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The Uptake of Advance Care Planning by Older Adults in New Zealand.

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Abstract

Advance Care Planning refers to planning for end-of-life care in a proactive and comprehensive manner, preferably using a planning template. This is the first nationwide study since the formal introduction of Advance Care Planning to New Zealand in 2010, to look at the level of uptake among older adults in New Zealand. Four thousand and twenty-eight participants were surveyed about completion of living wills, enduring powers of attorney and advance care plans.

Participants were also asked who they had discussed end-of-life matters with. The data was analysed using descriptive and inferential methods, including analysing demographic data for correlations with Advance Care Planning activities. Following the survey, nine participants were chosen by convenience sample to be interviewed. Thematic analysis was applied to the interview data. The interviews explored the contextual factors and decision-making processes underpinning end-of-life-care choices. The study found that uptake was low for all forms of planning documentation although enduring powers of attorney were the most commonly completed document. Advance Care Plan discussions occurred very regularly, with nearly half of the participants having discussions in the six months preceding the survey. These were most often with family and friends and seldom with health professionals. Bivariate correlation analysis showed weak to moderate correlations between age, physical health, gender, ethnicity, and Advance Care Plan activities. Logistic regression was used to explore the completion of advance care planning templates. This revealed that the most influential factors were completing a living will or enduring power of attorney; having a discussion with a legal representative; speaking with a spiritual advisor; and being non-Māori. The qualitative interviews found seven major themes covering knowledge of ACP, the process and timing of planning, independence, who should be part of the planning process and what had been learned from previous experiences. Overall, this study reveals that, despite health promotion efforts, uptake of formal Advance Care Planning remains low in New Zealand. Further work is needed to educate the public about Advance Care Planning and to support health professionals to initiate and maintain the ACP process.

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Chapter One: Introduction

Every life ends with death. Yet, as the meaning-makers and writers of our own life-stories, how we craft our dying remains unique to each of us. Advance Care Planning (ACP) is a concept intended to give us control over how we die and who we share the experience with. However, ACP is not only important to the individual, it is a concept that also has the potential to significantly influence the cost of healthcare at the population level. Globally healthcare costs are measured in the trillions of dollars and a significant percentage is spent on end-of-life care (EOLC). This means that influencing factors such as ACP become of broad international interest to healthcare communities, including those within New Zealand.

Mitchell (2017) gives what he calls “a timely warning” of “rapidly increasing end-of-life care needs” and the associated healthcare initiatives that are needed to meet them. It is within this framework of intensifying concern for an exploding older population and their EOLC needs, that this thesis explores the uptake of ACP by older adults within the New Zealand context.

Of course, the writer’s point of view informs all discourse. My point of view and personal interest in this topic are informed by my female gender, ‘baby-boomer’ status and ethnic origins. I was born in New Zealand and I identify as a Pākehā-New Zealander. My ancestry is Irish, English, and Scottish. To the extent that my profile fits that of an ACP consumer, I also, view this topic with an insider’s eye.

This thesis starts with a review of the research literature salient to ACP, with an emphasis on the New Zealand context. Firstly, ACP is defined, and its history is traced back to changes in medical technologies during the 1960s. Its economic significance, geographic spread, and the sociocultural challenges it faces are explored, before the evolution of its form, fit and function, from a legal transactional model to its current emphasis on communication

and relationships are reviewed. Then, the elements that make for a successful ACP intervention are examined, as is its success to date. The literature is reviewed with respect to ACP's significance for the community, family, and the older adult, and as promotion and implementation of ACP sits within the purview of the Public Health domain, the demographic profile of an ACP consumer is reviewed, and public health strategies are examined. Motivators and barriers to uptake are also discussed at the systemic, population and individual levels. Psychosocial theories are explored to explain the motivators and barriers to uptake. Finally, the introduction of ACP to New Zealand is described along with the historical and cultural context existing at the time of its introduction. The research on uptake of ACP within New Zealand is also detailed and the question is asked, 'How will this study add to the knowledge already existing on this topic?'

Definition and Parameters of Advance Care Planning

Advance Care Planning is the name given to the concept of planning for the end-stage of life. For the purposes of this thesis, the acronym ACP will refer to this concept, while the term 'advance care plan' or 'plan' will refer to a documented and comprehensive plan for EOLC. ACP's primary goal is to facilitate a "good death" according to an individual's personal measure. This reflects ACP's creation within the crucible of liberal individualism, supported by the western values of autonomy and self-determination (Owens & Cribb, 2013; Kyriacou, 2016; Azétsop & Rennie, 2010). In an individualistic society, the interests of the 'one' are given primacy over the interests of the 'many' through legal and other means (Fischer, 2008).

