patient may have sought to avoid (Nguyen et al., 2017; Teno et al., 2007). Doctors divested themselves of ACP process responsibilities, citing resource limitations, an episodic care focus, and their belief that GPs provide longitudinal, relatively holistic care whilst hospitals do not. This finding supports the proposal by Scott et al., (Scott et al., 2013) that GPs are best placed to engage patients in ACP, preferably with the support of specialists and health professionals. However, patients with a neurodegenerative disorder have a right to expect that any treating doctor will respect their ACP during decision-making incapacity, regardless of the healthcare setting.

Interestingly, doctors recognised that GPs are also under-resourced, a factor that then contributed to distrusting the reliability of ACP. Doctors often assumed that GPs would not have the level of specialised expertise of hospital doctors, and any lack of expertise would further antagonise the potential for patients to record binding directions inclusive of appropriate medical advice. Further, hospital doctors argued that ACPs should be revised periodically to ensure currency of wishes and directions, yet they did not accept responsibility for this undertaking. Instead, responsibility for managing ACP revisions was assigned to under-resourced GPs. Consequently, doctors demonstrated a distrust of Queensland's ACP processes which contributed to their ambivalence towards accepting an ACP at face value. Questions of reliability of ACP have been well documented (Corke et al., 2009; Leder et al., 2015; McCarthy, Meredith, Bryant, & Hemsley, 2017; Moore et al., 2019; Morrison, 2020; Willmott et al., 2013), however, these findings extend the current literature by helping to explain Queensland's public hospital system's delegitimisation of ACP.

Perhaps the most surprising finding related to systemic influences on ACP application was the dominant role of the ARP which doctors typically completed in consultation with families. In this research, doctors persistently asserted that the ACP of most relevance to inpatients was the ARP. The extent to which the hospital system appears to have encouraged and enabled doctors' deference to ARP as opposed to the statutory Advance Health Directive was noteworthy. Despite being regularly reoriented to the research's definition of ACP as a *patient-owned* Advance Health Directive or Statement of Choices, doctors persistently spoke about ARPs. Given doctors' acknowledgement that an Advance Health Directive is a legally binding document whilst an ARP is not, this result was unexpected. However, Queensland Health includes ARP within advance care planning documentation (Queensland Government, 2018a), which may partially explain doctors' pattern of referring to an ARP as an ACP.

Queensland Health designed the ARP to meet clinicians' needs in emergent situations (Queensland Health, 2020), and doctors reflected that, unlike Advance Health Directives, ARPs offer succinct evidence of a medical order which largely meets clinical needs. Doctors (wrongly) presumed it was Queensland Health policy to complete an ARP; they identified ARPs as readily accessible in hospital records (unlike community completed ACP); and they considered ARPs were more likely than patient-owned ACPs to be relevant to the situation. Queensland Health promotes ARPs as the desired outcome of inpatient ACP practices; however, it is not a policy that one be completed. The perceived relevance of an ARP to the clinical situation was related to the time-limited nature of ARP (maximum 12 months currency) in contrast to patient-owned ACP which have no renewal requirements. Further, doctors expressed concern about the potential implications of patients' poor healthcare literacy when completing an ACP, with no requirement for rigorous or transparent processes. Importantly, unlike the Advance Health Directive, ARPs are most often completed or revised as required by hospital doctors (therefore public hospital colleagues), allowing doctors greater investment in hospital-based advance care planning. This research appears to be the first Queensland-based research to demonstrate the dominant role of ARP when doctors are asked to explain their perspectives and practices when applying ACP to treatment decisions of persons with a neurodegenerative disorder.

Disturbingly, despite privileging the ARP as the ACP of most consequence within hospitals, doctors were dissatisfied with the training of junior doctors, and often, the appropriateness of orders contained within ARPs. Results showed that ARP training was inadequately resourced, leaving junior doctors (who often complete ARPs) dependent on the variable skills and training capacity of their peers and more senior doctors. Troublingly, even doctors who lack expertise may exercise medical control over cognitively impaired patients' agency by generating an ARP and neglecting or disregarding the patient's Advance Health Directive. This result suggests support for the recent findings of Bryant et al., (Bryant et al., 2020) who ascertained that junior doctors in New South Wales have been inadequately supported by the healthcare system to develop skills in resuscitation planning, and despite doctors' confidence, they demonstrated significant knowledge gaps impacting the quality of the resuscitation order. Hence, doctors who complete ARPs without incorporating known ACP, or who rely on an ARP without critical review, further diffuse the patient's power (as represented within their ACP) and systematically leave the patient's voice in the balance.

6.6 Constraints of Limited Resourcing

Another persistent theme was a link between limited hospital resources and doctors' engagement with ACP. Doctors reasoned that the public healthcare system emphasises resource efficiencies rather than holistic patient care over time. Organisational constraints imposed on public hospitals (and therefore doctors) caused by a growing demand for healthcare and limited resources in Australia have been reported in detail elsewhere (Australian Medical Association, 2020; Dixit & Sambasivan, 2018; Duckett & Breadon, 2014). As expected then, doctors in this research bore systemic pressure to prioritise their time and most doctors considered discussion with an incompetent patient's family was the best and most expeditious route to establishing what a patient's wishes would likely be. Reassuringly yet sadly, doctors consistently argued that they would like to spend more time hearing patients' voices if allocated sufficient resources to do this. Further, doctors recognised the importance of incorporating multidisciplinary advice and protecting relationships with families, all of which require time and resourcing. Given the potential consequences of medical decisions made on behalf of incompetent patients, healthcare providers should ideally be resourced to enable doctors to deliver genuinely person-centred care (Busch, Moretti, Travaini, Wu, & Rimondini, 2019), yet participants in this research argued they are not.

6.7 Accessing ACP

A frequent barrier to incorporating ACP into hospital-based decision-making was the perceived inaccessibility of ACP. Although ACP inaccessibility has been noted by others (Rhee, Zwar, & Kemp, 2012; Scott et al., 2013; Walker et al., 2018), this research demonstrated that clinicians were ill-equipped to use the ACP Tracker, making the purpose-built portal of limited value as a source of efficient access to Queensland ACP records. Accordingly, doctors considered discussion with families as the most efficient means of ascertaining incompetent patients' treatment preferences, overlooking the patient's earlier voice. Not only were document management processes poorly understood, but critically, notwithstanding the legal authority inherent in an Advance Health Directive, doctors were not mandated (in law or policy) to seek access to ACP.

As noted in Chapter One, procedures describing ACP processes in Queensland are localised and therefore variable between hospitals. It is also worth remembering that ACPs are usually completed in community settings, and they remain the property and responsibility of the document owner (principal). Despite Queensland ACP templates recommending that people share their finalised documents with key people and healthcare settings, this may not eventuate. As a result, hospital staff are generally beholden to third parties to grant access, if indeed the document is accessible at all. In the absence of healthcare consumers providing their ACP to repositories such as My Health Record or hospital records, and hospital staff utilising records management systems effectively, timely access will remain a barrier to ACP application. Hospital systems have responsibility for embedding ACP in routine practice and facilitating knowledge of incompetent patients' earlier wishes through the accessibility of ACPs (Australian Commission on Safety and Quality in Health Care, 2017), yet these findings suggest doctors require further resources (such as training) to inform their practice. Further, any attempt to improve ACP accessibility would require a broad approach aimed at engaging and educating both healthcare consumers and clinicians (Buck et al., 2021).

6.8 Summary

In summary, this research has elucidated systemic contributors to the non-application of ACPs of patients with a neurodegenerative disorder during hospitalisation in North Queensland public hospitals. If ACPs are to deliver to patients the pledged voice during voicelessness, barriers to the application of ACP must be addressed. Firstly, doctors have difficulty understanding and applying Queensland law in the clinical context, a situation that remains to be addressed by Queensland Health, universities, and professional bodies. In the absence of proposed law reform to improve the fit between Queensland legislation and medicine, education and training which teaches doctors about the law as it relates to ACP and withholding or withdrawing life-sustaining treatment should be made mandatory for all Queensland Health doctors. Additionally, clinicians should be systematically trained to use the available ACP Tracker; and consumers should be encouraged and assisted (such as through outpatient clinic appointments and correspondence) to make available their ACPs for upload to medical records. ACP clinical practices should be audited and targeted for quality improvement measures as required. Further, ACPs should be conceptualised as living documents that are reviewed and renewed for the duration of the person's life, in an ongoing process actively facilitated by healthcare organisations and clinicians. Instead, hospital doctors are enculturated to defer to *in-house* ARPs, resulting in delegitimised patient-owned ACP. Therefore, health service training in ARP could be used to improve doctors' understanding of the important role of patient-owned ACPs. To what extent Version 5 of the Queensland Advance Health Directive will address the needs of doctors remains to be tested. Results revealed in this research suggest that the *elephant in the room* is the concept that death equates to a failure of medicine, which remains to be addressed by hospital and health services, universities, and professional bodies alike. By supporting doctors to recognise the limits of medicine and hear the voices of patients who have prepared for incapacity by generating an ACP, healthcare systems will take a significant step towards meeting their obligation to partner with consumers in the delivery of patient-centred, comprehensive care.

Chapter 7: Advance Care Plans and North Queensland Public Hospital Doctors – A Grounded Theory

7.1 Introduction

This chapter presents my research findings as a theoretical model of the application of advance care plans (ACPs) of persons with neurodegenerative disorder in North Queensland public hospitals. The model explains a *diffusion of patients' power* that is attributable to doctors' *power over* medical decisions: doctors exercise their *power to* accept or reject a patient's authority represented within an ACP. In this research, doctors prioritised their profession's *power over* and *power to*, by forming temporal shared decision-making partnerships (*power with)* and leading an agreed, contemporaneous healthcare plan. Although doctors recommend ACP to give patients a powerful voice in healthcare; as gatekeepers in medical decision-making, doctors exercise a relational autonomy approach to applying the ACP. Despite the potentially conflicting interests of patient agents, doctors assert that they protect patients by leading decision-making in the patients' presumed best interests. To do this, doctors usually make decisions in consultation with family which offers doctors the benefit of avoiding overt interpersonal conflict. Systemic factors such as workplace culture and resource limitations correspondingly reinforce doctors' power and influence over patients' power. As a result, the patient's voice, represented within an ACP, *hangs in the balance*.

Figure 7.1 diagrammatically represents the layers of influence that exist between ACP generation and doctors' response to ACP in public hospital practice. The identified themes represent complex human processes that inevitably overlap and are not mutually exclusive.

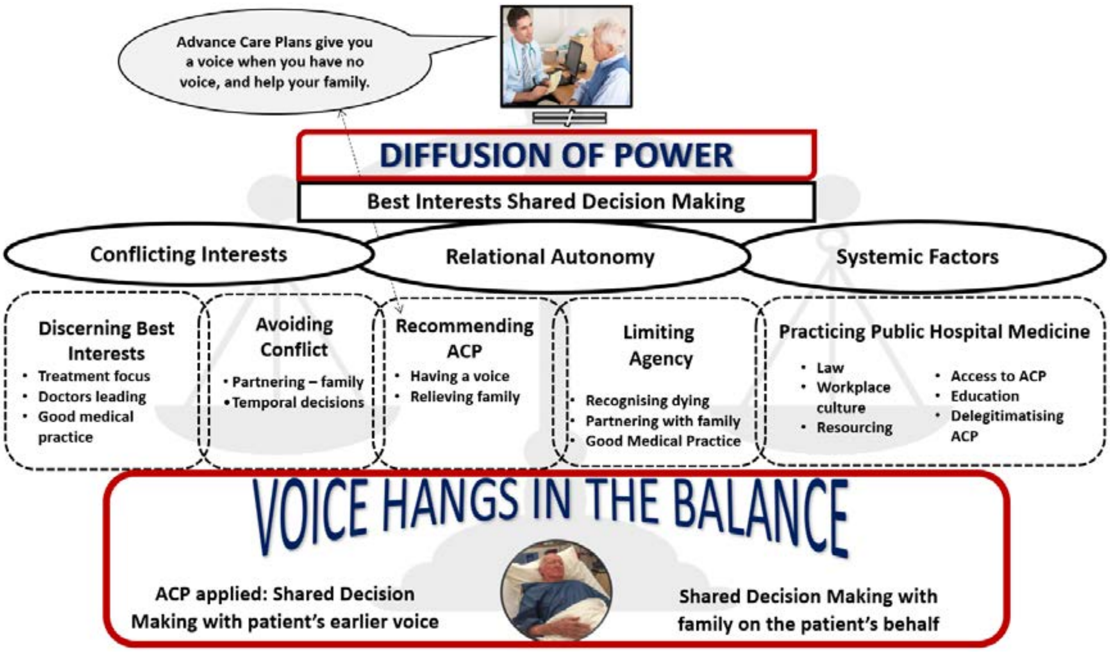

Figure 7.1: Diagrammatic representation of the theoretical model of the application of ACP of persons with neurodegenerative disorder

7.2 Summary of Theory

An individual's power to retain a voice through ACP is diffused upon entry into the hospital whereupon competing influences threaten a patient's voice, which *hangs in the balance* whilst treatment is explored. Doctors form bedside shared decision-making relationships, most often with family, and formulate a temporal healthcare plan that is believed to be in the patients' best interests. The application of an ACP is dependent on the doctor's willingness to partner with the patient through a written record of an earlier voice. In contrast, doctors typically partner with patients and families in a relational autonomy practice when the medical facts are most clear. Doctors consider this form of shared decision-making reduces risks to both patient and family's *current* best interests. Hence, despite the premise of ACPs generally and Advance Health Directives specifically, applying an ACP is a complex process. Ultimately, the clinical application of an ACP reflecting the earlier voice of a person with neurodegenerative disorder hangs in the balance because doctors determine what influence, if any, the ACP will have on healthcare decision-making.

7.3 Diffusion of Power

Non-urgent best interests care requires that doctors become clear about their patient's prognosis and healthcare preferences (Australian Commission on Safety and Quality in Health Care, 2014a), and by law, obtain informed consent to healthcare (*Guardianship and Administration Act 2000* (Qld), s64). Individualised healthcare planning and consent are considered essential elements of patient-centred care which are enhanced by discussion and shared decision-making (Australian Commission on Safety and Quality in Health Care, 2021). Appropriately, patient-centred care is celebrated as a positive development in modern medical care (Sandman & Munthe, 2010). People who generate an ACP seek to retain their centrality, or voice, by communicating their healthcare values, goals, and preferences to treating doctors. However, doctors maintain gatekeeper power to exercise authority over the patients' earlier voice by discerning ACP applicability and thus accepting or rejecting its application. As a result, on entry into the hospital system, the voice of the patient is met by obstacles that result in a diffusion of the patient's power. Influences upon the diffusion of power through ACP include the potentially conflicting interests of bedside agents (addressed in Chapter Four) and systemic factors (addressed in Chapters Five and Six). The patient's voice hangs in the balance whilst doctors' and families' voices formulate temporal shared decisions in the presumed best interests of the patient.

7.3.1 Shared Decision-making with a Patient's Earlier Voice: Applying the ACP

Although competent adults are consistently told that ACPs give them a voice despite voicelessness, ACPs also present doctors with a conundrum: doctors, accustomed to leading decision-making, are unable to negotiate with a document. Further, ACPs indicate the values, goals and preferences of the person, yet only to the extent that the person understood their options and the consequences of decisions at the time of completion (Bradley, Brasel, & Schwarze, 2010). The extent to which the person understood the implications of their decisions, and the degree to which the ACP represents the authentic values, goals, and preferences of a person with a neurodegenerative disorder, is often unclear. In this research, it also became apparent that doctors perceive ACPs as useful for enabling a person to avoid hospitalisation and therefore to die in their home, rather than in hospital. Should the person present to the hospital, doctors' default response is to intervene and treat with a view to delaying death (Browne, Kupeli, Moore, Sampson, & Davies, 2021; Buchbinder & Harris, 2021; Richfield & Johnson, 2019). As discussed in Chapter Four, hearing a dying patient's voice through an ACP which refuses life-sustaining interventions gives voice to the patient only when decision-makers agree that the person is dying and should be respected to do so. In essence, whilst the patient's earlier voice is heard when doctors agree to apply the ACP, such application is semantic if death is inevitable. Instead, ACPs should be read and their contents respected in any situation involving incapacity of the patient, thereby giving voice to the patient in line with the purpose of ACP.

7.3.2 Shared Decision-making with Family on Patient's Behalf

For a myriad of reasons including doctors' power over decision-making, ACPs present doctors with *wicked problems* to be resolved. ACPs are patient-owned and doctor-interpreted communications that put the voices of both patients and doctors on a potential collision course. The voice of a patient remains in the balance until action is taken to either apply the ACP or generate a new plan in the presumed best interests of the patient (and often, their family). Where a new plan is agreed, the patient's earlier voice is neglected, challenged, set aside, or usurped in a process that weighs a patient's earlier voice against the doctor and family's influence. As expressed by Varpio (Varpio et al., 2017, p. 354), "wicked problems are not resolved with true-or-false conclusions; instead, solutions are stakeholder-dependent judgements of better-or-worse alternatives that work in a specific context for the moment". Accordingly, for better or worse, temporal decision-making which is shared between doctors and family continues to threaten the person's earlier voice.

Families are important yet unequal partners within an asymmetrical power structure. From doctors' perspectives, ACP provides limited reliable information (Burkle, Mueller, Swetz, Hook, & Keegan, 2012), whilst the family retain considerable power to complain, or conversely, to interpret and represent the voice of the patient. Interestingly, people with neurodegenerative disorder in this research, themselves aware of the potential for unforeseen complications and not always trusting doctors, endorsed doctor-family temporal shared decision-making. Such endorsement only serves to validate the relational autonomy practice of doctors. As discussed in Chapter Four, relational autonomy refers to social connectedness and relationships between people (Mackenzie & Stoljar, 2000). Consequently, adopting broad agreement by taking a relational autonomy approach to shared decision-making may either enhance the patients' voice (where a temporal voice advocates for the ACP) or cost the patient their voice. At the same time, families retain or gain a voice in shared decision-making, and doctors are in the position of navigating the invisible and subjective line between the presumed best interests of both patient and family.