However, the realities, and by implication a definitive understanding of ACP as an applied process, is made complex by, developing medical technologies that extend life, the involvement of the judicial system, relational and power dynamics, and the individual's psychosocial responses to planning for death. Gilissen et al. (2017) attest to this multiplicity of influencing factors by defining ACP as a "continual, dynamic process of reflection and

dialogue between patients, family and care providers concerning preferences and values for future treatment and care including end-of-life care and is aimed at enhancing the concordance between preferences and actual care or treatments received” (p. 48). Black (2007) adds to this understanding by summarising ACP as a process, a covenant, a shared activity, an exercise in clarifying values, beliefs, and goals to guide future treatment, and of use to more domains than just the medical (p. 41).

The choices made during the ACP process can range from pre-death decisions around end-of-life care and treatment, such as what treatment to have and where to die, to post-death decisions, such as writing a will and organ donation. However, for the purposes of this thesis, ACP is defined as covering health care during the pre-death period only. Within the health domain, this stage is referred to as the palliative care continuum, a time which can continue for weeks or months (Passmore, 2013).

The process of planning then, brings opportunities for an individual’s voice to be heard, even past the point where the ability to speak has been lost. However, to achieve this requires careful ongoing negotiation with disparate others and a willingness by those involved to fulfil another person’s wishes. This is a social, cultural, and medical process that has continued to evolve from its historical beginnings as a response to new medical technologies for the extension of life.

However, there are also voices warning of ACP and its outcomes. For instance, Robins-Browne, Palmer and Komesaroff (2014) warn against the glorifying and subsequent “routinisation” of ACP as an unequivocal good. They state that “If ACP is to help ease the burden of decision-making, then the focus must be on making ethically sound decisions rather than seeking a single ‘correct’ decision” (p. 959).

History

ACP was originally developed as a client-centred method for guiding the use of the life-prolonging medical treatments which were proliferating and becoming default practices

in the 1960s (Brauner, 2016; Lovell & Yates, 2014). These medical advances allowed more severely brain damaged patients to survive longer with intensive medical intervention (Perkins, 2007). However, the quality of a life lived under such extreme circumstances as long-term coma, soon became the subject of bioethical and legal debate. The debates centred on the “right to die” and were triggered by several well-known medical cases, one of which concerned an American coma patient named Karen Ann Quinlan (Cantor, 2001). This patient had sustained brain damage to the point of being in a permanent vegetative state but was kept alive through artificial nutrition and the use of a respirator. Her father asked the court for guardianship of his daughter’s ‘person’ and argued on her behalf to have the respirator removed. The court agreed to the removal of the respirator, acknowledging in its judgement, the new ground it was breaking “*the law, equity and justice must not themselves quail and be helpless in the face of modern technological marvels presenting questions hitherto unthought of.*” (Supreme Court of New Jersey, 1976). While the Quinlan case was one of the first of its kind, it is likely that the judicial system will continue to be asked for judgements triggered by new medical technologies and the evolving bioethical discussions attached to them. ACP continues to face this, and other challenges, during its geographic spread and conceptual evolution.

Geographic Spread of Advance Care Planning

The global interest in ACP is attested to by the fact that the number of publications on the subject doubled from 2005-2010 to 2010-2015 (Johnson, Butow, Tattersall & Kerridge, 2017), albeit much of this discourse is still centred within western countries where ACP finds it most comfortable fit. Moving out from the United States, ACP was embraced by other individualistic societies including Canada, the United Kingdom, Australia, and New Zealand.

ACP is now moving beyond the English-speaking, western world and is the subject of discussion and implementation in a range of countries such as India, Spain, and Japan (Deodhar, 2016; Cantalejo, Lorda & Gutiérrez, 2004; Aoki et al., 2017). This expansion has

been encouraged by international institutions such as the World Health Organisation (WHO), which has issued suggestions and guidelines for older-adult health and palliative care (WHO, 2018; De Lima & Pastrana, 2016). The expansion of interest in ACP also coincides with the growing palliative care movement which provides specialisation and choice for EOLC (Duffin, 2014; Kavalieratos et al., 2016). The recent geographic spread of the ACP concept speaks, not only to the value that it is perceived to have for EOLC, but to its potential economic significance. In this respect, ACP has a double ‘bottom-line’.

Economic Significance of Advance Care Planning

The double bottom-line.

ACP developed in response to social and technological changes. However, change is intrinsic to these domains, so why is the development of ACP even worthy of mention? One answer to this question lies in the price tag attached to ACP choices. Certainly, the health sector considers ACP to be an economic instrument that has the potential to contain health costs through directing choice. For instance, Johnson et al. (2017) contend that ACP has an applied function in several health domains by reason of lowering health care costs, reducing futile treatment, supporting families, and standardising medical practice. In this sense, bioethics is in dialogue with business ethics. Although, it must also be said that the small number of studies on the fiscal implications of ACP and their heterogenous nature are limitations to making clear statements on cost-related outcomes (Dixon, Matosevic & Knapp, 2015). Yet, despite these limitations, the literature shows that ACP can be a factor in reducing healthcare costs. But how significant are these costs?