7.4 Diffusing the Voice of the Patient

7.4.1 Requiring Certainty

As explained in Chapter Four, participating doctors consistently endorsed the primacy of knowing patients' healthcare goals and respecting patients' right to a voice in their healthcare. The communication of such information is the objective of ACP, yet this research shows that the patients' voice is often subjugated to the voice of others when treatment decisions are made within hospitals. The key reason for this appears to be that when family members are available, doctors negotiate shared decisions with the family who represent the patient. Doctors believe that doctors are the appropriate leaders in medical decision-making and have both the right and the responsibility to be confident that treatment aligns with both good medical practice and their patients' likely preferences (Moore et al., 2019). ACPs in isolation generally fail to satisfy this need for certainty (Bradley et al., 2010; Morrison, 2020). Although in some cases ACPs do reflect a person's informed choices, doctors hold concerns about unintended consequences (such as preventable death) occurring from the inappropriate or naïve application of an ACP (Bradley et al., 2010). Validating this concern is the prospect raised by participants with a neurodegenerative disorder (as seen in Chapter Four) that principals can change their mind, become powerless to communicate new preferences, and ultimately, be rendered voiceless by their ACP. Given the right of individuals to change their mind and the difficulty this poses during voicelessness, it stands to reason that doctors will first seek to satisfy themselves of ACP applicability (Moore et al., 2019). Accordingly, the application of ACP occurs at doctors' discretion and generally, the earlier voice of a patient with neurodegenerative disorder hangs in the balance because doctors privilege temporal consent to healthcare which is most often obtained in partnership with the family.

7.4.2 Distrusting ACP

Threats to a patient's earlier voice are exacerbated by poor ACP construction processes. The lack of transparency about ACP construction leaves the door open to doubts that the principal made not only informed decisions, but decisions that accorded with their values. Whilst individuals seek to give voice to their values, goals and preferences, there are generally no guarantees that ACP gives voice to informed choices (Arruda et al., 2020; Moore et al., 2019). Some adults do not have the health literacy required to understand the consequences of their choices, and the risk of unintended consequences is worsened by there being no requirement in law that they gain or incorporate medical advice. For example, a person may fear hunger or thirst at the end of life and thus endorse receiving artificial nutrition and hydration, yet not understand that this may lead to surgically implanted percutaneous endoscopic gastrostomy (PEG) or uncomfortable nasogastric or intravenous feeding. When unable to clarify patients' choices and gain temporal informed consent from an incapacitated inpatient, doctors are primed to discuss decisions with family.

Not surprisingly, doubts about the integrity of the ACP process are intensified when the patient's decisions contradict what the doctor considers is appropriate healthcare. In this research, such cases were typically associated with a patient endorsing what doctors considered unduly burdensome (or *futile*) interventions, the delivery of which would be inconsistent with good medical practice. Conversely, where the patient's voice rejects life sustaining-treatment and this aligns with what doctors and families judge to be appropriate healthcare, concerns about processes diminish because doctors consider there are no decisions to be made. Overall, ACPs record the voice of a person at a point in time, without process transparency, and they are afforded limited opportunity to speak for the patient. Instead, the patient's written voice is held in the balance whilst doctors develop contemporaneous healthcare plans, with or without significant consideration of an ACP.

7.4.3 Gaining Consent

National auditable accreditation standards promote the ethically superior concept of patient-centred care through authentically shared decision-making, including through ACP (Australian Commission on Safety and Quality in Health Care, 2017). Although useful bioethical doctor-patient shared decision-making models exist (see (Sandman & Munthe, 2009, 2010)), these relate to competent patients and neglect the option of ACP for incompetent patients. As explained at the outset of this thesis, there is no requirement in Queensland law that doctors ask for their patients' ACP, and doctors are excused from applying directions that they believe are inconsistent with good medical practice *(Powers of Attorney Act 1998* (Qld) s103). This fact gives doctors considerable scope to maintain their power over medical decision-making and reduces their consideration of the ACP unless the ACP meets the doctor's needs. Although traditional medical decision-making is described as paternalistic (Buchanan, 1978) with negative "bad old days" connotations (Savulescu, 1995, p. 327), doctors in this research equated paternalism with the concept of empathy and beneficence. This argument implies a moral superiority (Groll, 2014) of contemporaneous shared decisions of bedside agents over the patient's earlier voice within an ACP. As a result, doctors make no apology for protecting patients from their earlier voice unless the patient's preferred healthcare is uncontentious.

Doctors are driven to preserve life, delay death, practice good medicine and protect their patient's interests. When doctors do apply an ACP, death is considered all but inevitable. Most often, doctors take a relational approach to decision-making to balance patients', families', and doctors' interests. Reliance on families to represent the patients' voice meets doctors' needs by mitigating the risk of complaint and improving confidence in decisions, however, the degree to which this serves patients' best interests cannot be known. Through partnerships with families, doctors navigate, negotiate and lead decisions in the direction that doctors think is most appropriate, thus maintaining the hierarchy of medical voices over patients' voices. Accordingly, the benefits of ACP are yet to be reflected in routine practice (Scott et al., 2013) which currently weighs the patient's voice against alternative means of shared decision-making. Although paternalism carries negative connotations of yesteryear from which modern medicine tries to distance itself, doctors associate paternalism with responsible leadership. Accordingly, ACPs in use during the research period did not, in most cases, give patients a voice that doctors heard, leaving the voice of patients with neurodegenerative disorders hanging in the balance.

7.5 Strengths and Limitations of the Research

7.5.1 Strengths

Firstly, although my status as a simultaneous insider (clinician and advance care planner) and outsider (daughter and researcher) may be interpreted by some as a conflict, this duality allowed me powerful insights throughout data collection and analysis (Charmaz, 2014; Gough & Lyons, 2016). This fact was raised during the Confirmation of (doctoral) Candidature review by Professor Ben White, who said: *"I know the candidate is within a health service so it may be that that may assist (although other ethical issues will of course need to be managed)".* As a psychologist I am immersed in a field of introspective clinical interviews (Gough & Lyons, 2016); I remain mindful of political aspects of power and knowledge; and I think creatively about ways to develop and communicate knowledge (Gemignani et al., 2014). I reflected on the possibility that participants known to me might respond in a socially desirable way (Uziel, 2010; Van de Mortel, 2008), whereby they might tell me what they thought I wanted to hear. To counter this I found creative ways to explore attitudes, such as by asking clinicians to explain a situation that might not have involved them directly, thus providing them with a degree of distance and perceived safety. I also asked clinicians whether an ACP situation had ever troubled them, intruded on their thoughts, or disturbed their sleep. These questions enabled me to recognise that some doctors remained emotionally uncomfortable long after a clinical event, making them *secondary victims* in the end-of-life decision-making (Seys et al., 2013).

In concordance with ethical research conduct (National Health Medical Research Council, 2007 updated 2018), being a Queensland Health clinician insider assisted me to understand the language and workplace culture of clinicians and to relate to situations that participants explained (Yanos & Ziedonis, 2006). As an insider, participants trusted me with their stories, as evidenced by the richness of the data gathered and the representation of senior doctors of varied ages, gender, subspecialty, and years of practising. My authentic respect for the perspective of participants appeared to facilitate participants powerfully expressing themselves. Given that I evolved my lens from one of frustration on behalf of consumers, allied health clinicians and nurses to one of appreciating the nuanced complexities associated with doctors' use of ACPs, is testimony to the tenets of constructivist ground theory methods.

7.5.2 Limitations

This research also has several limitations that warrant explanation. Firstly, as explained in Chapter Three, I limited patient illness type to neurodegenerative disorders, therefore ACP application in the context of other medical conditions was outside the scope of this research. The decision to restrict illness type to neurodegenerative disorders reflected my primary interest in this field and provided a means of containing the subject matter. Secondly, the clinician participants came from two major regional hospital and health services, and data collection relied on self-report. Doctors in other regions may respond differently to the existence of an ACP. It is also possible that doctors' clinical behaviour deviates from self-report, however, this was balanced by including nurses, allied health clinicians and consumers in data collection and using this data to guide questions posed to doctors. Thirdly, despite efforts to engage doctors from other units and of junior status, for reasons unknown the research did not achieve engagement from all subspecialties or equal representation of doctor seniority. Further, with data collection occurring during the novel coronavirus disease 2019 (COVID-19) pandemic, positive attitudes towards ACP may have predominated, reflecting a heightened interest in end-of-life care at that time. All doctors were supportive of ACPs (to varying degrees) and therefore those who disregard them entirely were underrepresented. Therefore, the theory grounded in this research is not intended to be generalised to other populations or all doctors.

Importantly, despite efforts to recruit broadly and include data from participants with a wide range of experiences and cultural backgrounds, another limitation was the underrepresentation of consumer participants. For example, participants with a neurodegenerative disorder were agreeable to their families (or health attorneys) remaining involved in healthcare decision-making. This was despite generating an Advance Health Directive to manage their own decisions, in part to alleviate family from guilt. I did not achieve data from those who might complete an Advance Health Directive to avoid their family's involvement and therefore avoid relational autonomy in shared decision-making. Similarly, I was unable to recruit family members who disregarded the patient's ACP. It is possible that such candidates did not recognise that their experience made them eligible to participate. I also acknowledge that the research may lack cultural relevance to some groups within society who may offer alternative explanations for ACP non/application.

7.6 Conclusion

As stated at the outset of this thesis, ACPs are used in all Australian states and territories to give adults a voice in their future healthcare. Through emotive advertising and messaging, people are encouraged to believe that an ACP will speak for them when they cannot speak for themselves. Importantly, the right of individuals to remain key decision-makers in their healthcare is accepted in medical ethics and law, yet ACPs do not guarantee patients a voice as proposed, and literature exploring doctors' explanations is limited. If the perspectives of doctors who have responsibility for hearing the patients' voices remain unclear, so too will the probability that the patient's voice will not be heard.

Because of my experience and advocacy in the field, I undertook this research to explain doctors' non/application of ACPs to treatment decisions of incapacitated people with a neurodegenerative disorder in North Queensland public hospitals. What I have discovered is that the powerful voice of the patient is diffused upon entry into the hospital system, largely because the patient has entered the arena of medical decision-making where the modus operandi of doctors is to delay death. Doctors engage in temporal shared decision-making, most often in partnership with families who may or may not advocate for the application of an ACP. My research highlights that the application of ACP to shared decision-making is often difficult, multifaceted, *socially messy* (Horn, 2001) and beset by *wicked problems* (Morrison, 2020; Rittel & Webber, 1973). Instead, conflicting interests of bedside agents and powerful systemic factors add layers of challenges to *hearing* patients' *written* voices, leaving ACP to contribute just one piece of a complex decisional puzzle. As such, decision-making models stand to be expanded to acknowledge the reality that shared decision-making, a celebrated *patient-centred care* ideal, warrants that a patient's voice through ACP rightly be afforded a (timely) seat at the table. Despite the proposed benefits of ACP, patients remain caught in the cross hairs between medicine and law where the patient's voice hangs in the balance and the benefits of ACP remain to be actualised.

7.7 Implications

7.7.1 Practice

This research casts doubt on the utility of ACP to speak on behalf of incapacitated patients. Accordingly, I propose that a *top-down, bottom-up and side-to-side* approach to meeting the needs of all stakeholders is overdue and should be implemented. Top-down refers to Queensland Health (the Department), bottom-up refers to adults who may choose to engage in ACP, and side-to-side refers to lateral networks (such as multidisciplinary colleagues, general practitioners, and support groups). Incapacitated patients are admitted to hospitals for a myriad of reasons beyond their control and they are entitled to expect that their ACP will speak for them.

- ACP construction would be enhanced by multidisciplinary advice and maintained as iterative, living documents. This could be achieved by a collective approach whereby any healthcare clinician could offer support and advice to an individual in the context of ACP construction and/or document revision. Where a patient experiences a change in circumstances (such as a new diagnosis or the progression of illness), clinicians could take responsibility for offering a patient the opportunity to plan future healthcare and document ACPs in medical records.
- ACPs may be enhanced by clear communication between stakeholders (such as multidisciplinary clinicians, general practitioners and patients) regarding a person's prognosis. This could be achieved by clinicians establishing the level of detail which other stakeholders require to generate an ACP that contains authentic healthcare choices. Clear communications necessitate shared responsibilities towards both giving and receiving relevant information (either in writing or through discussion) with a goal of maximising healthcare literacy.

- Doctors completing an Acute Resuscitation Plan for an incompetent patient should make every effort to incorporate the patient's ACP.
- ACP revisions should be prompted by events such as changes in health status, standard reviews (such as O*ver 75 health checks*) or driver's licence renewal. Period revisions of ACPs would be enhanced if considered the responsibility of all clinicians, rather than assigned to general practitioners alone.

A concerted effort by all stakeholder groups to improve the realisation of patient agency through ACP, the recognition of the limits of medicine and the value of dying with dignity, is essential. In the words of one participant:

> As a profession, medically, but also as a society, we're seeing death as a failure of care, something has been missed, something wasn't done, rather than seeing it as the end point that we are all destined to do. I think, because of that, there's not enough focus on the good death. There's not enough focus on dying with dignity. D2

Of particular concern to me as a psychologist is the angst expressed by many of the participants who live with guilt associated with a person's death. Patient advocates (such as family) who experienced the disregarding of an Advance Health Directive suffered substantial, long-term complex grief and guilt, whilst doctors associated inpatient death with a failure of medicine. Some doctors have difficulty recognising dying, the consequence of which includes the non-application of ACP. Difficulties prognosticating compounds doctors' internalised pressure to help patients delay death, at least within the hospital setting, and this should be addressed by healthcare system managers. Such angst contributes to doctors' failures in communication and other avoidance behaviours which in turn distresses families, clinicians, and, I would imagine, vulnerable, dying patients. In turn, practising medicine alongside unrealistic self-expectations and moral torment is unlikely to be conducive to effective communication and the provision of the best care. As one participating doctor said:

> There's a lot of internal pressure to not show weakness, that's a cultural problem in medicine… it's why there's so much depression and suicide in the medical profession. It's because of that sort of internal pressure and a lack of external support. D15

System managers such as Queensland Health, professional bodies and colleagues alike have responsibilities to psychologically support the mental health of all stakeholders. Clinicians may benefit from strategies such as death and dying being *built in* to mandatory education, training, in-services, and presentations (such as Grand Rounds and community events) to help normalise the inevitability of death. For example, where a presentation relates to the medical management of Parkinson's Disease, the presentation should also include end-of-life care for people with Parkinson's Disease.

It is simply in the best interests of all stakeholders, that clinicians and consumers be well supported in equal measure to their responsibilities.

7.7.2 Policy

Policy level improvements to enhance doctors' engagement with ACP remain to be addressed. Peak bodies such as registration boards, universities and healthcare system managers bear responsibilities for developing and implementing policies to ensure doctors are familiar with the law as it relates to withholding and withdrawing life-sustaining treatment and the application of ACP. Specifically:

- Peak bodies should deliver targeted education and training to increase doctors' knowledge of ACP. Further, incentives such as mandating state-specific education and training, and demonstrating competency, should be implemented.
- Healthcare system managers such as Queensland Health should implement mandatory education, training, and orientation programs for all doctors to ensure doctors are aware of the law (Parker et al., 2015). Education must address the interface between a patient-owned ACP and Queensland Health's Acute Resuscitation Plan to ensure doctors' compliance with the law.
- All Queensland Health clinicians should be trained in the use of available structures such as the ACP Tracker to ensure that where patients have provided their ACP to electronic medical records, these can be accessed promptly.
- All clinician groups should be trained to provide consumers with the opportunity to understand: the role and limitations of ACP; the purpose of reviewing decisions over time; the potential benefits of engaging multidisciplinary advice; and how to provide ACPs to public hospital medical records.

7.7.3 Research

To my knowledge, this research represents the first constructivist grounded theory to explain the factors associated with doctors' application of the ACP of people with a neurodegenerative disorder. Although the research drew on the rich perspectives of 45 generous participants, the extent to which the resultant theory applies to other populations (such as other illness types and other research regions) remains to be tested.

- Doctors from other regions and seniority, and those who object to the concept of ACP, should be included in future research where possible.
- The role of treatment culture (including paternalism versus shared decision-making) and the extent to which experiences associated with various medical specialties may explain the responses of doctors.
- The potential impact on specialists' knowledge of the law when specialty exams are nation-wide and laws are state-based.
- The influence of ACP outcome statements on medical decision-making.
- Stakeholders' understanding of the legal hierarchy for substitute decision-making and the potential benefit of education. Future research may extend the consent law knowledge study (Craig & Thompson, 2020, see Appendix K) which identified significant gaps in knowledge of multidisciplinary clinicians.
- The effectiveness of a top-down, bottom-up and side-to-side approach to meeting the needs of all stakeholders in relation to advance care planning.
- The perspectives of families who have, or believe they would, overlook or set aside the earlier voice of a person with a neurodegenerative disorder in favour of shared decision-making with doctors, remain to be discerned.
- Research could also explore the perspectives of those who choose to exercise their agency through ACP in a tangible effort to avoid the involvement of their families.

By understanding potentially competing voices, informed approaches addressing contradictions to ACP can be developed to improve alignment between premise and practice.

In time…

the butterfly makes its way out of its chrysalis,

freed from the threads that bound it,

stretches its wings and makes its way

into a world that is new to it…

It, too, seeks to leave a mark before death befalls it.

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Appendices

Appendix A: Licences

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Appendix B: Search Terms

Database	Terms
CINAHL	S1 TI ("living will*" OR "advance* care plan*" OR "psychiatric will*" OR "advance care directive*" OR "advance directive*" OR "power of attorney" OR "attorney power" OR "advance health care plan*" OR "advance medical plan* OR "decision making" OR consent OR autonomy OR "decision aid*" OR "patient choice*" OR "patient preference*") OR AB ("living will*" OR "advance* care plan*" OR "psychiatric will*" OR "advance care directive*" OR "advance directive*" OR "power of attorney" OR "attorney power" OR "advance health care plan*" OR "advance medical plan* OR "decision making" OR consent OR autonomy OR "decision aid*" OR "patient choice*" OR "patient preference*") OR SU ("living will*" OR "advance* care plan*" OR "psychiatric will*" OR "advance care directive*" OR "advance directive*" OR "power of attorney" OR "attorney power" OR "advance health care plan*" OR "advance medical plan* OR "decision making" OR consent OR autonomy OR "decision aid*" OR "patient choice*" OR "patient preference*") OR MW ("living will*" OR "advance* care plan*" OR "psychiatric will*" OR "advance care directive*" OR "advance directive*" OR "power of attorney" OR "attorney power" OR "advance health care plan*" OR "advance medical plan* OR "decision making" OR consent OR autonomy OR "decision aid*" OR "patient choice*" OR "patient preference*") S2 TI ("ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation") OR AB ("ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation") OR SU ("ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation") OR MW ("ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation") S3 (TI "ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation" OR AB "ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation" OR SU "ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation" OR MW "ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation") AND (S1 OR S2) S4 TI (hospice* OR hospital* OR "palliative care facilit*" OR "palliative care ward*" OR "acute care" OR "subacute care" OR "critical care" OR icu OR "intensive care" OR "emergency department*" OR ed OR inpatient* OR "hemodialysis unit*" OR "operating room*" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation" OR AB "ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment"

	OR "treatment refusal" OR "treatment limitation" OR SU "ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation" OR MW "ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation") AND (S1 OR S2)) OR AB (hospice* OR hospital* OR "palliative care facilit*" OR "palliative care ward*" OR "acute care" OR "subacute care" OR "critical care" OR icu OR "intensive care" OR "emergency department*" OR ed OR inpatient* OR "hemodialysis unit*" OR "operating room*") OR SU (hospice* OR hospital* OR "palliative care facilit*" OR "palliative care ward*" OR "acute care" OR "subacute care" OR "critical care" OR icu OR "intensive care" OR "emergency department*" OR ed OR inpatient* OR "hemodialysis unit*" OR "operating room*") OR MW (hospice* OR hospital* OR "palliative care facilit*" OR "palliative care ward*" OR "acute care" OR "subacute care" OR "critical care" OR icu OR "intensive care" OR "emergency department*" OR ed OR inpatient* OR "hemodialysis unit*" OR "operating room*") S5 TI (physician* OR cardiologist* OR endocrinologist* OR "foreign medical graduate*" OR gastroenterologist* OR geriatrician* OR hospitalist* OR nephrologist* OR neurologist* OR oncologist* OR otolaryngologist* OR physiatrist* OR pulmonologist* OR radiologist*) OR AB (physician* OR cardiologist* OR endocrinologist* OR "foreign medical graduate*" OR gastroenterologist* OR geriatrician* OR hospitalist* OR nephrologist* OR neurologist* OR oncologist* OR otolaryngologist* OR physiatrist* OR pulmonologist* OR radiologist*) OR SU (physician* OR cardiologist* OR endocrinologist* OR "foreign medical graduate*" OR gastroenterologist* OR geriatrician* OR hospitalist* OR nephrologist* OR neurologist* OR oncologist* OR otolaryngologist* OR physiatrist* OR pulmonologist* OR radiologist*) OR MW (physician* OR cardiologist* OR endocrinologist* OR "foreign medical graduate*" OR gastroenterologist* OR geriatrician* OR hospitalist* OR nephrologist* OR neurologist* OR oncologist* OR otolaryngologist* OR physiatrist* OR pulmonologist* OR radiologist*) S6 TI (rheumatologist* OR surgeon* OR urologist* OR doctor* OR "medical officer*") OR AB (rheumatologist* OR surgeon* OR urologist* OR doctor* OR "medical officer*") OR SU (rheumatologist* OR surgeon* OR urologist* OR doctor* OR "medical officer*") OR MW (rheumatologist* OR surgeon* OR urologist* OR doctor* OR "medical officer*") S7 TI (attitude* OR belief* OR barrier* OR emotion* OR practice* OR knowledge OR opinion* OR decision OR enabl* OR perception* OR understand* OR implement*) OR AB (attitude* OR belief* OR barrier* OR emotion* OR practice* OR knowledge OR opinion* OR decision OR enabl* OR perception* OR understand* OR implement*) OR SU (attitude* OR belief* OR barrier* OR emotion* OR practice* OR knowledge OR opinion* OR decision OR enabl* OR perception* OR understand* OR implement*) OR MW (attitude* OR belief* OR barrier* OR emotion* OR practice* OR knowledge OR opinion* OR decision OR enabl* OR perception* OR understand* OR implement*) S8 TI (mortality OR death OR dying OR palliati* OR "end of life" OR incapacit* OR "life support" OR resuscitat* OR dead) OR AB (mortality OR death OR dying OR palliati* OR "end of life" OR incapacit* OR "life support" OR resuscitat* OR dead)

	OR SU (mortality OR death OR dying OR palliati* OR "end of life" OR incapacit* OR "life support" OR resuscitat* OR dead) OR MW (mortality OR death OR dying OR palliati* OR "end of life" OR incapacit* OR "life support" OR resuscitat* OR dead) S9 TI (suicide OR euthanasia OR "assisted dying" OR "assisted death") OR AB (suicide OR euthanasia OR "assisted dying" OR "assisted death") OR SU (suicide OR euthanasia OR "assisted dying" OR "assisted death") OR MW (suicide OR euthanasia OR "assisted dying" OR "assisted death") S10 TI ("living will*" OR "advance* care plan*" OR "psychiatric will*" OR "advance care directive*" OR "advance directive*" OR "power of attorney" OR "attorney power" OR "advance health care plan*" OR "advance medical plan* OR "decision making" OR consent OR autonomy OR "decision aid*" OR "patient choice*" OR "patient preference*") OR AB ("living will*" OR "advance* care plan*" OR "psychiatric will*" OR "advance care directive*" OR "advance directive*" OR "power of attorney" OR "attorney power" OR "advance health care plan*" OR "advance medical plan* OR "decision making" OR consent OR autonomy OR "decision aid*" OR "patient choice*" OR "patient preference*") OR SU ("living will*" OR "advance* care plan*" OR "psychiatric will*" OR "advance care directive*" OR "advance directive*" OR "power of attorney" OR "attorney power" OR "advance health care plan*" OR "advance medical plan* OR "decision making" OR consent OR autonomy OR "decision aid*" OR "patient choice*" OR "patient preference*") OR MW ("living will*" OR "advance* care plan*" OR "psychiatric will*" OR "advance care directive*" OR "advance directive*" OR "power of attorney" OR "attorney power" OR "advance health care plan*" OR "advance medical plan* OR "decision making" OR consent OR autonomy OR "decision aid*" OR "patient choice*" OR "patient preference*") S11 TI ("ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation") OR AB ("ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation") OR SU ("ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation") OR MW ("ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation") S12 (TI "ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation" OR AB "ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation" OR SU "ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation" OR MW "ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation") AND (S10 OR S11)

	S13 TI (hospice* OR hospital* OR "palliative care facilit*" OR "palliative care ward*" OR "acute care" OR "subacute care" OR "critical care" OR icu OR "intensive care" OR "emergency department*" OR ed OR inpatient* OR "hemodialysis unit*" OR "operating room*" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation" OR AB "ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation" OR SU "ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation" OR MW "ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation") AND (S10 OR S11)) OR AB (hospice* OR hospital* OR "palliative care facilit*" OR "palliative care ward*" OR "acute care" OR "subacute care" OR "critical care" OR icu OR "intensive care" OR "emergency department*" OR ed OR inpatient* OR "hemodialysis unit*" OR "operating room*") OR SU (hospice* OR hospital* OR "palliative care facilit*" OR "palliative care ward*" OR "acute care" OR "subacute care" OR "critical care" OR icu OR "intensive care" OR "emergency department*" OR ed OR inpatient* OR "hemodialysis unit*" OR "operating room*") OR MW (hospice* OR hospital* OR "palliative care facilit*" OR "palliative care ward*" OR "acute care" OR "subacute care" OR "critical care" OR icu OR "intensive care" OR "emergency department*" OR ed OR inpatient* OR "hemodialysis unit*" OR "operating room*") S14 TI (physician* OR cardiologist* OR endocrinologist* OR "foreign medical graduate*" OR gastroenterologist* OR geriatrician* OR hospitalist* OR nephrologist* OR neurologist* OR oncologist* OR otolaryngologist* OR physiatrist* OR pulmonologist* OR radiologist*) OR AB (physician* OR cardiologist* OR endocrinologist* OR "foreign medical graduate*" OR gastroenterologist* OR geriatrician* OR hospitalist* OR nephrologist* OR neurologist* OR oncologist* OR otolaryngologist* OR physiatrist* OR pulmonologist* OR radiologist*) OR SU (physician* OR cardiologist* OR endocrinologist* OR "foreign medical graduate*" OR gastroenterologist* OR geriatrician* OR hospitalist* OR nephrologist* OR neurologist* OR oncologist* OR otolaryngologist* OR physiatrist* OR pulmonologist* OR radiologist*) OR MW (physician* OR cardiologist* OR endocrinologist* OR "foreign medical graduate*" OR gastroenterologist* OR geriatrician* OR hospitalist* OR nephrologist* OR neurologist* OR oncologist* OR otolaryngologist* OR physiatrist* OR pulmonologist* OR radiologist*) S15 TI (rheumatologist* OR surgeon* OR urologist* OR doctor* OR "medical officer*") OR AB (rheumatologist* OR surgeon* OR urologist* OR doctor* OR "medical officer*") OR SU (rheumatologist* OR surgeon* OR urologist* OR doctor* OR "medical officer*") OR MW (rheumatologist* OR surgeon* OR urologist* OR doctor* OR "medical officer*") S16 TI (attitude* OR belief* OR barrier* OR emotion* OR practice* OR knowledge OR opinion* OR decision OR enabl* OR perception* OR understand* OR implement*) OR AB (attitude* OR belief* OR barrier* OR emotion* OR practice* OR knowledge OR opinion* OR decision OR enabl* OR perception* OR understand* OR implement*) OR SU (attitude* OR belief* OR barrier* OR emotion* OR practice* OR knowledge OR opinion* OR decision OR enabl* OR

	perception* OR understand* OR implement*) OR MW (attitude* OR belief* OR barrier* OR emotion* OR practice* OR knowledge OR opinion* OR decision OR enabl* OR perception* OR understand* OR implement*) S17 TI (mortality OR death OR dying OR palliati* OR "end of life" OR incapacit* OR "life support" OR resuscitat* OR dead) OR AB (mortality OR death OR dying OR palliati* OR "end of life" OR incapacit* OR "life support" OR resuscitat* OR dead) OR SU (mortality OR death OR dying OR palliati* OR "end of life" OR incapacit* OR "life support" OR resuscitat* OR dead) OR MW (mortality OR death OR dying OR palliati* OR "end of life" OR incapacit* OR "life support" OR resuscitat* OR dead) S18 S14 OR S15 S19 (S14 OR S15) AND (S12 AND S13 AND S16 AND S17 AND S18)
Medline and Ovid	"advance care plan*" or "Advance directive*" or "Living will*" or " advance*care directive*" or "power of attorney" or "advance health care plan*" or "Advance medical plan*" or "Ulysses contract*" or "surrogate directive" or decision or "resuscitation order*" or contract or "refuse*treatment" or "treatment refusal" or "treatment limitation" Advance Care Plan* or Advance Directive* 2. "living will*" or "advance*care plan*" or "psychiatric will*" or "advance care directive*" or "advance directive*" or "power of attorney" or "attorney power" or "advance health care plan*" or "advance medical plan*" or "ulysses contract*" or "surrogate directive" or "advance*decision" or "resuscitation order" or contract or "refuse*treatment" or "treatment refusal" or "treatment limitation".mp. 3. 1 or 2 4. decision making or consent or autonomy or decision aid or patient choice or patient preference.mp. 5. "Attitude of Health Personnel" 6. ATTITUDE 7. ATTITUDE to death 8. attitude*or belief*or barrier*or emotion*or practice*or knowledge or opinion*or decision or enabl*or perception*or understand*or implement*.mp. 9. 5 or 6 or 7 or 8 10. mortality or death or dying or palliati*or end of life or incapacitat*or life support or resuscitation or dead.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 11. physician* or cardiologist* or endocrinologist* or foreign medical graduate* or gastroenterologist* or geriatrician* or hospitalist* or nephrologist* or neurologist* or oncologist* or otolaryngologist* or physiatrist* or pulmonologist* or radiologist* or rheumatologist* or

	surgeon*or urologist* 12. doctor* or medical officer.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 13. 11 or 12 14. hospital unit*or hemodialysis units, hospital/ or exp intensive care unit*or operating room*or exp hospital* 15. hospice*or hospital*or palliative care facilit*or palliative care ward*or acute care or subacute care or critical care or intensive care or emergency department or ed or inpatient*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 16. 14 or 15 17. The influence of medical enduring power of attorney and advance directives on decision-making by Australian intensive care doctors.m_titl. 18. Comparing doctors legal compliance across three Australian states for decisions whether to withhold or withdraw life-sustaining medical treatment: does different law lead to different decisions.m_titl. 19. 3 and 4 and 9 and 10 and 13 and 16 20. lawyer*or patient*or witness*or attorney*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 21. 19 and 20 22. exp EUTHANASIA/ 23. Suicide, Assisted/ 24. Suicide/ 25. (suicide or euthanasia or assisted dying or assisted death).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 26. 22 or 23 or 24 or 25
ACP no suicide Medline Ovid	1. exp Advance Care Planning/ or exp Advance Directives/ 2. (living will* or advance* care plan* or psychiatric will* or advance care directive* or advance directive* or power of attorney or attorney power or advance health care plan* or advance medical plan* or ulysses contract* or surrogate directive or advance* decision or

	resuscitation order or contract or refuse* treatment or treatment refusal or treatment limitation).mp. 3. 1 or 2 4. (decision making or consent or autonomy or decision aid or patient choice or patient preference).mp. 5. "Attitude of Health Personnel"/ 6. ATTITUDE/ 7. ATTITUDE to death/ 8. (attitude* or belief* or barrier* or emotion* or practice* or knowledge or opinion* or decision or enabl* or perception* or understand* or implement*).mp. 9. 5 or 6 or 7 or 8 10. (mortality or death or dying or palliati* or end of life or incapacitat* or life support or resuscitation or dead).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 11. physicians/ or cardiologists/ or endocrinologists/ or foreign medical graduates/ or gastroenterologists/ or geriatricians/ or hospitalists/ or nephrologists/ or neurologists/ or exp oncologists/ or otolaryngologists/ or physiatrists/ or physicians, women/ or pulmonologists/ or exp radiologists/ or rheumatologists/ or exp surgeons/ or urologists/ 12. (doctor* or physician or surgeon or medical officer).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 13. 11 or 12 14. hospital units/ or hemodialysis units, hospital/ or exp intensive care units/ or operating rooms/ or exp hospitals/ 15. (hospice* or hospital* or palliative care facilit* or palliative care ward* or acute care or subacute care or critical care or intensive care or emergency department or ed or inpatient*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 16. 14 or 15 17. (The influence of medical enduring power of attorney and advance directives on decision-making by Australian intensive care doctors).m_titl.

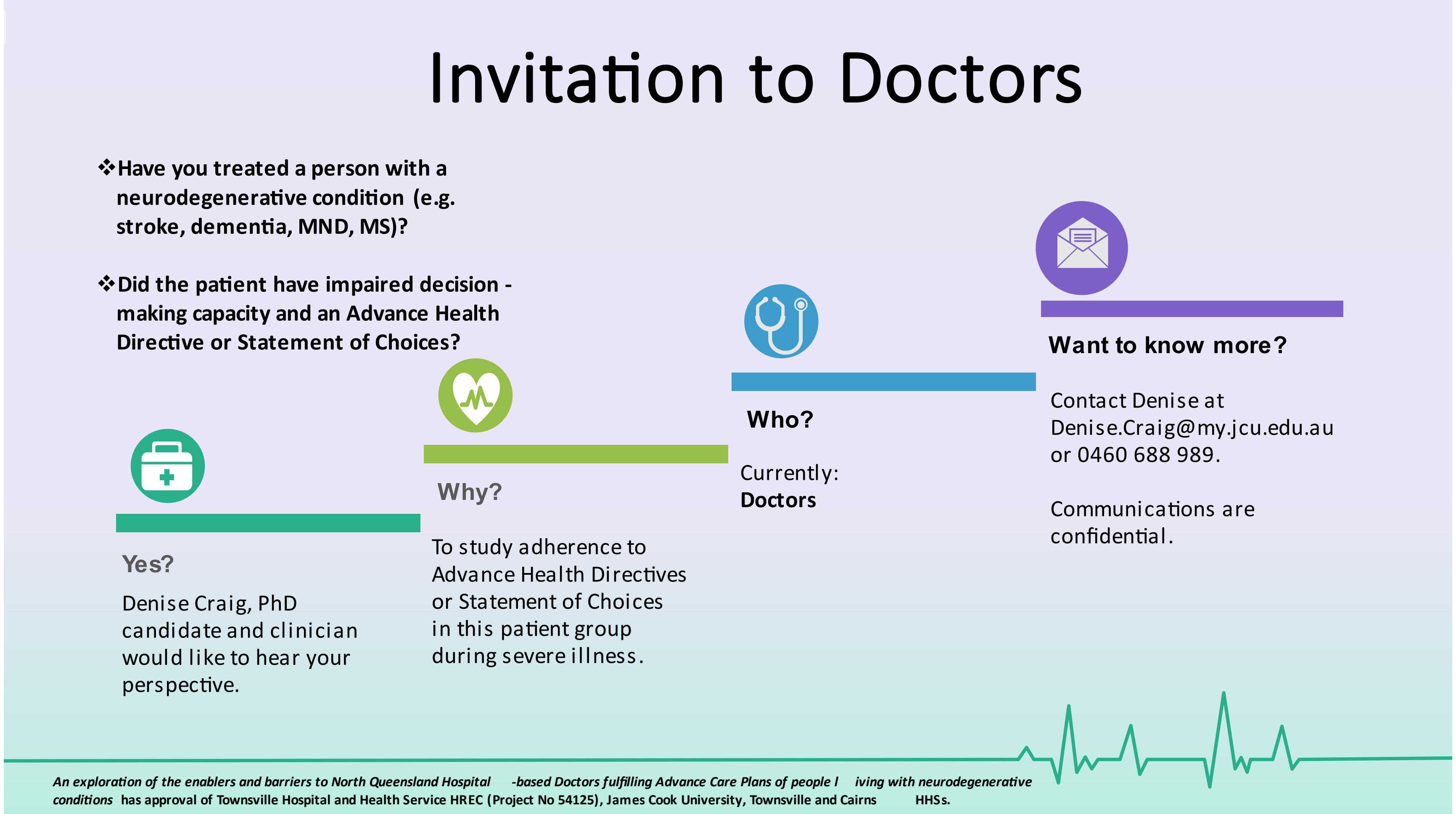
	18. (Comparing doctors legal compliance across three Australian states for decisions whether to withhold or withdraw life-sustaining medical treatment: does different law lead to different decisions).m_titl. 19. 3 and 4 and 9 and 10 and 13 and 16 20. (lawyer* or patient* or witness* or attorney*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 21. 19 and 20 22. exp EUTHANASIA/ 23. Suicide, Assisted/ 24. Suicide/ 25. (suicide or euthanasia or assisted dying or assisted death).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 26. 22 or 23 or 24 or 25 27. 21 not 26
ACP no suicide Emcare	1. exp Advance Care Planning/ or exp Advance Directives/ 2. (living will* or advance* care plan* or psychiatric will* or advance care directive* or advance directive* or power of attorney or attorney power or advance health care plan* or advance medical plan* or ulysses contract* or surrogate directive or advance* decision or resuscitation order or contract or refuse* treatment or treatment refusal or treatment limitation).mp. 3. 1 or 2 4. (decision making or consent or autonomy or decision aid or patient choice or patient preference).mp. 5. "Attitude of Health Personnel"/ 6. ATTITUDE/ 7. ATTITUDE to death/ 8. (attitude* or belief* or barrier* or emotion* or practice* or knowledge or opinion* or decision or enabl* or perception* or understand* or implement*).mp. 9. 5 or 6 or 7 or 8