Global healthcare costs.

Healthcare spending is substantial, both globally and within New Zealand. WHO (2017a) states that the total global expenditure for health in 2015 was US\$7.3 trillion. While the healthcare budget for New Zealand in the 2016/2017 fiscal year was NZ\$16.2 billion

(New Zealand Treasury, 2017). These figures represent a considerable public commitment to healthcare.

There is also potential for this expenditure to increase markedly given expected population trends. The United Nations (UN) are forecasting that the world's population will increase from its current level of 7.6 billion to almost 10 billion by the middle of this century (UN Population Fund, 2017). Statistics New Zealand (SNZ, 2016) project a similar trend for New Zealand, with the current population of 4.69 million increasing to between 5.29 to 6.5 million by 2043. While the rise in population is likely to be reflected in increased healthcare costs, spending connected to older adults is apt to be higher than for other life-stages.

Healthcare costs attached to ACP for older adults have an even higher than average impact for two reasons. First, this cohort represents a growing percentage of the population. WHO (2017b) states that the number of individuals aged 60 years and over will increase globally from 900 million in 2015 to 2 billion in 2050. This means an increase in this age range from 12% to 22% of the total global population.

Second, this cohort has a closer proximity to death than those in other life-stages. Seshamani and Gray (2004) found that both age and proximity to death impact significantly on health care expenditure, with proximity to death being the key factor to increased costs. For example, in the United Kingdom, the cost of hospital care increases seven-fold in the last three years of life (Seshamani & Gray, 2004). In Denmark, health expenditure in the last year before death is nine times the average for health costs (Christensen, Gørtz & Kallestrup-Lamb, 2016). While, in New Zealand, Blakely et al. (2015) found that, if death occurs around age 60 years of age, then 34% of the accumulated health costs have been spent within the 12 months prior to death. However, this drops as people age, reflecting healthcare practices in New Zealand, whereby more expensive interventions such as major surgery, may not be considered appropriate for the elderly (Blakely et al., 2015). It is this type of healthcare decision that is suitable for discussion as part of developing an advance care plan.

Despite the reduction in costly health options offered as people age, Blakely et al. (2015) still project an increase of 32% in healthcare costs for New Zealand, from 2011 to 2041, with respect to the last 12 months of life. They also make the point that this is based on data representing only 52% of health system costs and thus, by implication, the cost increase could be considerably more. Blakely et al.'s projection is partly based upon an expected population increase. In New Zealand, the population aged 65 years and older is expected to double by 2043 (SNZ, 2016). It is clear then, that the cost of healthcare for older adults in close proximity to death, remains a significant and increasing expense within the health system. This is an expense that sound ethical and fiscal policy would require to be under tight control and used to best effect, preferably in a manner acceptable to the health consumer. Of course, what is an acceptable use of health funding is always subject to normative sociocultural pressures.

Sociocultural Influences on the End-Stage of Life

Attitudes to death, and by extension, preparation for death, are culturally constructed, that is, they arise from the beliefs, values, and social norms of the society within which they are embedded (Arndt & Goldenberg, 2017; Hsu, O'Connor & Lee, 2009). What appear to be very similar sociopolitical and cultural values when viewed in trans-cultural outline, particularly through shared language, can be quite different at the societal level. Horn (2014) confirms this divergence when making the point that even the fundamental understanding of 'autonomy' is itself influenced by socio-political factors and can therefore vary from country to country. Sociocultural differences add to the complexity of orchestrating EOLC.

However, it is also human nature to categorise and simplify complex concepts, so meta-understandings of culture still inform the discussion around EOLC policy. For instance, collectivism and individualism are meta-understandings of cultural differences. To return to the example of autonomy, this concept, and its influence on the end-stage of life, is expressed as a contrasting factor between the collectivist and individualist cultural paradigms. Unlike

individualist cultures where autonomy and responsibility for self are privileged, in collectivist cultures, responsibility for the individual is understood to be subsumed by the group, and responsibility for wellbeing is seen as a collective endeavour informed by social norms that are based on cohesion and mutual obligation (Kyriacou, 2016). Members of these cultural archetypes are therefore understood to want to participate in differing ways in a loved one's dying.