	10. (mortality or death or dying or palliati* or end of life or incapacitat* or life support or resuscitation or dead).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
	11. physicians/ or cardiologists/ or endocrinologists/ or foreign medical graduates/ or gastroenterologists/ or geriatricians/ or hospitalists/ or nephrologists/ or neurologists/ or exp oncologists/ or otolaryngologists/ or physiatrists/ or physicians, women/ or pulmonologists/ or exp radiologists/ or rheumatologists/ or exp surgeons/ or urologists/
	12. (doctor* or physician or surgeon or medical officer).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
	13. 11 or 12
	14. hospital units/ or hemodialysis units, hospital/ or exp intensive care units/ or operating rooms/ or exp hospitals/
	15. (hospice* or hospital* or palliative care facilit* or palliative care ward* or acute care or subacute care or critical care or intensive care or emergency department or ed or inpatient*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
	16. 14 or 15
	17. (The influence of medical enduring power of attorney and advance directives on decision-making by Australian intensive care doctors).m_titl.
	18. (Comparing doctors legal compliance across three Australian states for decisions whether to withhold or withdraw life-sustaining medical treatment: does different law lead to different decisions).m_titl.
	19. 3 and 4 and 9 and 10 and 13 and 16
	20. (lawyer* or patient* or witness* or attorney*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
	21. 19 and 20
	22. exp EUTHANASIA/
	23. Suicide, Assisted/
	24. Suicide/
	25. (suicide or euthanasia or assisted dying or assisted death).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
	26. 22 or 23 or 24 or 25

	27. 21 not 26
Psych Info	(su(mortality OR death OR dying OR palliati* OR "end of life" OR incapacit* OR "life support" OR resuscitat* OR dead) OR ab(mortality OR death OR dying OR palliati* OR "end of life" OR incapacit* OR "life support" OR resuscitat* OR dead) OR ti(mortality OR death OR dying OR palliati* OR "end of life" OR incapacit* OR "life support" OR resuscitat* OR dead)) AND ((((((su("living will*" OR "advance* care plan*" OR "psychiatric will*" OR "advance care directive*" OR "advance directive*" OR "power of attorney" OR "attorney power" OR "advance health care plan*" OR "advance medical plan*") OR ab("living will*" OR "advance* care plan*" OR "psychiatric will*" OR "advance care directive*" OR "advance directive*" OR "power of attorney" OR "attorney power" OR "advance health care plan*" OR "advance medical plan*") OR ti("living will*" OR "advance* care plan*" OR "psychiatric will*" OR "advance care directive*" OR "advance directive*" OR "power of attorney" OR "attorney power" OR "advance health care plan*" OR "advance medical plan*")) OR (su("ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation") OR ab("ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation") OR ti("ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation"))) OR (su("decision making" OR consent OR autonomy OR "decision aid*" OR "patient choice*" OR "patient preference*") OR ab("decision making" OR consent OR autonomy OR "decision aid*" OR "patient choice*" OR "patient preference*") OR ti("decision making" OR consent OR autonomy OR "decision aid*" OR "patient choice*" OR "patient preference*"))) AND ((su(physician* OR cardiologist* OR endocrinologist* OR "foreign medical graduate*" OR gastroenterologist* OR geriatrician* OR hospitalist* OR nephrologist* OR neurologist* OR oncologist* OR otolaryngologist* OR physiatrist* OR pulmonologist* OR radiologist*) OR ab(physician* OR cardiologist* OR endocrinologist* OR "foreign medical graduate*" OR gastroenterologist* OR geriatrician* OR hospitalist* OR nephrologist* OR neurologist* OR oncologist* OR otolaryngologist* OR physiatrist* OR pulmonologist* OR radiologist*) OR ti(physician* OR cardiologist* OR endocrinologist* OR "foreign medical graduate*" OR gastroenterologist* OR geriatrician* OR hospitalist* OR nephrologist* OR neurologist* OR oncologist* OR otolaryngologist* OR physiatrist* OR pulmonologist* OR radiologist*)) OR (su(rheumatologist* OR surgeon* OR urologist* OR doctor* OR "medical officer*") OR ab(rheumatologist* OR surgeon* OR urologist* OR doctor* OR "medical officer*") OR ti(rheumatologist* OR surgeon* OR urologist* OR doctor* OR "medical officer*"))) AND (su(hospice* OR hospital* OR "palliative care facilit*" OR "palliative care ward*" OR "acute care" OR "subacute care" OR "critical care" OR icu OR "intensive care" OR "emergency department*" OR ed OR inpatient* OR "hemodialysis unit*" OR "operating room*") OR ab(hospice* OR hospital* OR "palliative care facilit*" OR "palliative care ward*" OR "acute care" OR "subacute care" OR "critical care" OR icu OR "intensive care" OR "emergency department*" OR ed OR inpatient* OR "hemodialysis unit*" OR "operating room*") OR ti(hospice* OR hospital* OR "palliative care facilit*" OR "palliative care ward*" OR "acute care" OR "subacute care" OR "critical care" OR icu OR "intensive care" OR "emergency department*" OR ed OR inpatient* OR "hemodialysis unit*" OR

	"operating room*"))) AND (su(attitude* OR belief* OR barrier* OR emotion* OR practice* OR knowledge OR opinion* OR decision OR enabl* OR perception* OR understand* OR implement*) OR ab(attitude* OR belief* OR barrier* OR emotion* OR practice* OR knowledge OR opinion* OR decision OR enabl* OR perception* OR understand* OR implement*) OR ti(attitude* OR belief* OR barrier* OR emotion* OR practice* OR knowledge OR opinion* OR decision OR enabl* OR perception* OR understand* OR implement*))) NOT (su(suicide OR euthanasia OR "assisted dying" OR "assisted death") OR ab(suicide OR euthanasia OR "assisted dying" OR "assisted death") OR ti(suicide OR euthanasia OR "assisted dying" OR "assisted death"))) AND (rtype.exact("Peer Reviewed Journal") AND la.exact("ENG") AND ccl.exact(("Professional Personnel Attitudes & Characteristics" OR "Health & Mental Health Services" OR "Inpatient & Hospital Services" OR "Medical Treatment of Physical Illness" OR "Home Care & Hospice" OR "Professional Ethics & Standards & Liability" OR "Professional Psychological & Health Personnel Issues" OR "Cancer" OR "Health Psychology & Medicine" OR "Neurological Disorders & Brain Damage" OR "Cardiovascular Disorders" OR "Organizational Behavior" OR "Gerontology" OR "Personnel Attitudes & Job Satisfaction") NOT ("Health & Mental Health Treatment & Prevention" OR "Professional Education & Training" OR "Clinical Psychopharmacology" OR "Physical & Somatoform & Psychogenic Disorders" OR "Nursing Homes & Residential Care" OR "Promotion & Maintenance of Health & Wellness" OR "Clinical Psychological Testing" OR "Specialized Interventions" OR "Health Psychology Testing" OR "Outpatient Services" OR "Psychological Disorders" OR "Psychotherapy & Psychotherapeutic Counseling" OR "Behavioral & Psychological Treatment of Physical Illness" OR "Civil Rights & Civil Law" OR "Psychological & Physical Disorders" OR "Schizophrenia & Psychotic States" OR "Drug & Alcohol Rehabilitation" OR "Substance Abuse & Addiction" OR "Immunological Disorders" OR "Military Psychology" OR "Community & Social Services" OR "Occupational & Employment Testing" OR "Tests & Testing" OR "Rehabilitation" OR "Affective Disorders" OR "Artificial Intelligence & Expert Systems" OR "Cognitive Processes" OR "Behavior Disorders & Antisocial Behavior" OR "Consumer Attitudes & Behavior" OR "Criminal Law & Adjudication" OR "Developmental Disorders & Autism" OR "Engineering & Environmental Psychology" OR "Impaired Professionals" OR "Intelligent Systems" OR "Interpersonal & Client Centered & Humanistic Therapy" OR "Mass Media Communications" OR "Neuroses & Anxiety Disorders" OR "Behavior Therapy & Behavior Modification" OR "Childrearing & Child Care" OR "Consumer Psychology" OR "Criminal Rehabilitation & Penology" OR "Developmental Psychology" OR "Drug & Alcohol Usage (Legal)" OR "Forensic Psychology & Legal Issues" OR "Human Factors Engineering" OR "Industrial & Organizational Psychology" OR "Management & Management Training" OR "Mental Retardation" OR "Neural Networks" OR "Neuropsychology & Neurology" OR "Personality Traits & Processes" OR "Police & Legal Personnel" OR "Psychosocial & Personality Development" OR "Research Methods & Experimental Design" OR "Social Processes & Social Issues" OR "Social Structure & Organization" OR "Statistics & Mathematics" OR "Vision & Hearing & Sensory Disorders" OR "Working Conditions & Industrial Safety")) AND me.exact(("Empirical Study" OR "Quantitative Study" OR "Qualitative Study" OR "Interview" OR "Longitudinal Study" OR "Retrospective Study" OR "Followup Study" OR "Field Study" OR "Clinical Trial" OR "Systematic Review" OR "Treatment Outcome" OR "Meta Analysis" OR "Metasynthesis") NOT ("Focus Group" OR "Prospective Study" OR "Clinical Case Study" OR "Literature Review"

	OR "Mathematical Model" OR "Nonclinical Case Study" OR "Scientific Simulation" OR "Brain Imaging")) AND PEER(yes)))
Scopus	TITLE-ABS-KEY "living will*" OR "advance* care plan*" OR "psychiatric will*" OR "advance care directive*" OR "advance directive*" OR "power of attorney" OR "attorney power" OR "advance health care plan*" OR "advance medical plan*" OR "ulysses contract*" OR "surrogate directive" OR "advance* decision" OR "resuscitation order" OR contract OR "refus* treatment" OR "treatment refusal" OR "treatment limitation" AND TITLE-ABS-KEY hospice* OR hospital* OR "palliative care facilit*" OR "palliative care ward*" OR "acute care" OR "subacute care" OR "critical care" OR icu OR "intensive care" OR "emergency department*" OR ed OR inpatient* OR "hemodialysis unit*" OR "operating room*" AND TITLE-ABS-KEY physician* OR cardiologist* OR endocrinologist* OR "foreign medical graduate*" OR gastroenterologist* OR geriatrician* OR hospitalist* OR nephrologist* OR neurologist* OR oncologist* OR otolaryngologist* OR physiatrist* OR pulmonologist* OR radiologist* OR rheumatologist* OR surgeon* OR urologist* OR doctor* OR "medical officer*" AND TITLE-ABS-KEY "decision making" OR consent OR autonomy OR "decision aid*" OR "patient choice*" OR "patient preference*" AND TITLE-ABS-KEY attitude* OR belief* OR barrier* OR emotion* OR practice* OR knowledge OR opinion* OR decision OR enabl* OR perception* OR understand* OR implement* AND TITLE-ABS-KEY mortality OR death OR dying OR palliati* OR "end of life" OR incapacit* OR "life support" OR resuscitat* OR dead AND TITLE-ABS-KEY lawyer* OR patient* OR witness* OR attorney* AND NOT TITLE-ABS-KEY suicide OR euthanasia OR "assisted dying" OR "assisted death"



Invitation to Doctors

- ❖**Have you treated a person with a neurodegenerative condition (e.g. stroke, dementia, MND, MS)?**
- ❖**Did the patient have impaired decision-making capacity and an Advance Health Directive or Statement of Choices?**

Yes?

Denise Craig, PhD candidate and clinician would like to hear your perspective.

Why?

To study adherence to Advance Health Directives or Statement of Choices in this patient group during severe illness.

Who?

Currently: **Doctors**

Want to know more?

Contact Denise at Denise.Craig@my.jcu.edu.au or 0460 688 989.

Communications are confidential.

An exploration of the enablers and barriers to North Queensland Hospital-based Doctors fulfilling Advance Care Plans of people living with neurodegenerative conditions has approval of Townsville Hospital and Health Service HREC (Project No 54125), James Cook University, Townsville and Cairns HHSs.

Invitation to Nurses & Allied Health

- ❖Have you treated a person with a neurodegenerative condition (e.g. dementia, MND, MS)?
- ❖Did the patient have impaired decision making capacity and an Advance Health Directive or Statement of Choices?

Yes?

Denise Craig, PhD candidate and clinician would like to hear your perspective.

Why?

To study adherence to Advance Health Directives or Statement of Choices in this patient group during severe illness.

Who?

Currently:
Nurses
Allied Health clinicians.

Next phase:
Doctors

Want to know more?

Contact Denise at
Denise.Craig@my.jcu.edu.au
or 0460 688 989

Communications are confidential.

An exploration of the enablers and barriers to Hospital-based Doctors fulfilling Advance Care Plans of people living with neurodegenerative conditions in North Queensland has approval of Townsville Hospital and Health Service HREC (Project No 54125), James Cook University, Townsville and Cairns HHSs.

INFORMATION SHEET – Person diagnosed with Neurocognitive Disease.

PROJECT TITLE: **"An exploration of the enablers and barriers to Hospital-based Doctors fulfilling Advance Care Plans of people living with neurodegenerative conditions in North Queensland."**

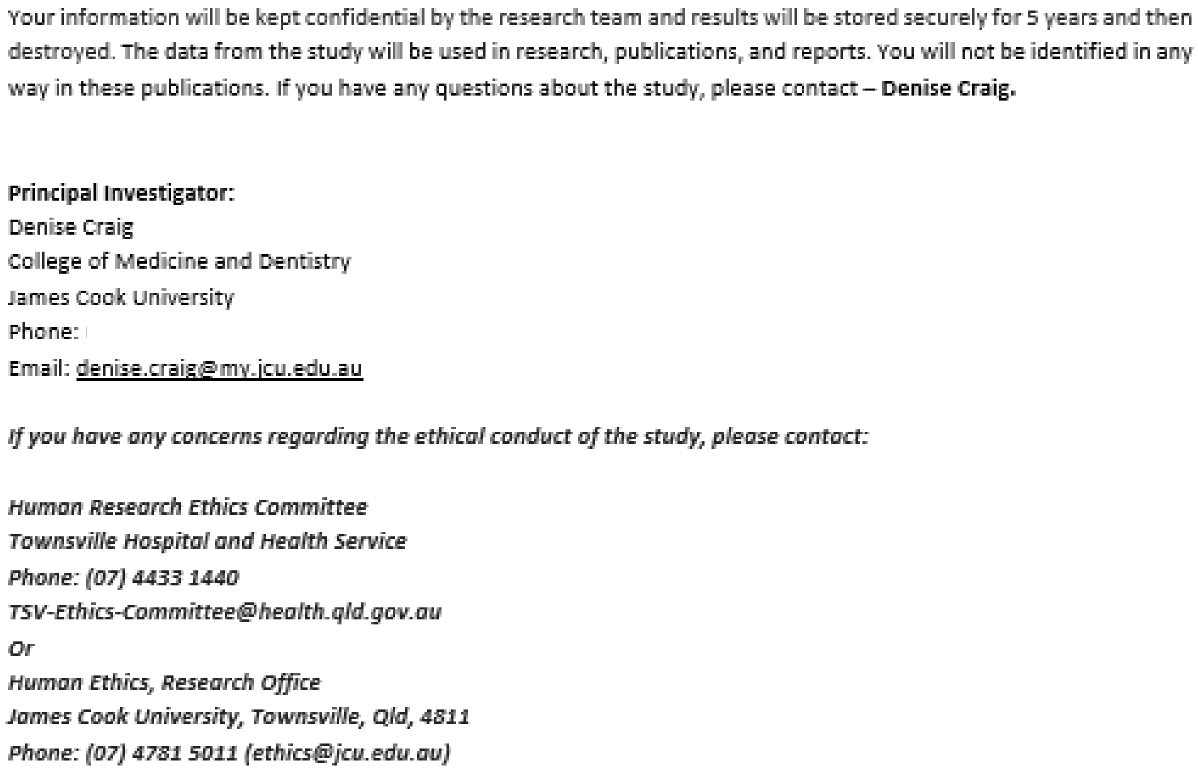
If you have been diagnosed with a neurodegenerative disease (e.g. MND, MS, Parkinson's Disease or dementia), you are invited to take part in a research project. This research will explore the experience of doctors treating people who have an Advance Care Plan. The researcher would also like to understand the reasons that people complete an Advance Care Plan. An Advance Care Plan in Queensland is usually an Advance Health Directive or a Statement of Choices. This research is important because it will help to explain doctors' reasons for following or not following patients' advance care plans.

This study has the approval of the Townsville Hospital and Health Service Human Research Ethics Committees (HREC) Project No 54125 on 15.08.2019 and James Cook University on 18.09.2019. The study is being conducted by Denise Craig (PhD student/Health Professional) under the supervision of Dr Robin Ray, Dr Desley Harvey and Associate Professor Mandy Shircore, and it will contribute to Denise's Doctor of Philosophy degree at James Cook University.

If you choose to participate, the researcher will ask you about your motivations for completing an Advance Care Plan, and for your opinion about what the Advance Care Plan will do for you if you are ever in hospital and unable to make all of your own decisions. **If you agree to be involved, you will be invited to take part in a face to face (or Skype or telephone) interview, which will be recorded**. The interview should take about 30 to 90 minutes at an agreed time and place. You will be offered a $50 voucher for your time during participation

If you have difficulty communicating your thoughts, someone who is close to you could be asked to provide their lawful consent to you participating in this study, if you agree to this. Taking part in this study is voluntary and you can stop at any time. **Your choice to participate will not impact on the care you receive.** If you know of others who might be interested in this study, please pass on this information sheet to them so they may contact Denise to volunteer for the study.

Any personal and health information obtained about you which will identify you will remain confidential and will be used only for the purposes of this study. However, under exceptional circumstances we may be required to disclose information you have provided. This might occur where disclosure is required by law, for example, if you were to advise us that you were the victim of a criminal act while you were receiving health services, or it mandatory policy directives compel us to do so. For example, if you advise us of serious misconduct or negligence by a staff member.



Your information will be kept confidential by the research team and results will be stored securely for 5 years and then destroyed. The data from the study will be used in research, publications, and reports. You will not be identified in any way in these publications. If you have any questions about the study, please contact – **Denise Craig.**

Principal Investigator:
Denise Craig
College of Medicine and Dentistry
James Cook University
Phone:
Email: denise.craig@my.jcu.edu.au

If you have any concerns regarding the ethical conduct of the study, please contact:

Human Research Ethics Committee
Townsville Hospital and Health Service
Phone: (07) 4433 1440
TSV-Ethics-Committee@health.qld.gov.au
Or
Human Ethics, Research Office
James Cook University, Townsville, Qld, 4811
Phone: (07) 4781 5011 (ethics@jcu.edu.au)

JAMES COOK UNIVERSITY
AUSTRALIA

Queensland
Government

INFORMATION SHEET – Family/Carer/Advocate

PROJECT TITLE: **"An exploration of the enablers and barriers to Hospital-based Doctors fulfilling Advance Care Plans of people living with neurodegenerative conditions in North Queensland."**

You are invited to share your experience of doctors in North Queensland public hospitals following or not following the written Advance Care Plan of someone close to you who has (or had) an illness such as Motor Neurone Disease, Multiple Sclerosis, Parkinson's Disease, Dementia, or similar. The research will also explore the reasons that doctors in hospitals give for following (or not following) the written plans of these patients. An Advance Care Plan in Queensland is usually an Advance Health Directive or a Statement of Choices. This research is important because it will help to explain doctors' reasons for following or not following patients' advance care plans.

This study has the approval of the Townsville Hospital and Health Service Human Research Ethics Committees (HREC) Project No 54125 on 15.08.2019 and James Cook University on 18.09.2019. The study is being conducted by Denise Craig (PhD student/Health Professional) under the supervision of Dr Robin Ray, Dr Desley Harvey and Associate Professor Mandy Shircore, and it will contribute to Denise's Doctor of Philosophy degree at James Cook University.

This study will ask for your opinion about whether you believe the Advance Care Plan of a person you are close to was followed when the person was in hospital. If the person died in hospital, you are still welcome to participate. **If you agree to be involved, you are invited to take part in a face to face (or Skype or telephone) interview, which will be recorded.** The interview should take about 30 to 90 minutes at an agreed time and place.

Taking part in this study is voluntary and you can stop taking part at any time. **Your choice to participate will not impact on the care you (or the person you will be speaking about) receive.** If you know of others who might be interested in this study, please pass on this information sheet to them so they may contact Denise to volunteer for the study.

Any personal and health information obtained about you which will identify you will remain confidential and will be used only for the purposes of this study. However, under exceptional circumstances we may be required to disclose information you have provided. This might occur where disclosure is required by law, for example, if you were to advise us that you were the victim of a criminal act while you were receiving health services, or it mandatory policy directives compel us to do so. For example, if you advise us of serious misconduct or negligence by a staff member.

Your information will be stored securely on a password protected computer and any written information will be stored in a locked filing cabinet accessible only to the researchers. All paper and computer files will be destroyed after five years. The data from the study will be used in research, publications, and reports. You will not be identified in any way in these publications.

If you have any questions about the study, please contact – **Denise Craig.**

Principal Investigator:
Denise Craig
College of Medicine and Dentistry
James Cook University
Phone:
Email: denise.craig@my.jcu.edu.au

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Or
Human Ethics, Research Office
James Cook University, Townsville, Qld, 4811
Phone: (07) 4781 5011 (ethics@jcu.edu.au)

INFORMATION SHEET – Clinicians

PROJECT TITLE: **"An exploration of the enablers and barriers to Hospital-based Doctors fulfilling Advance Care Plans of people living with neurodegenerative conditions in North Queensland."**

If you are a clinician who has experienced inpatient treatment of someone diagnosed with a neurodegenerative disease (e.g. MND, MS, Parkinson's Disease, Dementia), you are invited to take part in a research project. This project will explore your experience of doctors in North Queensland hospitals following or not following the written Advance Care Plans (ACP) of patients with a neurodegenerative disease. An ACP in Queensland is usually an Advance Health Directive or a Statement of Choices.

The overall aim of the study is to explore factors associated with hospital doctors fulfilling the documented wishes of patients with neurodegenerative illness. This research is important because it will help to explain doctors' reasons for following or not following patients' ACPs.

This study has the approval of the Townsville Hospital and Health Service Human Research Ethics Committees (HREC) Project No 54125 on 15.08.2019 and James Cook University on 18.09.2019. The study is being conducted by Denise Craig (PhD student/Health Professional) under the supervision of Dr Robin Ray, Dr Desley Harvey and Associate Professor Mandy Shircore, and it will contribute to Denise's Doctor of Philosophy degree at James Cook University.

This study will ask for your experience of how doctors respond to Advance Care Plans of this patient group when the patient no longer has the capacity to consent to inpatient care. **If you agree to be involved, you are invited to take part in a face to face (or Skype or telephone) interview, which will be recorded.** The interview should take about 30 to 90 minutes at an agreed time and place. Should you become distressed discussing your experiences, you are encouraged to contact the Employee Assistance Program OPTUM on 1800 604 640.

Taking part in this study is completely voluntary and you can stop taking part at any time. **Your choice to participate will not impact on your employment with your health service.** If you know of others who might be interested in this study, please pass on this information sheet to them so they may contact Denise to volunteer for the study.

Any information you provide will be anonymized and will be used only for the purposes of this study. However, under exceptional circumstances we may be required to disclose information you have provided. This would occur where disclosure is required by law. Your information will be kept confidential by the research team and results will be stored securely for 5 years and then destroyed as per protocol. The data from the study will be used in research, publications, and reports. You will not be identified in any way in these publications.

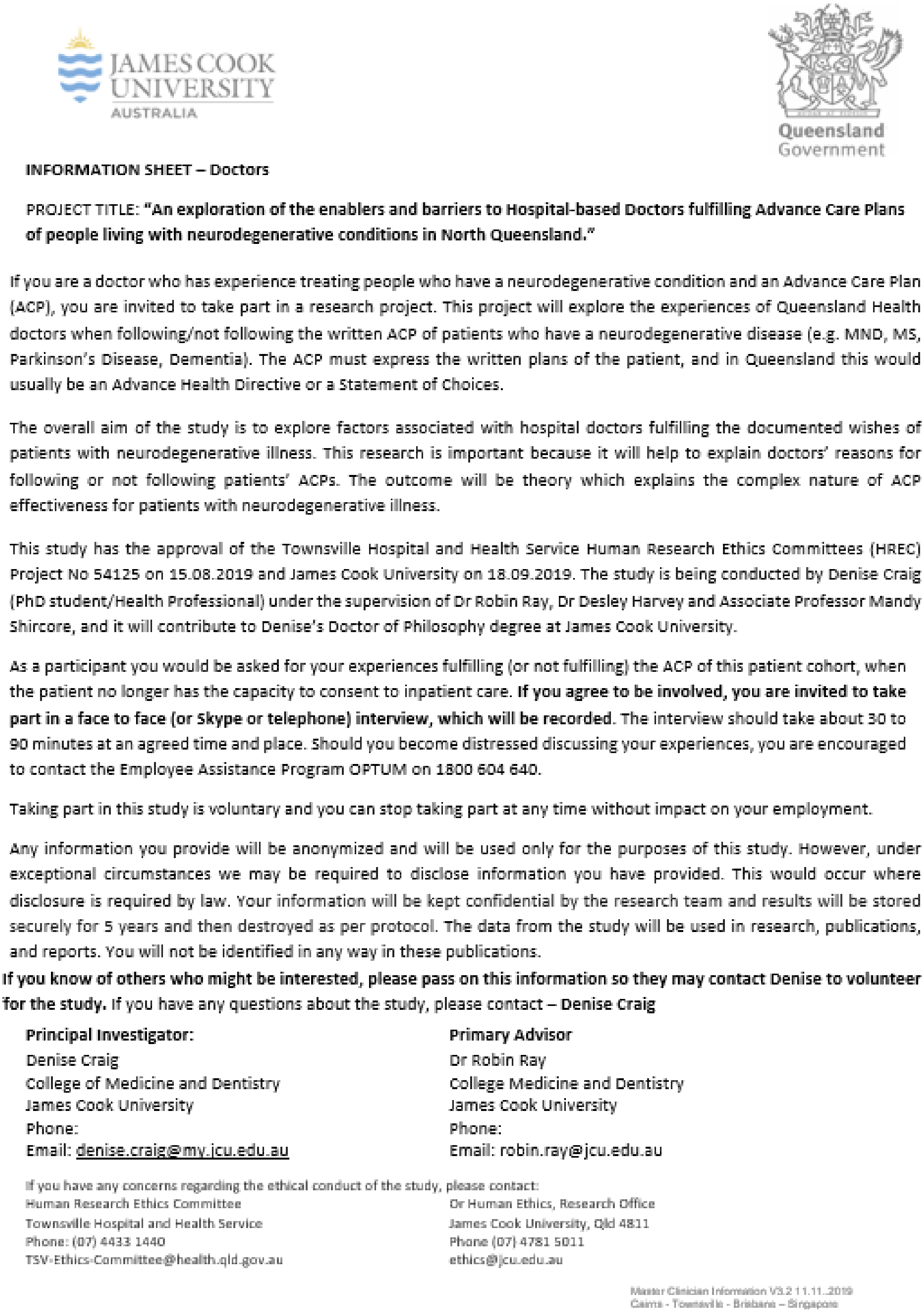
If you have any questions about the study, please contact – **Denise Craig**

Principal Investigator:
Denise Craig
College of Medicine and Dentistry
James Cook University
Phone:
Email: denise.craig@my.jcu.edu.au

Primary Advisor
Dr Robin Ray
College Medicine and Dentistry
James Cook University
Phone:
Email: robin.ray@jcu.edu.au

If you have any concerns regarding the ethical conduct of the study, please contact:
Human Research Ethics Committee
Townsville Hospital and Health Service
Phone: (07) 4433 1440
TSV-Ethics-Committee@health.qld.gov.au

Or Human Ethics, Research Office
James Cook University, Qld 4811
Phone (07) 4781 5011
ethics@jcu.edu.au



INFORMATION SHEET – Doctors

PROJECT TITLE: **"An exploration of the enablers and barriers to Hospital-based Doctors fulfilling Advance Care Plans of people living with neurodegenerative conditions in North Queensland."**

If you are a doctor who has experience treating people who have a neurodegenerative condition and an Advance Care Plan (ACP), you are invited to take part in a research project. This project will explore the experiences of Queensland Health doctors when following/not following the written ACP of patients who have a neurodegenerative disease (e.g. MND, MS, Parkinson's Disease, Dementia). The ACP must express the written plans of the patient, and in Queensland this would usually be an Advance Health Directive or a Statement of Choices.

The overall aim of the study is to explore factors associated with hospital doctors fulfilling the documented wishes of patients with neurodegenerative illness. This research is important because it will help to explain doctors' reasons for following or not following patients' ACPs. The outcome will be theory which explains the complex nature of ACP effectiveness for patients with neurodegenerative illness.

This study has the approval of the Townsville Hospital and Health Service Human Research Ethics Committees (HREC) Project No 54125 on 15.08.2019 and James Cook University on 18.09.2019. The study is being conducted by Denise Craig (PhD student/Health Professional) under the supervision of Dr Robin Ray, Dr Desley Harvey and Associate Professor Mandy Shircore, and it will contribute to Denise's Doctor of Philosophy degree at James Cook University.

As a participant you would be asked for your experiences fulfilling (or not fulfilling) the ACP of this patient cohort, when the patient no longer has the capacity to consent to inpatient care. **If you agree to be involved, you are invited to take part in a face to face (or Skype or telephone) interview, which will be recorded.** The interview should take about 30 to 90 minutes at an agreed time and place. Should you become distressed discussing your experiences, you are encouraged to contact the Employee Assistance Program OPTUM on 1800 604 640.

Taking part in this study is voluntary and you can stop taking part at any time without impact on your employment.

Any information you provide will be anonymized and will be used only for the purposes of this study. However, under exceptional circumstances we may be required to disclose information you have provided. This would occur where disclosure is required by law. Your information will be kept confidential by the research team and results will be stored securely for 5 years and then destroyed as per protocol. The data from the study will be used in research, publications, and reports. You will not be identified in any way in these publications.

If you know of others who might be interested, please pass on this information so they may contact Denise to volunteer for the study. If you have any questions about the study, please contact – **Denise Craig**

Principal Investigator:	**Primary Advisor**
Denise Craig	Dr Robin Ray
College of Medicine and Dentistry	College Medicine and Dentistry
James Cook University	James Cook University
Phone:	Phone:
Email: denise.craig@my.jcu.edu.au	Email: robin.ray@jcu.edu.au

If you have any concerns regarding the ethical conduct of the study, please contact:

Human Research Ethics Committee
Townsville Hospital and Health Service
Phone: (07) 4433 1440
TSV-Ethics-Committee@health.qld.gov.au

Or Human Ethics, Research Office
James Cook University, Qld 4811
Phone (07) 4781 5011
ethics@jcu.edu.au

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Appendix D: Consent Forms

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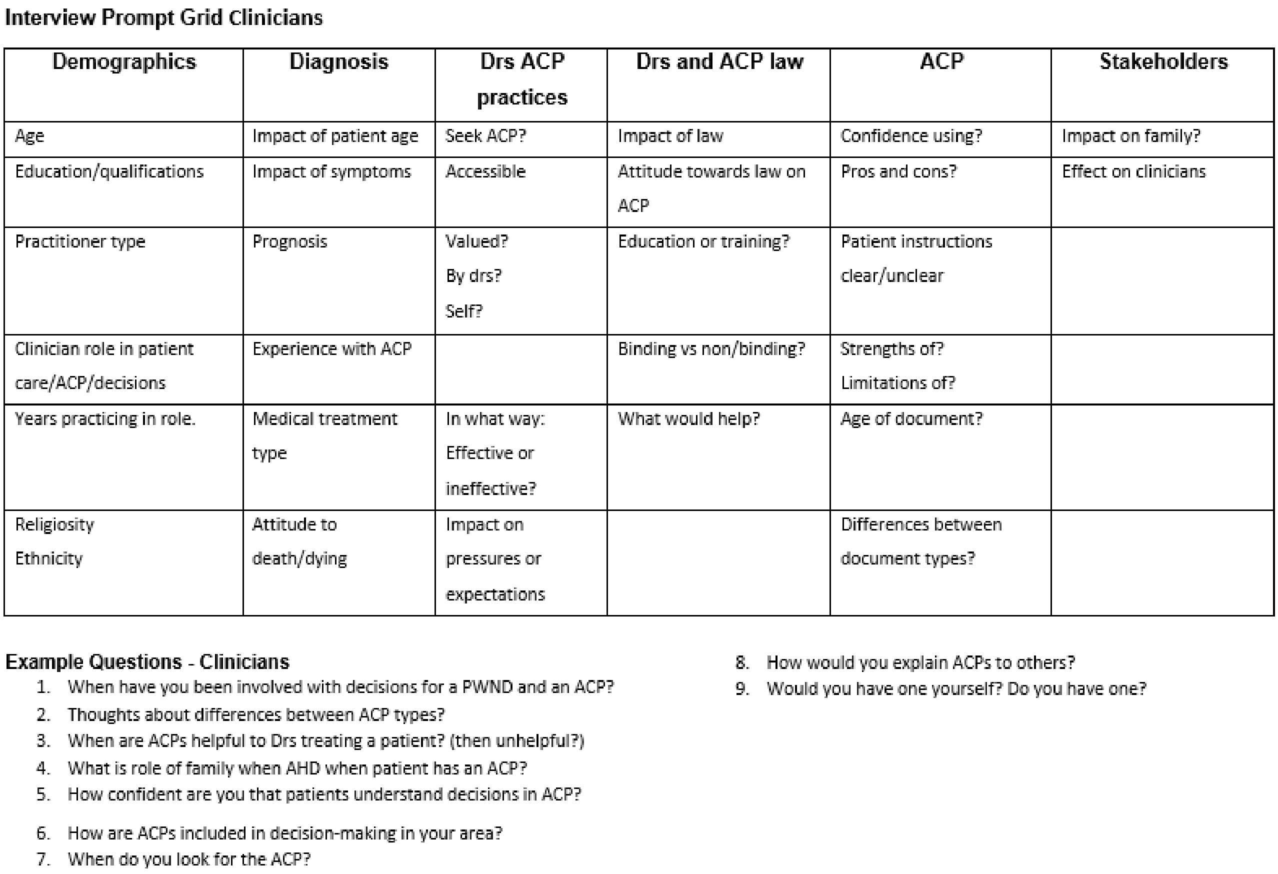
Appendix E: Interview Guides



Interview Prompt Grid Clinicians

Demographics	Diagnosis	Drs ACP practices	Drs and ACP law	ACP	Stakeholders
Age	Impact of patient age	Seek ACP?	Impact of law	Confidence using?	Impact on family?
Education/qualifications	Impact of symptoms	Accessible	Attitude towards law on ACP	Pros and cons?	Effect on clinicians
Practitioner type	Prognosis	Valued? By drs? Self?	Education or training?	Patient instructions clear/unclear	
Clinician role in patient care/ACP/decisions	Experience with ACP		Binding vs non/binding?	Strengths of? Limitations of?	
Years practicing in role.	Medical treatment type	In what way: Effective or ineffective?	What would help?	Age of document?	
Religiosity Ethnicity	Attitude to death/dying	Impact on pressures or expectations		Differences between document types?	

Example Questions - Clinicians

1. When have you been involved with decisions for a PWND and an ACP?
2. Thoughts about differences between ACP types?
3. When are ACPs helpful to Drs treating a patient? (then unhelpful?)
4. What is role of family when AHD when patient has an ACP?
5. How confident are you that patients understand decisions in ACP?
6. How are ACPs included in decision-making in your area?
7. When do you look for the ACP?
8. How would you explain ACPs to others?
9. Would you have one yourself? Do you have one?

Interview Prompt Grid – People with neurodegenerative disorder

Demographics	Diagnosis	Health	Doctors	ACP	Network	Values
Age	Early symptoms	Illnesses	GP	Type	Partner	Lifetime
Relationships	Understanding the illness	Medical treatment	Specialist	Motivation	Family	Post-diagnosis
Education	Prognosis	Doctors	Hospitals	Expectations	Friends	Future care
Employment	Lived experience	Losses	Role in ACP	Binding vs non	Agreement	Consistency of goals?
Religious		Values		Experience of planning		Priorities
Ethnicity				Clarity/confidence		
				Storage		

Example Questions

1. I wonder if you could tell me about your health at the moment...
2. Thinking about your health, can you tell me for what matters most to you?
3. Can you tell me about the decisions you've made in your advance care plan?
4. What led you to complete your advance care plan?
5. What do you think the health directive will do for you?
6. Did your GP or anyone else help you to complete it?
7. How do you want doctors to use your ACP (prompt – followed absolutely, a guide, etc)
8. Do you have any particular fear about your future health care?