Is it always helpful though, to consider culture through a categorical lens, slicing and dicing human values into distinct cultural paradigms? In fact, the differences between collectivism and individualism are points on a continuum rather than disparate states of being (Kyriacou, 2016). It is this understanding that allows these meta-ontologies to occupy the same geographical and conceptual space with some hope of mutual respect and eventual harmony.

New Zealand is just such a society where individualism and collectivism exist together, albeit in the form of a dominant individualistic culture and a collectivist indigenous subculture. It is this type of power imbalance that can disenfranchise members of one culture with respect to accessing EOLC processes and resources. This makes it particularly important for the successful implementation of ACP, that the interface between the values held by the society implementing ACP and the sociocultural values underlying the creation and evolution of the ACP concept, do not differ in fundamental ways.

Sociocultural Values of Advance Care Planning

The sociocultural context is a challenge to the primary goal of ACP, which is to facilitate a good death according to an individual's own measure. Of course, what the individual understands a good death to be, is informed by sociocultural influences. The same can be said for how to plan for a good death. Therefore, an ACP process created in one sociocultural context may not support the communication and decision-making styles of another. It is not surprising then, that given the polycultural nature of the world, there is an

effort to stretch the ACP concept to incorporate differing sociocultural norms. In this respect, like any ‘immigrant’, ACP is on a journey of acculturation as it moves out from its individualistic beginnings.

Advance Care Planning in Pluralistic Societies

How then can ACP be of use in a pluralistic setting where more than one group has a recognised claim to society’s resources? This question comes into stark focus when it is applied to a collectivist subculture existing within an individualist society, such as is the case in New Zealand. For instance, Baydala, Hampton, Kinuwa, Kinuwa and Kinuwa Snr (2006) talk about the subordination of indigenous personal and cultural meanings by the western medicalisation of the dying process. It appears socially normative that health systems in many societies are now committed to preserving autonomous, self-determined outcomes in relation to end-of-life planning. This is illustrated in Biondo, Lee, Davison and Simon’s (2016) international review of 46 health system outcome studies. From the 14 outcomes identified, the patient’s family are explicitly mentioned only once (p. 726). Crawley (2005) also points out the disparity between the use of EOLC services among differing cultural groups, assigning this in large part to bias and discrimination by healthcare providers. In other words, having those value-based ACP conversations and accessing culturally-appropriate services can be difficult for an indigenous culture with an alternative ontology. Certainly, for the indigenous Māori culture in New Zealand there is recognition that the autonomous decision-making model should stretch to acknowledge the rights of family to be included (Frey, Raphael, Bellamy & Gott, 2014).

However, ACP as a values-based process which emphasises the importance of communication and shared understandings, has the potential to support cross-cultural dialogue in a positive manner. On the other hand, not all traditional ACP tools suit the values of all cultures. For instance, advance directives in their standardised form, do not reflect cultural differences (Zager & Yancy, 2011).

Given the challenges that accompany this cultural journey, it is not surprising that ACP appears to be finding its broadest use and most comfortable fit in its values and relational-based form because it is within this form that ACP is at its most flexible. Yet, ACP's beginnings were not initially relationally focussed. They grew out of a wish to redress an increasing ethical and practical disconnection between the medical imperative to preserve life and the quality of the life that was being preserved. It was a legal battle against the Hippocratic Oath, specifically the tensions between the Principles of Autonomy and Beneficence, which started the ACP journey. However, it was the effects of changing perspectives over time, differing sociocultural influences, and the pressure to succeed because of its economic importance, that required ACP to evolve and adapt to achieve its goals.

Evolution of Form, Fit and Function

To borrow a metaphor from the manufacturing domain, aspects of ACP cluster into sub-concepts of form, fit and function. For the purposes of this thesis, form includes process, content, and instrumentation, while fit refers to adaptation within various sociocultural contexts, and function refers to the uses ACP is expected to fulfil. All three have been the subject of evolution and all three overlap and impact on each other.

Form.

Legal transactional model.

The form of ACP has changed from a legal transactional model to a relational communications-based model, from an emphasis on formal planning to a recognition of the usefulness of a range of other more informal expressions of planning. Formal planning for the purposes of this thesis, are actions committed to writing, such as completion of an enduring power of attorney (EPA) or letters to family about personal wishes for EOLC. Informal planning refers to the participants' values-based thinking about end-of-life issues as well as discussions and the verbal development of understandings with others.

Historically, ACP took the form of legal documents such as living wills and EPAs (Black, 2007). Living wills record an individual's wishes for medical treatment and particularly the refusal of treatment. An EPA refers to the legal appointment of a substitute decision-maker for either property or welfare matters. A substitute decision-maker for welfare concerns is the legally recognised person entrusted to make decisions on another individual's behalf for health-related matters in certain circumstances.