Interview Prompt – Family

1. For the records, could tell me about X's diagnosis and the effect his illness had.......
2. What can you tell me about X's attitude towards his future health care?
3. How did it come about that X's completed an advance care plan?
4. Can you tell me a bit more about the decisions X made in his advance care plan?
5. How did he go about completing it? ....Did someone help him?
6. Could you tell me what you noticed once X was in hospital?
7. Did the advance care plan seem to have a role in treatment decisions?
8. How would you have liked decisions about X's care to have been managed?
9. Did you ever advocate for the advance care plan (X's decisions) to be upheld?
    a. What effect did that have on you?
10. What advice would you give to doctors who treat people in a similar situation to X's?
11. How do you feel about completing an advance care plan for yourself?

Interview prompt – doctors

Demographics

Interview prompt for doctors.

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

At what point do you look for the ACP??

Have any ACP treatment decisions ever troubled you?

What is role of family when AHD addresses the matter?

How is the decision maker or consent to healthcare ascertained?

How well do doctors recognise pending death and dying?

What do you think are the obstacles to difficult conversations?

Do other disciplines get involved in ACP adherence?

Who are the key decision makers for people with cognitive impairment? Why?

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

Would you have one yourself? Do you have one?

Do AHDs save families from making difficult decisions?

Appendix F: Research Ethics and Site Specific Approval Letters

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Appendix G: Example Memos

Example memo dated 6 September 2020.

I started by renaming ‘HOSPITALS AS DOCTORS' WORKPLACE’ to 'PRACTICING MEDICINE ON ANUNEQUAL PLAYING FIELD'. This too is vague and probably still not right? Under PRACTICING MEDICINE ON AN UNEQUAL PLAYING FIELD, the ‘being time pressured and process driven’ might merge. Certainly there's overlap. Although I've left in the AHC comments about the system prompting for AHDs, it sometimes feels as though it doesn't fit there. I've left it because it's still a system driver for doing less to people, I think.

I also think I could adapt some of this further to 'loss of a person-centred care' model. It's HOSPITALS AS SERVICE PROVIDERS, institutions with many faces, where people come for service. In some sense the patient misses out - however well intended (???) the doctor works within a massive organisation with all of the issues that go with massive organisations, and the patient has lost a vote. Doctors, AHC/nurses and family work within the options of the system to decide what's GMP in the patient's best interests.

Lengthy reflection on this while tending the garden. What's going on for doctors that they rely on the ARP? Is it:

- protecting themselves from onerous task associated with lengthy documents that can need interpretation,
- feeling 'covered' as one said (sounded like a legal sense),
- culture fostered by Queensland Health which created the form to make it quick and easy (so a politically correct plan),
- it's the quickest way of getting both family consent and a current plan,
- it's 'the only way' to communicate to health workers 'what the intentions of treatment are' (D11).

Are doctors somewhat victims too, to the Queensland Health machine often dominated by non-clinical decision-makers at the top? Within the machine are many moving parts - other doctors and also multidisciplinary teams which appear to buck and hold them to account. Is it that the system (like many systems) is just so huge, complex & impersonal that they're far from perfect, and open to being abused?

Doctors are intelligent, thinking, feeling, sensitive souls ('not automatons' as D9 said) who are often distrusted (expressed well by D15, D13 and D5) who learn how to win people over. Are they doing what they need to do to be ok and minimise their moral torment, be the good doctor they seek to be? Is it as Atul Gawande suggests, the satisfaction of competence that's their priority - being technically skilled and able to solve difficult, intricate problems, giving them a sense of identity? Is the patient with problems that the doctor can't solve a threatening scenario.

I may want to go back into ARP and code wherever it shows the disconnect between hospital and community - ARP for Hospital (acute), AHD for community (advanced/long term view).

I see that currency of plans increases confidence - one of the things they like about it. I think it's splitting the responsibility - another doctor might have done it first, otherwise do it with current knowledge and consent from family (who need to be ok for the doctor to be ok). The ARP clearly undermines the AHD.

Another, dated 18 June 2021, demonstrated early grappling with the concept of shared decision-making as identified within the data.

What process/es is at issue here.

- Busy medical systems with variability of practice e.g. life experience, lack of education, policy to do ARP
- Drs trained to recommend treatment for presenting illness;
- Justifying ACP nonadherence;
- Prefer to engage with family and have everyone be all right.

How does this process develop?

- policy is ARP?
- Lack of education;
- Easier to engage family who have temporal knowledge and can take in facts?

How does the research participant act while involved in this process?

- Neglects ACP until death identified as probable,

What does the participant profess to think and feel whilst involved in the process?

- Best Medical Practice is the mantra;
- Doctors like the ACP but want improvements to it.

What might his/her observed behaviour indicate?

- Preference to treat and not prioritise ACP?
- Preference to engage with family

When, why and how does the process change?

1. In the end only when death is anticipated/medical treatment has reached its limit.

2. If family are seen as unreasonable & Dr wants a tool to use/tip the balance,

3. End stage review of ACP for end of life wishes.

What are the consequences of the process?

- ACP are usually not included in treatment plans. Family take over. The benefits are thought to be that family are more likely to be aware of choices.
- The patient makes their own decisions and feel better having done it
- The plan can be used to help alleviate family from guilt.

Based on Atul Gawande (Gawande, 2014, p.200).

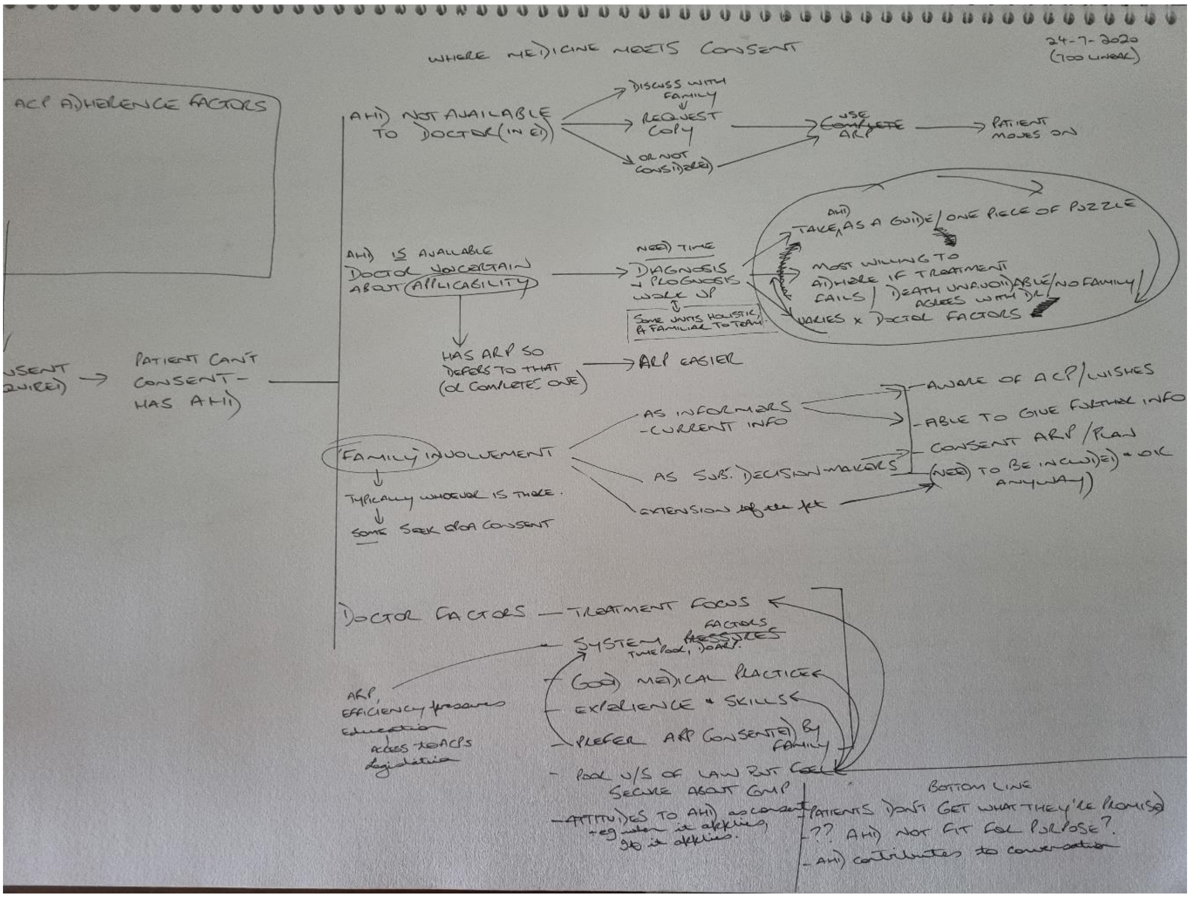
Most traditional doctor patient relationship is paternalist -- doctors believe they know what's best and patients must receive what doctors think best for them.

Second type is 'informative' so patients given the information and they must choose. Doctor is the technical expert, and the patient decides. This system increases knowing less and less about patients and more and more about science. Excellent when choices are clear, trade-offs are straightforward, and people have clear preferences. Patients get what they want and are completely autonomous.

Third type - interpretive (aka shared decision making) helps patients to determine what they want. Asks: What matters most? Well then X is most likely to give you that outcome.

Is what I'm seeing suggestive of a preference for Type 3 - interpretive decision-making? Doctor still thinks paternalistically in that doctor has a lot of facts at hand and patient has now lost capacity. Patient can't be fully informed (when completing AHD) - it hasn't happened yet, so AHD gives a flavour only. Maybe it's a Type 4 decision making - helps proxies to determine what they want. e.g. Ask family what matters most about this current illness presentation and provide medical recommendation re treatment (but it’s not holistic).

Similarly, the following photos show freehand sketches of mind maps which reflect early ideas of the concepts arising from the data.



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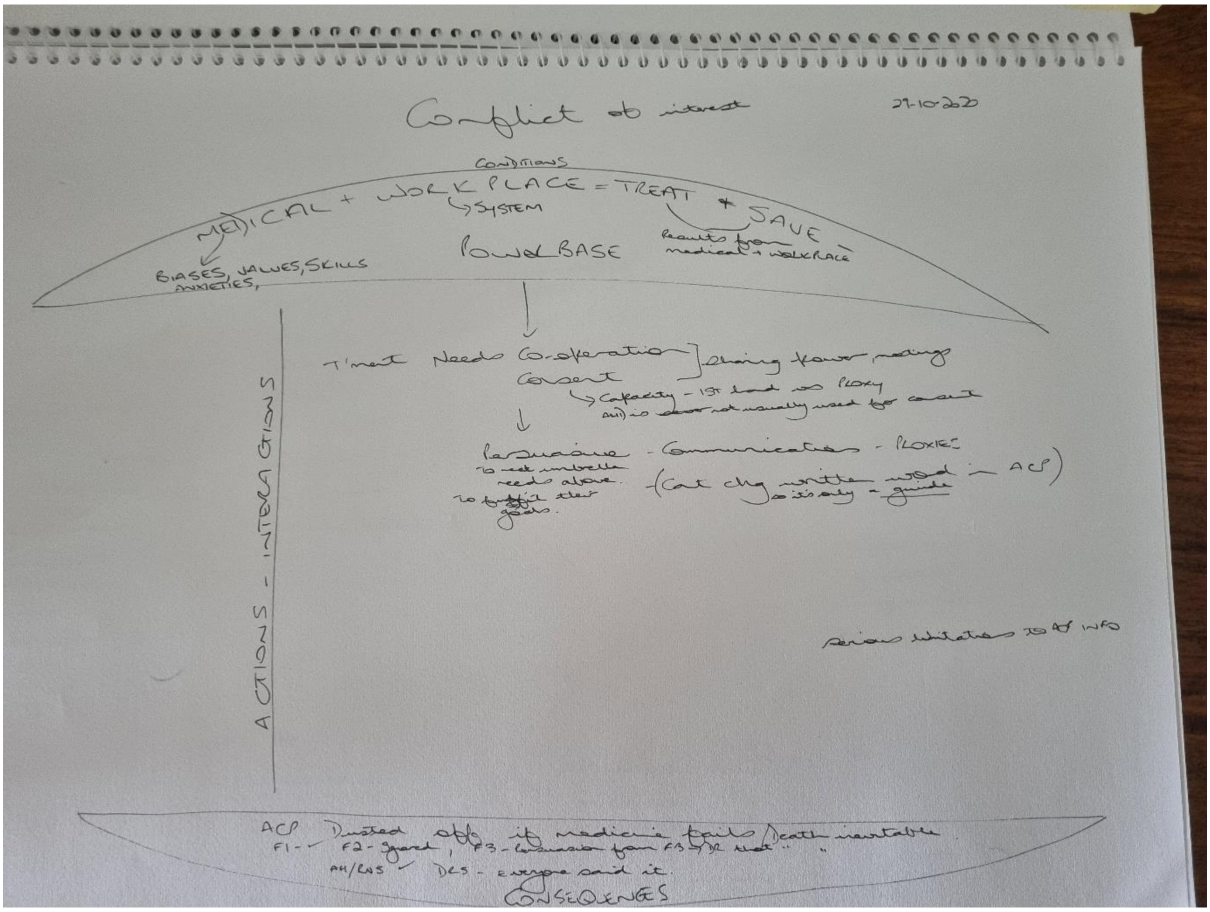
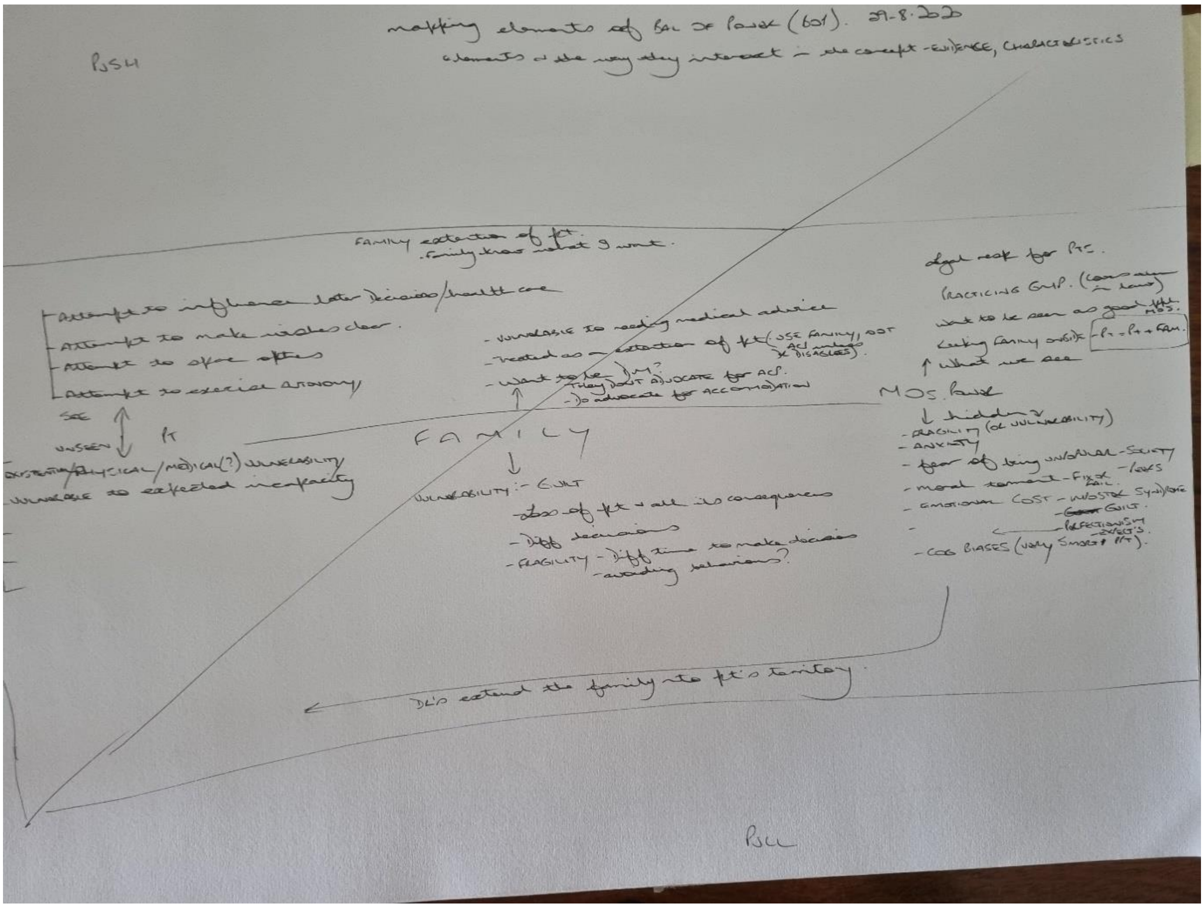
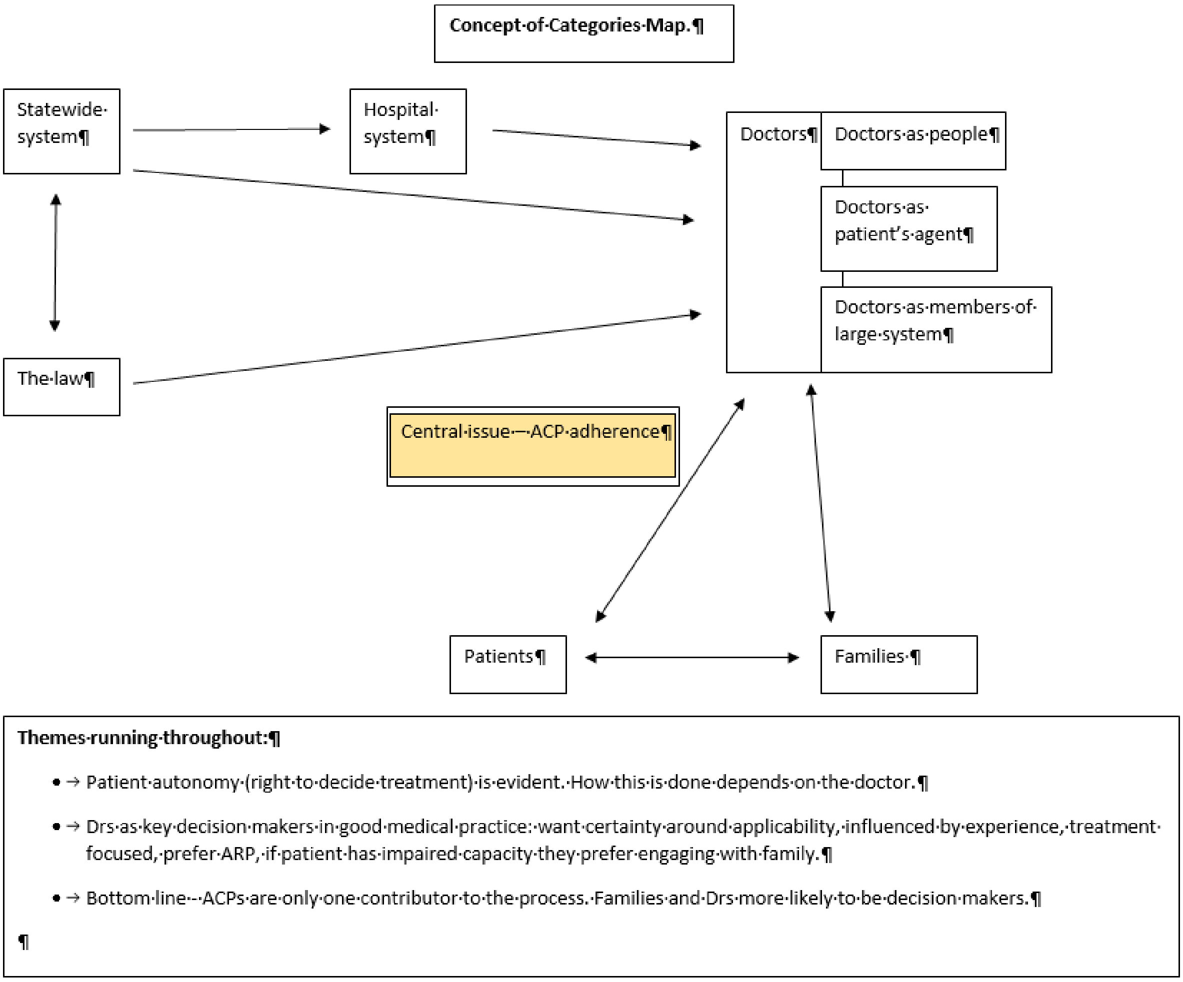

Conflict of interest
27-10-2020
CONDITIONS
MEDICAL + WORK PLACE = TREAT + SAVE
↳SYSTEM
Results from medical + WORKPLACE
POWER BASE
BIASES, VALUES, SKILLS ANXIETIES,
T'ment Needs Co-operation
Consent
sharing power, readings
↳ Capacity - 1st level as PROXY
AD) is ~~[illegible]~~ not usually used for consent
Persuasive - Communications - PROXIES
to meet umbrella needs above.
to fulfill their goals.
(Cat chg written word in ACP)
so it's only a guide
ACTIONS - INTERACTIONS
serious limitations to AD INFO
ACP Dusted off if medicine fails / Death inevitable
F1 - ✓ F2 - Scared, F3 - Persuasion from F3 → DR that " "
AH/RNS ✓ DLS - everyone said it.
CONSEQUENCES


mapping elements of BAL OF POWER (BOP). 29-8-2020
elements & the way they interact - the concept - EVIDENCE, CHARACTERISTICS
PUSH
FAMILY extension of pt.
- Family know what I want.
- Attempt to influence later Decisions / health care
- Attempt to make wishes clear.
- Attempt to offer options
- Attempt to exercise autonomy
SEE
UNSEEN
Pt
- EXISTENTIAL/PHYSICAL/MEDICAL(?) VULNERABILITY
- VULNERABLE to expected incapacity
- VULNERABLE to needing medical advice
- Treated as an extension of pt (USE FAMILY, NOT ACI unless pt DISAGREES).
- Want to be DM?
THEY DON'T ADVOCATE for ACP.
- Do advocate for ACCOMMODATION
FAMILY
VULNERABILITY :- GUILT
- Loss of pt + all its consequences
- Diff decisions
- FRAGILITY - Diff time to make decisions
- avoiding behaviours?
legal risk for PTS.
PRACTICING GMP. (Consent in law)
want to be seen as good MDS.
keeping FAMILY onside - Pt = Pt + FAM.
↑ What we see
MDS Power
↓ hidden
- FRAGILITY (OR VULNERABILITY)
- ANXIETY
- fear of being unpopular - SCRUTINY
- moral torment - FIX OR FAIL. - losses
- EMOTIONAL COST - IMPOSTER SYNDROME
- ~~Guilt~~ GUILT.
- PERFECTIONISM - EXPECT'S.
- COG BIASES (very SMART PT).
DL's extend the family into pt's territory.
PULL

Example concept map recorded 24 July 2020:



Themes running throughout:

- Patient autonomy (right to decide treatment) is evident. How this is done depends on the doctor.
- Drs as key decision makers in good medical practice: want certainty around applicability, influenced by experience, treatment focused, prefer ARP, if patient has impaired capacity they prefer engaging with family.
- Bottom line – ACPs are only one contributor to the process. Families and Drs more likely to be decision makers.

References

Gawande, A. (2014). *Being mortal : medicine and what matters in the end*. First edition. New York : Metropolitan Books, Henry Holt and Company, 2014. https://search.library.wisc.edu/catalog/9910208781002121

Appendix H: Quality Criteria

Criteria	**Questions**
Credibility	Has your research achieved intimate familiarity with the setting or topic? Are the data sufficient to merit your claims? (Consider the range, number and depth of observations contained in the data.) Have you made systematic comparisons between observations and between categories? Do the categories cover a wide range of empirical observations? Are there strong logical links between the gathered data and your argument and analysis? Has your research provided enough evidence for your claims to allow the reader to form an independent assessment, and agree with your claims?
Originality	Are your categories fresh? Do they offer new insights? Does your analysis provide a new conceptual rendering of the data? What is the social and theoretical significance of this work? How does your grounded theory challenge, extend or refine current ideas, concepts and practices?
Resonance	Do the categories portray the fullness of the studied experience? Have you revealed both liminal and unstable taken-for-granted meanings? Have you drawn links between larger collectives or institutions and individual lives, when the data so indicate? Does your grounded theory make sense to your participants or people who share their circumstances? Does your analysis offer them deeper insights about their lives and worlds?
Usefulness	Does your analysis offer interpretations that people can use in their everyday worlds? Do your analytic categories suggest any generic processes? If so, have you examined these generic processes for tacit implications? Can the analysis spark further research in other substantive areas? How does your work contribute to knowledge? How does it contribute to making a better world?

Example self-reflection questions provided by Charmaz (Charmaz, 2014, p.337-338) used to satisfy myself and my advisory panel of the quality of this study.

References

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). Sage.

Appendix I: Systems Factors example Coding Tree

Initial Coding	Focused Codes	Major Themes	Overarching Category
· Being unclear – 'so much grey' · Practicing medicine not law; · Being protected by good medical practice	· Being unclear – 'so much grey' · Marrying law and medicine	Practicing medicine within a legal construct.	Practicing Public Hospital Medicine
· Working to diagnose and treat; · Going into medicine to help people; · Being siloed;	· Disconnecting Hosp and community; · Being socialised to treat · Hospitals as workplaces · Prioritising ARP	Workplace culture	
· "Efficiency efficiency efficiency";	· Being constrained by resources	Constraints of limited resourcing	
· ACP is voluntary; · Relying of being given access; · Unfamiliar with ACP Tracker	· accessing ACP is voluntary; · being ill-equipped to access ACP	Access to ACP	
· Having limited education about end of life and ACP; · Learning in an ad hoc manner	· Being ill-prepared by generic education	Education as it relates to law and end of life	
· Giving GPs' responsibility · GPs ill-equipped; · ACPs lacking transparency	· Disconnecting hospital and primary care; · Deferring to ARP; · Distrusting ACP	Delegitimising ACP	

Appendix J: COREQ

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

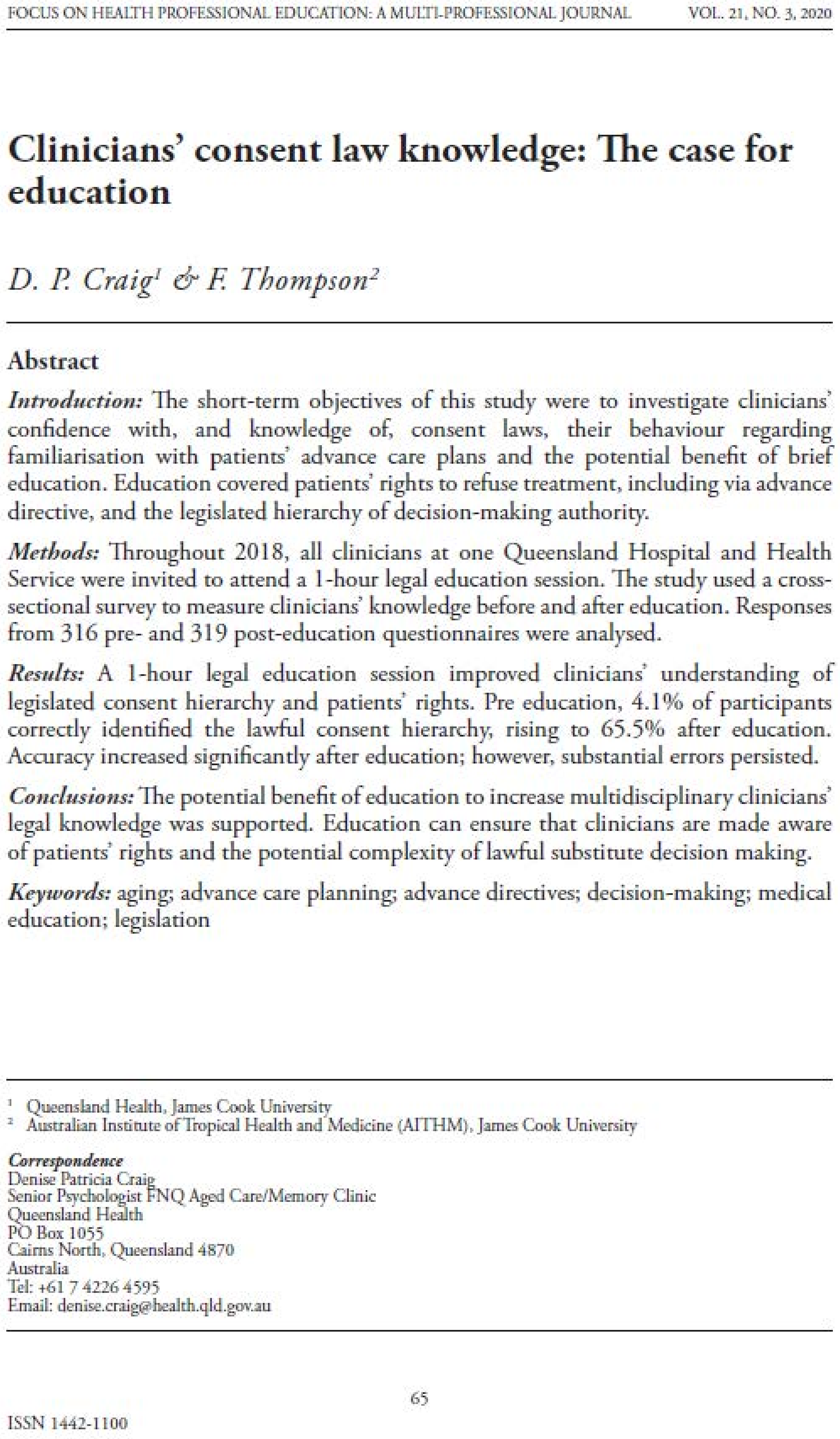
A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	73, 74
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	i
Occupation	3	What was their occupation at the time of the study?	85, 88
Gender	4	Was the researcher male or female?	i
Experience and training	5	What experience or training did the researcher have?	2-7
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	88
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	70, 74
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	2-7, 17-18
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	17-18, 65-67
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	70-71
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	70-71
Sample size	12	How many participants were in the study?	88
Non-participation	13	How many people refused to participate or dropped out? Reasons?	72
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	75
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	75
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	90
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	102, 134, A.E
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	74
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	76
Field notes	20	Were field notes made during and/or after the inter view or focus group?	75
Duration	21	What was the duration of the inter views or focus group?	76
Data saturation	22	Was data saturation discussed?	71
Transcripts returned	23	Were transcripts returned to participants for comment and/or	74, 82

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	77
Description of the coding tree	25	Did authors provide a description of the coding tree?	106, 137, AI
Derivation of themes	26	Were themes identified in advance or derived from the data?	8, 67, 77
Software	27	What software, if applicable, was used to manage the data?	76
Participant checking	28	Did participants provide feedback on the findings?	82
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	See Ch. 4 & 5
Data and findings consistent	30	Was there consistency between the data presented and the findings?	See Ch. 4 & 5
Clarity of major themes	31	Were major themes clearly presented in the findings?	See Ch. 4 & 5
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	See Ch 4 - 6

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Appendix K: Consent Law Knowledge (Craig & Thompson, 2020)



FOCUS ON HEALTH PROFESSIONAL EDUCATION: A MULTI-PROFESSIONAL JOURNAL VOL. 21, NO. 3, 2020

Clinicians' consent law knowledge: The case for education

D. P. Craig[1] *& F. Thompson*[2]

Abstract

Introduction: The short-term objectives of this study were to investigate clinicians' confidence with, and knowledge of, consent laws, their behaviour regarding familiarisation with patients' advance care plans and the potential benefit of brief education. Education covered patients' rights to refuse treatment, including via advance directive, and the legislated hierarchy of decision-making authority.

Methods: Throughout 2018, all clinicians at one Queensland Hospital and Health Service were invited to attend a 1-hour legal education session. The study used a cross-sectional survey to measure clinicians' knowledge before and after education. Responses from 316 pre- and 319 post-education questionnaires were analysed.

Results: A 1-hour legal education session improved clinicians' understanding of legislated consent hierarchy and patients' rights. Pre education, 4.1% of participants correctly identified the lawful consent hierarchy, rising to 65.5% after education. Accuracy increased significantly after education; however, substantial errors persisted.

Conclusions: The potential benefit of education to increase multidisciplinary clinicians' legal knowledge was supported. Education can ensure that clinicians are made aware of patients' rights and the potential complexity of lawful substitute decision making.

Keywords: aging; advance care planning; advance directives; decision-making; medical education; legislation

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Introduction

In Australia, statutory laws regulate patient consent to healthcare. These laws, which vary by state and territory, cover issues such as consent to receive, withhold or withdraw healthcare, whether an advance care plan (ACP) is binding and who is authorised to make treatment decisions. An ACP can express a person's values, beliefs and treatment preferences and is intended to guide clinical decision making (Sellars et al., 2015) and provide an individual with self-determination in healthcare until death (Royal Australian College of General Practitioners, 2012). In Queensland, competent adults have the right to record their healthcare choices within legally binding ACP documents—an enduring power of attorney (EPOA) and/or advance health directive (AHD), pursuant to the Powers of Attorney Act 1998 (Qld) and the Guardianship and Administrative Act 2000 (Qld). These powers are "enduring" because the decision will endure despite a person's later loss of decision-making capacity. Enduring documents can be used to nominate proxy healthcare decision makers and provide an adult with a means of consenting to the provision or withholding of future healthcare. These documents are powerful tools that should be understood by patients/proxies/families and clinicians.

Doctors are key partners in medical decision making, making their understanding of healthcare consent laws essential. Research has highlighted gaps in doctors' knowledge (Cartwright, White, et al., 2016; Parker et al., 2015; White, Willmott, Cartwright, Parker, & Williams, 2015, 2016; White, Willmott, Cartwright, et al., 2017; White, Willmott, Williams, et al., 2017; Willmott, White, Close, et al., 2016) and tensions between legislation and "ethics", such as doctors' preference for a flexible, family and/or clinical decision-making model (Burkle et al., 2012; Cartwright, Montgomery, et al., 2014; Corke et al., 2009; White, Willmott, Williams, et al., 2017; Willmott, White, Close, et al., 2016; Willmott, White, Parker, et al., 2016; Willmott, White, Tilse, & Wilson, 2013; Wong et al., 2012). Despite the obligation (in non-urgent situations) to obtain lawful consent to provide healthcare, doctors are reported to have poor understanding of legislated substitute decision-making authority (Cartwright, White, et al., 2016; White, Willmott, Cartwright, Parker, & Williams, 2015), and many do not routinely review ACP records that represent their patients' prior treatment choices (Cartwright, Montgomery, et al., 2014; Wong et al., 2012). Doctors primarily claim ethical reasons (e.g., patient-related clinical factors) for end-of-life healthcare decision making (Burkle et al., 2012; Corke et al., 2009; White, Willmott, Cartwright, Parker, & Williams, 2016; White, Willmott, Williams, et al., 2017; Wong et al., 2012) and appear to have limited knowledge of ACP-related law (Cartwright, Montgomery, et al., 2014). These issues may result in the denial of patients' rights and leave doctors at risk of complaint. One theme throughout the above literature is the suggestion by researchers that legal education for doctors should be increased.

Whilst competent patients have the right to autonomy, they are often reliant on the advice of their doctors when consenting to healthcare. Therefore, doctors are rightly perceived as key contributors in complex healthcare decisions. All clinicians, however, bear responsibility to act within relevant legislation. End-of-life healthcare legal education for clinicians appears to be gaining support, e.g., End of Life Law for

Clinicians online training modules (White, Willmott, Yates, et al., 2019); however, engagement in education historically has been inconsistent (Parker et al., 2015). Without training, clinicians may unintentionally deny patient rights, yet Queensland Health does not provide mandatory legal education or routinely ensure clinicians understand their responsibilities. Accordingly, clinicians' knowledge and the potential benefit of targeted legal education is unknown and remains to be investigated.

A 1-hour education session was developed and delivered by the Hospital and Health Service senior legal counsel in conjunction with the first author (an aged care specialist clinician). The content of the education included introductory level patient rights relevant to AHD, EPOA and substitute decision maker (SDM) consent. The education also included case scenarios and an opportunity for questions. Throughout 2018, 35 sessions were provided within Hospital and Health Service venues (hospital, community and videoconference facilities) at a range of times to accommodate as many clinicians as possible. Hospital and Health Service executives and managers encouraged clinicians to attend.

The aim of this study was to assess the usefulness of a 1-hour education session in increasing clinicians' knowledge of patient consent legislation. The short-term objectives were to investigate clinicians' confidence with, and knowledge of, consent laws, their behaviour regarding familiarisation with patients' ACPs and the potential benefit of brief education. This study appears to be the first to explore clinicians' understanding of commonly encountered aspects of Queensland legislation relating to EPOA, AHD and consent.