These documents are also known, collectively and separately, as advance directives and their purpose is to empower individuals to make choices past the endpoint of their personal competence. Competence in this context is defined as the "capacity (a) to understand the nature, and to foresee the consequences, of decisions in respect of matters relating to his or her personal care and welfare; and (b) to communicate decisions in respect of those matters" (New Zealand Parliamentary Counsel Office, n.d).

Living wills.

Physicians, the judicial system, and health-consumers have all expressed ambivalence about the use of living wills. Physicians do not always choose to adhere to an individual's pre-stated wishes, often because they are not relevant to the eventual health circumstance the person finds themselves in (Perkins, 2007). Sudore and Fried (2010) summarised this as being the result of changes in an individual's preferences or values over time or in response to a change in circumstances, a circumstance that is complicated by the problems associated with predicting the disease and care-needs trajectory with accuracy.

Sanders, Schepp and Baird (2011) illustrated another important risk associated with ACP in their review of the use of partial do-not-resuscitate orders, when they concluded that respecting patients' autonomy can adversely affect patient welfare by isolating one aspect of medical decision-making from the complex and emmeshed totality of an unfolding medical situation. Thus, trying to reduce medical concepts and choices to the lowest common

denominator to make them understandable to lay individuals, carries the twin risks of irrelevance or harm.

The judicial system is also ambivalent about the use of living wills. In New Zealand, if an individual's wishes are pursued into court, the judicial system is careful not to silence the medical community's voice completely and will therefore only consider upholding patient-wishes with respect to treatment refusal, and then only in limited circumstances (Kersey, 2015).

Health-consumers have expressed their ambivalence through their choice not to complete a living will. For instance, Yadav et al. (2017) found in their systematic review of research on the subject, that only 29.3% of Americans had completed a living will, while Schröder, Hommel and Sahn (2016) found in their study of 1,260 German participants, that only 15% had completed a living will and 20% had not heard of the concept. Schröder et al.'s findings attribute the low completion rate to an inability to anticipate future decisions and a fear of adverse effects, such as the application of a patient's wishes to an inappropriate situation.

This ambivalence goes some way to explaining the findings of Prendergast's (2001) review into the outcome of using living wills. He found that they did not improve communication between the patient and professional, nor reduce the end-of-life resources used in a hospital setting, nor change care decisions. It appears then, that living wills promise more control over EOLC than they can deliver (Perkins, 2007).

Enduring Power of Attorney.

The uptake of EPAs is higher than for living wills, however there are still issues with its acceptance. For example, Jeong, Ohr, Pich, Saul, and Ho's (2015) survey of 229 culturally diverse older adults in Australia found that, while 37.5% of those from Anglo-Celtic descent had an EPA, the uptake among other ethnicities was much smaller. They also found lack of knowledge about EPAs to be an issue, while other barriers to completion

included the complexity of the documentation and the time it took to complete. In New Zealand, a survey of 100 participants also found the uptake of EPA to be low among older adults although those of New Zealand-European descent had completed EPAs more often than other ethnicities (Park & Astell, 2017). Again, participants commented on a lack of knowledge of EPAs while Park and Astell also referred to cost of EPAs as a potential barrier to uptake. Clearly, the legal transactional form of ACP had not been very successful in empowering health-consumers, therefore a paradigm shift was the only way forward.

Communication-based model.

Following the disappointing outcomes of written orders such as advance directives, the ACP paradigm shifted to a relational and communications-based form. In this form, legal documents were reduced to instruments in a larger toolkit and improved communication was the new hope for translating patients' wishes into medical action (Sabatino, 2010; Vearrier, 2016). Advance directives came to be viewed as 'conversation-starters' (Pfeifer et al., 1994) and more recently, suggestions have been made that the ACP process should include educating individuals and their significant others about effective in-the-moment decision-making, rather than relying on pre-written statements that may or may not apply to a given health event (Sudore & Fried, 2010).

Thus, at its heart, the new form of ACP refers to a shared understanding between key collaborators of an individual's wishes for the future (Robinson et al., 2012). Who the collaborators are, depends on the pragmatics of the specific healthcare situation as well as the value-based priorities of the individual themselves. For instance, in addition to the individual, planning may include health professionals, family, friends, spiritual advisors or other professionals, such as solicitors and accountants. Within the New Zealand context, the Ministry of Health (MOH, 2011) shares this view of ACP as a "process of discussion and shared planning for future health care" whose value "lies not solely in these outcomes but in the conversations and the shared understandings that eventuate" (p. 1).

As part of this paradigm shift, the emphasis on effective communication as a factor in the ACP process, began to assume more importance, and communication initiatives were launched to normalise death discourse and trigger planning for EOLC. Examples include, The Stanford Letter Project (Stanford Medicine, 2018) and The Conversation Project (The Conversation Project, 2018). In addition, new ACP models were devised, such as The Respecting Choices ® model which treats ACP as a values-based, inclusive, and relational process. The Respecting Choices model has proven to be effective in appreciably increasing completion of advance directives among diverse ethnicities (Pecanac, Repenshek, Tennenbaum & Hammes, 2014). Prendergast (2001) acknowledged the success of this model compared to the disappointment of the legal transactional form of ACP.

Following the paradigm shift, ACP can be characterised as a person-centred series of value-based conversations, with the choice to put wishes in writing for added clarity and authority (Storey & Sherwen, 2013). The wide acceptance of this evolution in form makes it clear that ACP, albeit originally an exercise in self-determination, is in fact a process that works best when it extends beyond the individual and into the liminal space of shared understandings and collaboration with others. Effective communication is therefore key to the success of ACP. This has implications, not only for the form ACP takes, but also the instruments used in service of its goals.

The ACP toolkit continues to evolve as new instruments to assess, measure and facilitate the ACP process are developed. Examples of these new instruments include the development of a tool to assess what stage individuals are at in their readiness to engage in ACP discussions; structured question prompts for health professionals to elicit ACP information from their patients; a mobile application to encourage and record ACP decisions; websites for ACP engagement using motivational interviewing and other techniques; training programmes for ACP facilitators; death education for the public; and an ACP game as a novel way to engage individuals in thinking about EOLC matters. (Cision, 2015; Prince-Paul &

DiFranco, 2017; Reynolds & Croft, 2011; Shingleton & Palfai, 2016; Sudore et al., 2014; Van Scoy et al., 2017).

Advance Care Planning Templates.

Perhaps the most important of all the new instruments developed as a response to the paradigm shift, is the advance care planning template or checklist. Several versions have been developed (e.g., Lockett et al., 2015; National Advance Care Planning Cooperative, 2017b). They provide a proactive and systematic way to trigger comprehensive decision-making based on deeper values-based thinking. Examples of template questions include ‘What is important to you, what do you value most?’ and ‘How involved do you want to be in treatment decisions?’ (National Advance Care Planning Cooperative, 2017b). These types of templates can also be the precursors to more formal planning.

The common thread running through the development of all these instruments is the commitment to a communications-based model of ACP and an understanding that a range of outreach initiatives are required to promote uptake within diverse populations.

Fit.

It is finding a way to adapt within these diverse populations that had led to the evolution of ACP in terms of fit. Adaption in this respect reflects both the polycultural nature of the world as well as the changes wrought on sociocultural norms by time and changing resources. For instance, in New Zealand, health literacy has been identified as a barrier to Māori accessing palliative care (MOH, 2017). The challenge for ACP within this context is to facilitate the understanding of EOLC choices in a culturally appropriate way so that equal access to health resources is promoted for Māori.

Of course, implicit in most models of communication is the two-way nature of the interaction. This opens opportunities for the health consumer to be influenced in their understandings and choices by the ACP process. Another question is then raised, ‘Is ACP unwittingly an instrument for assimilating its users to dominant cultural norms? Thus, the

evolution of fit can carry with it important ethical questions that reflect the discordance which comes with overlaying one set of sociocultural norms upon another. It also can bring into question the function of ACP.

Function.

Function refers to the uses that ACP is expected to fulfil. The original function of ACP was to empower individuals to choose healthcare options that would lead to a good death. The focus was on acceptance or refusal of treatment choices. However, the focus and therefore the function of ACP, has evolved with the change to a relational communications-based model. It now includes resolution of spiritual, psychological, and social issues that may arise during the ACP journey (Storey & Sherwen, 2013). The function has also shifted focus in other ways, including ACP's use as a financial instrument for healthcare providers wanting to save public health dollars. This is a pronounced shift in function for ACP and one driven by a strong economic imperative. It appears that ACP is now a 'portmanteau' concept reflecting multiple overlapping functions that together make up a sum larger than its parts. ACP is now about much more than an individual's last few months of life. It is about society's level of comfort with the idea of death, as well as how privileged this life-stage is compared to other life-stages. This is demonstrated by the financial resources attached to the facilitation of a good death. What elements are needed to achieve these goals and whether ACP has been demonstrably successful in applied settings are the next questions to be asked.

Effectiveness of Advance Care Planning

To be effective ACP needs to be a flexible and iterative process, initiated at the right time, completed in a reflexive and inclusive manner, and based on the best medical information available. Effectiveness also requires that the process be successfully implemented within the healthcare setting, including having the relevant information easily accessible when needed (Lakin et al., 2016).