Methods

Study design and participants

The study was a cross-sectional survey of clinicians' consent law confidence and knowledge before and after 1 hour of education. Between February and November 2018, all clinicians (~ 4,000) in the North Queensland region Hospital and Health Service were invited to participate via Hospital and Health Service newsletters and emails. Of these, n = ~535 (13% of Hospital and Health Service clinicians) attended and were invited to complete a knowledge questionnaire immediately before and after the education and an overall post-session satisfaction questionnaire. Attendance rates ranged between 3 and 70 per session, and some groups were not surveyed as anonymity was compromised by small group size. Remote area participants accessed sessions via video conference and entered data directly into an online SurveyMonkey questionnaire (SurveyMonkey Inc., San Mateo, California, USA). A total of 778 questionnaires (combined pre and post) were returned from participants. The participants were community and acute sector clinicians from medicine, nursing, social work, psychology, occupational therapy and physiotherapy who were working within the regional and remote Hospital and Health Service facilities. As this was a quality improvement activity, exemption from ethics approval was obtained from the Far North Queensland Human Research Ethics Committee (HREC/18/QCH/31 – 1206 QA). Face-to-face attendees signed consent forms, whilst online participants consented as a part of the online survey process. Under section 279A of the Queensland Public Health Act (2005), unidentifiable participant data will be made available upon request.

In 18.1% of all questionnaire responses, one or more of the nine knowledge questions were not attempted. These incomplete questionnaires were excluded, resulting in a sample size of 635 responses. Within this sample, there were 316 (59%) responses from clinicians pre education and 319 (59.6%) post education. While there was considerable overlap in participants between these groups, data were unable to be linked at an individual level between groups, and the groups were not identical in terms of membership. For example, some clinicians who completed the pre-education questionnaire did not go on to provide a post-education questionnaire and some clinicians who completed the post-education questionnaire were "new" to the study and did not provide a pre-education questionnaire.

Survey instruments

Questionnaires were designed by the first author in consultation with Hospital and Health Service senior legal counsel. Participants could leave questions blank and still progress through the questionnaire, which took approximately 6 minutes to complete. Paper-based questionnaire data were later entered into SurveyMonkey Inc. by the first author and an assistant.

The pre-education questionnaire comprised 13 questions of closed categorical, Likert-scale and free-text response formats. Included was a vignette (Cartwright, White, et al., 2016; White, Willmott, Cartwright, Parker, & Williams, 2016) that asked participants to choose between an estranged husband, son (EPOA for finances), daughter/carer, same-sex partner and a public guardian for SDM consent. Content was divided into six sections: 1) participant familiarity with EPOA/AHD, 2) confidence with EPOA/AHD, 3) beliefs about a person's right to refuse treatment, 4) knowledge of the legislated hierarchy for SDM consent, 5) the role of appointed health attorneys and 6) any additional comment. Figure 1 (below) shows the Queensland legislated order of priority for consent to healthcare, which was used to inform questions on SDM consent. The post-education questionnaire altered one question to assess clinicians' intention to routinely familiarise themselves with EPOA/AHD in future, and all other questions remained the same.

Participant responses were anonymised, and no personal identifiers or demographic information were collected.

Data analysis

Pre- and post-education data were not linked at an individual level. To accommodate this study design during analyses, participants were considered as members of two mutually-exclusive groups, and tests for differences between independent samples were used. Results for categorical and dichotomous variables are presented as proportions. All continuous variables had skewed distributions, and results are presented as medians (med) with interquartile ranges (iqr).

Figure 1
Legislative Hierarchy of Substitute Decision Makers for Adults With Impaired Capacity

Adults with impaired capacity:
Order of priority for dealing with health matter consent
Guardianship and Administration Act 2000 (Qld), s66, and Powers of Attorney Act 1998 (Qld) s63.

1. **Advance Health Directive** if a direction about the matter was made.
2. **Tribunal appointed guardian** for the matter.
3. **Attorney/s appointed in most recent enduring document**.
4. **Statutory Health Attorney**. The first of the following people who is readily available and culturally appropriate:
   a. Spouse if the relationship is close and continuing
   b. An adult who has the care of the adult and is not a paid carer of the adult
   c. An adult who is a close friend or relation and not a paid carer of the adult
5. **Public Guardian**

The distribution of proportions between the pre- and post-education groups (Table 1) were examined using Chi^2 analyses. Fischer's exact tests were used when any cell had less than five observations. Continuous variables were compared between these same groups using Wilcoxon rank-sum tests. Spearman's rank correlation was used to examine the relationship between confidence and knowledge within each group. A p-value less than 0.05 was considered significant. All analyses were undertaken in Stata 14 software package (Stata Corp, College Station, Texas, USA).

Results

Prior to education, half (49.1%) of all participants reported routinely familiarising themselves with patients' EPOA/AHD (Table 2). There was a significant correlation between confidence with EPOA documents and knowledge of laws and rights for the clinicians both before (Spearman's Rho = 0.249, $p < 0.001$) and after (Spearman's Rho = 0.124, $p = 0.028$) education.

Knowledge scores for clinicians post education (med = 8, iqr = 7–9) were significantly higher than pre education (med = 6, iqr = 5–7) ($z = -16.9$, $p < 0.001$) (Table 1). Similarly, the proportion of clinicians who answered all nine knowledge questions correctly post education (n = 130, 40.1%) was substantially greater compared to pre education (n = 5, 1.5%, Figure 2). Participant satisfaction questionnaire data indicated a high degree of satisfaction with the program (data not tabled).

Competent patients' right to refuse treatment

Before the education, 98.7% of participants agreed a patient has a right to refuse treatment. This result was comparable post education ($p = 0.185$, Table 1). If patient death could occur sooner as a result of refusing treatment, acknowledgement of the patient's refusal right reduced for clinicians pre education (94.0%) and not post education (99.4%). If the patient's refusal rationale was disagreeable or withheld,

Table 1

Pre and Post Education Measures of Health Professionals' Behaviour and Knowledge Regarding Enduring Documents, Chi-Squared and Wilcoxon Rank-Sum Comparisons Between Groups

	Clinicians: Pre Education			Clinicians: Post Education			Comparison	
Questions	**Yes** # (%)	**No** # (%)	**Unsure** # (%)	**Yes** # (%)	**No** # (%)	**Unsure** # (%)	**Chi^2/Z**	**P**
Total participants	316 (100.0)			319 (100.0)				
Knowledge (n = 9 questions) [Med (IQR)]	6 (5–7)			8 (7–9)			-16.9	0.000
Refuse life sustaining treatment								
Q4. Refuse	312 (98.7)	4 (1.3)		317 (99.4)	1 (0.3)		1.8	0.185
Q5. Refuse—despite reason	265 (83.9)	51 (16.1)		298 (93.4)	20 (6.3)		15.5	0.000
Q8. Refuse—if may cause death sooner	297 (94.0)	2 (0.6)	16 (5.1)	317 (99.4)	0 (0.0)	2 (0.6)	13.5	0.000
Q6. SDM—identified	13 (4.1)	291 (92.1)		209 (65.5)	106 (33.2)		259.1	0.000
Q12. Correct SDM in scenario	83 (26.3)	209 (66.1)		220 (69.0)	72 (22.6)		128.7	0.000
Estranged husband	27 (8.5)			9 (2.8)				
Son/EPOA	5 (1.6)			3 (0.9)				
Daughter/carer	65 (20.6)			46 (14.4)				
Same-sex partner (correct)	83 (26.3)			220 (69.0)				
Public guardian	32 (10.1)			10 (3.1)				
Unsure	80 (25.3)			4 (1.3)				
	True # (%)	**False** # (%)	**Unsure/Other** # (%)	**True** # (%)	**False** # (%)	**Unsure/Other** # (%)	**Chi^2/Z**	**P**
Q7. Attorney is SDM (within lawful limits)	199 (63.0)	23 (7.3)	93 (29.4)	299 (93.7)	9 (2.8)	10 (3.1)	93.1	0.000
Q11. Attorney represents patient (special health matters excluded)	206 (65.2)	31 (9.8)	79 (25.0)	294 (92.2)	15 (4.7)	10 (3.1)	74.5	0.000
Q9. SDM–AHD (True) vs Attorney (False)	240 (75.9)	35 (11.1)	32 (10.1)	300 (94.0)	9 (2.8)	5 (1.6)	41.7	0.000
Q10. SDM–AHD (True) vs Family (False)	282 (89.2)	13 (4.1)	20 (6.3)	313 (98.1)	3 (0.9)	3 (0.9)	20.4	0.000

Note: Clinicians pre education completed the survey before the education workshop; clinicians post education completed the survey after the education workshop; SDM = substitute decision maker, EPOA = enduring power of attorney, AHD = advance health directive, Med = median, IQR = interquartile range

Figure 2
Number of Correct Knowledge Questions, by Education Group

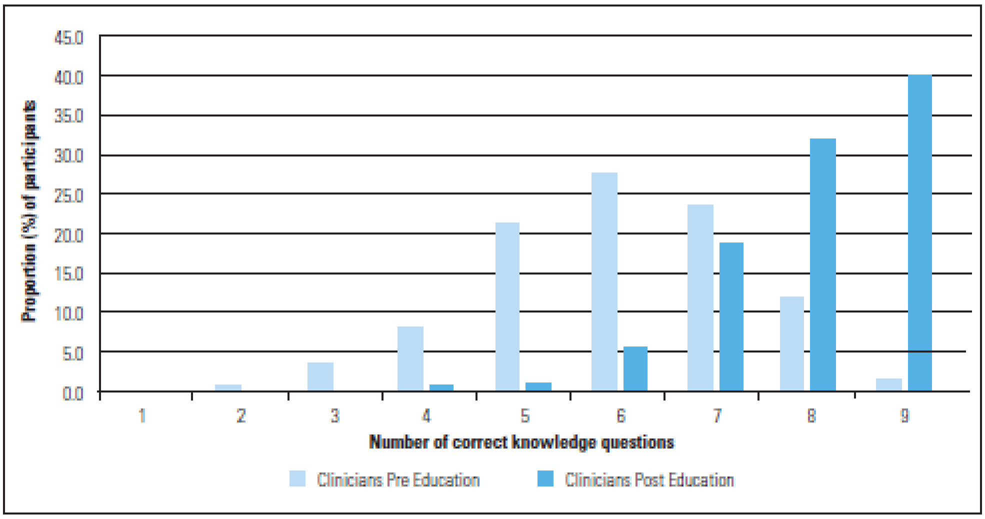

Table 2
Pre and Post Education Measures of Health Professionals' Confidence Regarding Enduring Documents, Chi-Squared and Wilcoxon Rank-Sum Comparisons Between Groups

	Clinicians: Pre Education		**Clinicians: Post Education**		**Comparison**	
Questions	**#**	**(%)**	**#**	**(%)**	**Chi^2/Z**	**P**
Total participants	316	(100.0)	319	(100.0)		
Behaviour (n = 1 question)						
Q1. Familiarise with EPOA/AHD	155	(49.1)	283	(88.7)	131.9	< 0.001
Confidence levels (n = 2 questions)						
Q2. Confidence with EPOA						
[Med (IQR)]	3	(2–4)	4	(4–4)	-11.5	< 0.001
(1) *Not confident*	39	(12.3)	3	(0.9)	142.2	< 0.001
(2) *A little*	89	(28.2)	18	(5.6)		
(3) *Neutral*	65	(20.6)	35	(11.0)		
(4) *Moderate*	96	(30.4)	202	(63.3)		
(5) *Very confident*	19	(6.0)	55	(17.2)		
Q3. Confidence with AHD						
[Med (IQR)]	3	(2–4)	4	(4–5)	-12.9	< 0.001
(1) *Not confident*	39	(12.3)	3	(0.9)	171.3	< 0.001
(2) *A little*	98	(31.0)	20	(6.3)		
(3) *Neutral*	70	(22.2)	32	(10.0)		
(4) *Moderate*	87	(27.5)	173	(54.2)		
(5) *Very confident*	15	(4.7)	82	(25.7)		

Note: Clinicians pre education completed the survey before the education workshop; clinicians post education completed the survey after the education workshop; SDM = substitute decision maker, EPOA = enduring power of attorney, AHD = advance health directive, Med = median, IQR = interquartile range acknowledgement of refusal right reduced to 83.9% pre education, which was significantly different post education (93.4%, $p < 0.001$, see Table 1).

Legislated substitute decision maker consent

When asked to correctly order the five consent options for an adult without decision-making capacity (see Figure 1), only 4.1% of clinicians were able to do so before education, compared to 65.5% of clinicians after education ($p < 0.001$, Table 1). When asked to choose from a given SDM scenario, only 26.3% of participants without education identified the lawful SDM compared to 69.0% post education ($p < 0.001$).

Role of appointed health attorneys

Over half (63.0%) of participants pre education and almost all (93.7%) post education agreed that an appointed health attorney is the lawful SDM ($p < 0.001$, Table 1). Three quarters (75.9%) of participants pre education and almost all (94.0%) post education indicated they would prioritise the AHD over a request from an attorney ($p < 0.001$). A high proportion of both these groups (89.2% and 98.1%, respectively) indicated they would prioritise the AHD over the request of a family member ($p < 0.001$).

Discussion

The aim of this study was to assess the usefulness of a 1-hour education session aimed at increasing clinicians' knowledge of consent laws. The objectives were to investigate whether clinicians routinely familiarise themselves with their patients' ACPs and measure consent law confidence and knowledge before and after a specifically designed education program. Overall, results indicate clinicians often did not familiarise themselves with ACPs and they had inadequate understanding of some aspects of the law relating to EPOA, AHD and consent. Knowledge scores were positively correlated to confidence and were significantly higher among clinicians who had attended an education session, although substantial errors in identification of SDMs persisted.

This study revealed a strong linear correlation between clinician confidence and mean correct scores. This result supports the findings of White, Willmott, Cartwright, Parker and Williams (2016) and suggests that clinicians who are most confident do typically hold higher level knowledge of law in relation to EPOA/AHD and consent. Despite this, most of the confident participants made errors relating to treatment refusal rights and/or the legal hierarchy for the provision of consent. Confidence and knowledge were significantly higher among participants who attended the education session, indicating that targeted education can help to address critical knowledge gaps, at least in the short term.

Patients who provide ACPs to a hospital and health service as a means of exercising their right to autonomy surely have expectations that clinicians will review and respect their documented choices. It seems possible, however, that this does not consistently occur. Fifty percent of clinicians reported not routinely familiarising themselves with ACPs. Many participants spoke of difficulty accessing ACPs and/or that ACPs are the domain of doctors and social workers. Of note, treating clinicians are not required by legislation to proactively seek documented ACPs, and enduring authority commences only if the patient is unable to provide direct consent. Accordingly, many clinicians would not perceive a need to initiate a review of an ACP; however, post education, clinicians reported increased intention to do so. Improved legal knowledge appears to encourage clinicians to review documentation, which is likely to improve the patient–clinician partnership and healthcare outcomes.

A competent patient's right to refuse healthcare is considered a fundamental right in most Western nations. In this study, almost all participants agreed that a competent person has the right to refuse life-sustaining healthcare; however, they were less likely to agree when the patients' rationale was considered of poor quality or if no rationale was offered at all. After education results improved, however, a surprising proportion of clinicians continued to indicate insufficient understanding about limitations to the rights of a competent patient to refuse treatment. It seems likely that clinicians at times evaluate patients' reasons and deny rights where differences of opinion or values occur, making further education to all clinicians critical.

Almost no clinicians correctly identified the legislated healthcare consent hierarchy when the patient cannot consent directly. These data support earlier findings and recommendations for education (Cartwright, Montgomery, et al., 2014; Parker et al., 2015; White, Willmott, Cartwright, Parker, & Williams, 2015, 2016; Willmott, White, Parker, et al., 2016). Whilst correct results increased significantly after education, one third of clinicians continued to make substantial errors, such as listing the statutory health attorney first, the AHD last and/or an enduring health attorney as a low priority. Patients could rightly expect hospital and health services and clinicians to have appropriate knowledge and diligent consent procedures in place; however, this may not be the case. We suggest incorporating introductory legal information within orientation programs and procedure documents, as well as providing mandatory education to all clinicians as a matter of priority.

With AHD prevalence relatively low (White, Tilse, et al., 2014), it is often statutory decision makers who are required to consent to healthcare. Accordingly, participants were presented with a vignette and asked to choose the lawful decision maker. Before education, one quarter of participants were unsure and only 26% recognised the partner as the lawful decision maker. The estranged husband and public guardian were endorsed by 9% and 10% of respondents, respectively. Some respondents chose two or three people (e.g., partner, daughter and son) to act together, suggesting they felt unable to choose between these close contacts. Whilst correct responses post education increased and "unsure" responses reduced to near zero, incorrect responses persisted. Results indicate that clinicians continued to hold fixed or false beliefs, and they potentially accept unlawful consent in some circumstances, in breach of patient rights. Life and death decisions made by unlawful proxies leave patients and families at risk of substantial discontent and clinicians and the hospital and health service at risk of formal complaint.

Implications

The potential benefit of education to increase clinicians' knowledge of consent law was supported in this study.

Several strategies are recommended to assist clinicians and patients to partner in healthcare. Relevant education should be provided regularly, and hospital and health services should ensure that all procedures and consent documents reflect the legislative order for consent. Clinicians should ascertain the legal substitute decision maker/s (not "next of kin") and staff should be provided with tools (e.g., lanyard card) to help clarify the lawful order for consent. Patient goals and ACPs should be reviewed regularly. Associated outcomes should be monitored and strategies adjusted as required.

Limitations

This study constituted a quality improvement activity within one hospital and health service; however, we believe it makes a worthwhile contribution to the investigation of potential benefits of clinician legal education. Improvement in knowledge long term was not tested. Whilst the survey instruments were designed in consultation with knowledge experts (including a senior doctor), no pilot study or item validation occurred. Participants could skip items, resulting in incomplete questionnaires being excluded from analyses, which may have biased the study sample towards confident participants who were willing to answer every question. Responses for individuals were not linked, and there was not complete continuity between participants in the pre and post groups (i.e., not all participants in the pre-education group went on to provide a post-education response). As a result, within-person change from pre to post education was not investigated. To enhance anonymity, this study did not seek demographic, discipline or experience data, so demographic analysis was not achievable. The results warrant further research focusing on clinicians' legal knowledge and associated education needs, and the extent to which information is retained over a longer period.

Conclusion

To our knowledge, this is the first study of its type to explore clinicians' understanding of Queensland's consent laws before and after tailored education. Understanding clinician knowledge and discerning a worthwhile education strategy are critical to ensure that patients' right to self-determination is observed and not disrupted by clinicians who are unaware of associated rights and responsibilities. Patients may also survive illness against their will, perhaps with the burden of additional incapacity. Most notably, this study identified a high level of misunderstanding among clinicians about a patient's right to refuse treatment and the legislated hierarchy for consent. Substantial gains were achieved after 1 hour of targeted education. Given the national accreditation standards of high-level comprehensive care for patients attending health facilities (Australian Commission on Safety and Quality in Health Care, 2014), we recommend that legal education addressing consent law and patients' rights to receive, withhold or withdraw healthcare be provided to all clinicians as a matter of priority.

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