There are some indications that the implementation of ACP is achieving these process-oriented goals, and in addition, is proving effective in unlooked for ways. For instance, Bischoff, Sudore, Miao, Boscardin and Smith (2013), in their study of 4,399 participants, found an association between ACP and improved quality of EOLC, as measured by healthcare utilisation statistics. ACP has also been found to reduce anxiety, depression, and post-traumatic stress for surviving relatives (Detering, Hancock, Reade & Silvester, 2010).

However, there are other indications that ACP implementation has yet further to go. For example, Sellars, Silvester, Masso and Johnson (2015), in an Australian national survey into the effectiveness of ACP implementation in palliative care services, found considerable evidence of the need to further embed the ACP process into the palliative care domain and to attend more carefully to the wishes of the client. Some of the elements that are important to implementing a successful ACP programme within the palliative care domain include, good facilitation skills along with the inclusion of important collaborators in the process and addressing the care needs in multiple settings (Qaseem et al., 2008).

The effectiveness of ACP also varies according to the diagnostic category, the timing of completion during the disease trajectory, patient demographics including profession, communication; and the type of ACP instrument used. For example, ACP is used more often with those diagnosed terminal diseases such as cancer (Glaudemans, van Charante & Willems, 2015). It can also be effective when implemented with dementia patients in the earlier stages of the disease (Dening, Jones & Sampson, 2011).

Given the level of complexity implied in all these influencing variables, it might be easier to follow Houben, Spruit, Groenen, Wouters and Janssen's (2014) advice to search for a structured form of ACP to fit a standard care model. However, a formulaic form of ACP underestimates the uniqueness and complexity of diverse circumstances, including the need to attend to varied patient characteristics and attitudes. For instance, despite indications that

ACP can be effective if undertaken in the earlier stages of dementia, the uptake of ACP among this group is particularly low, potentially reflecting communication issues among the key participants in the process (Sinclair, Oyeboode & Owens, 2016). On the other hand, knowledge of ACP among health professionals, a very ‘death literate’ group, increases participation in informal values-based planning but does not increase the uptake of formal advance directives (Rainsford & Glasgow, 2016).

Other studies have been more equivocal about whether research into ACP has provided a reasonable level of certainty that ACP is effective. The message from these studies is that further research with clearer outcome measures are needed to confirm such findings (Brinkman-Stoppelenburg, Rietjens & van der Heide, 2014; Dening, Jones & Sampson, 2011; Gilissen et al., 2017; Hagen et al., 2015; Walczak, Butow, Bu & Clayton, 2016).

Implementing ACP within a public health system where services may be fragmented, and time and other resources are limited, can be very challenging. This may go some way in explaining why globally, the individual uptake of ACP has been limited (Hagen et al., 2015; Lovell & Yates, 2014; Rhee, Zwar & Kemp, 2012; Sullivan & Dickerson, 2016). Yet, the spread of the ACP concept and commitment to its implementation continues, not only because of its economic significance, but its significance for community, family, and the older individual.

Significance of ACP for Community and Family

It is at the community level that the influences on ACP come into sharper relief because it is at this level that the collaborators in an individual’s advance care plan are to be found. It is also at this level that it becomes clearer that the Principle of Autonomy provides an incomplete foundation for ACP. This principle views the individual-self as independent and atomistic, disregarding the influence of significant personal relationships. Ikonomidis

and Singer (1999) make the point however, that ACP can be flexible enough to overcome this by incorporating elements of decision-making that extend beyond the needs of the individual.

Through its shared nature, ACP recognises that to be human is also to be connected to others on a very personal level. The end-stage of life is therefore a time of grief and transformation for an individual's family, friends, and local community, in that they lose someone integral to their lives and continue thereafter to bear the ongoing psychological consequences of how that person died. Children say goodbye to a parent, spouses lose their life-partner, friends say goodbye to a friend and communities farewell one of their own. The manner of a person's death may also be felt by those involved as a judgement on their level of care. In this sense, a good death is not only measured by the dying individual, but also by others who feel connected to them. For instance, the manner of death is a source of judgement, even at the community level. When someone dies alone, communities often express distress through published condemnation of their own failings (Seale, 2004).

ACP has the potential to incorporate and negotiate these plural points of view about what constitutes an acceptable death. This can bring comfort to those that remain as well as to the dying individual who may wish to shield significant others from any distress or difficulty their passing may cause (Tang et al., 2014). However, these community and familial views of dying are one step removed from the personal experience of dying, and it is the individual's experience of their own death that is at the heart of the ACP concept.

Significance of ACP for the Older Adult

ACP is particularly suitable for the type of long-term, terminal illness often experienced by older adults. More than 87% of adults over the age of 60 years die from diseases such as cancer and heart disease (WHO, 2011) and it is these types of chronic diseases, with trajectories that are somewhat predictable, which are particularly suitable for future-focussed health planning (Glaudemans, van Charante and Willems, 2015; Khandelwal, Benseker, Coe & Curtis, 2016). However, it is also these illnesses that attract advances in

pharmaceutical and health technologies, which in turn encourage a higher rate of intervention requiring the patient to be hospitalised to receive them (Bekelman et al., 2016; Kilgore, Patel, Kielhorn, Maya & Sharma, 2017; Vearrier, 2016). The use of modern technologies and the cost of hospitalisation are two important topics of discussion around the economic value of ACP. The potential of recent technologies and the accessibility of healthcare resources, such as hospital care, are also topics of interest for those tasked with the promotion of ACP.

Advance Care Planning as a Public Health Issue

EOLC has not always been viewed as a public health issue, there has been a shift in the scope of public health to incorporate it. Blank (2011) described the starting-point for this shift when he talked about ‘death policy’ not being favoured by politicians or health professionals because death is often considered synonymous with failure and saturated with sensitive and moral-laden issues. Given these beliefs, public health has traditionally concerned itself with health-promotion and life-extension rather than management of the dying process (Fried, Bullock, Iannone & O’Leary, 2009; Prince-Paul & DiFranco, 2017; Rao, 2015). However, planning for EOLC is now perceived to be a health behaviour and is therefore seen as fitting within the parameters of public health (Abba, Byrne, Horton & Lloyd-Williams, 2013; Ernecoff, Keane & Albert, 2016). In response, the public health domain has used its traditional mechanisms to promote ACP.

Regulation or Nudging.

Public health initiatives such as ACP are either regulated or ‘nudged’ into action (Hansen, Skov & Skov, 2016). Regulation reflects the legal transactional model of ACP. The United States Patient Self-Determination Act (1991) is an example of support through regulation where a legal requirement exists for health professionals to supply advance directive information to healthcare consumers (Dresser, 2016; Prendergast, 2001). Giving legal status to substitute decision-makers by way of an EPA is yet another example. Regulation represents an enforcement of social change.

On the other hand, “nudging” is a more informal process which in turn reflects the change from a legal transactional model to a communications-based model (Sabatino, 2010). Nudging is a process of informing and encouraging without legal coercion. Nudging acknowledges that human decision-making is ‘boundedly rational’, in that it is limited by context, such as the knowledge available at the time a decision is made, combined with the attitudes derived from the individual’s cognitive schema (Hansen, Skov & Skov, 2016). ACP as a health behaviour, is nudged through an emphasis on education, supporting discussions about ethics, and reducing the barriers to planning for EOLC (Bravo et al., 2016; Hagen et al., 2015; Owens & Cribb, 2013; Tamayo-Velázquez et al., 2010; Webb & Casarett, 2017). Effective nudging also requires an understanding of the target population.

Demographic Factors.

There are several demographic factors associated with ACP uptake including, being female, older in age, being part of the dominant culture in western countries, having higher education and higher income, increased level of functional impairment, diagnosis of a chronic illness, and exposure to palliative and residential care environments (Lovell & Yates, 2014; Inoue, 2016). However, correlation between these factors and the uptake of ACP may also be instrument-specific. For instance, Ko, Lee and Hong (2016) researched completion of advance directives among 204 older individuals on lower-incomes, finding that sociodemographic factors such as age, ethnicity, gender, income and church attendance did not impact on completion, although fair or poor self-reported health status and social connectedness in the form of access to a proxy decision-maker did have an impact. However, given that this study sourced participants living in two supportive housing facilities in the same geographic area, and all belonged to the same senior centre, then it could be expected that a certain amount of homogeneity exists within the participant population, meaning that demographic differences did not have the contrast necessary to show significance. Hart et al. (2018) also suggested a possible confound when they noted that demographic differences in

advance directive completion, such as those for men, the ethnic minority, and less educated individuals in fact disappeared when equal access to advance directive completion was made available to all.

Of course, demographics are population specific, requiring public health promoters to have a clear sociocultural understanding of the context they are operating within and how best to promote uptake of ACP. New Zealand does not compel ACP discussions through regulation as does the United States, but like other western countries, it gives a secondary level of regulatory support to ACP, for instance, through legislation supporting advance directives. However, in general, New Zealand relies on nudging to promote ACP uptake.

It appears though, from the limited knowledge and uptake of ACP by health consumers internationally, that public health promoters have not yet been completely successful in negotiating the psychosocial and practical factors affecting individual decisions to use the ACP model. How then is ACP currently promoted to the individual, especially given the complexity of the information and subsequent health choices required (Webb & Casarett, 2017)?

Public health strategies.

A health process cannot be successfully implemented if there is a lack of knowledge about its existence, or how to access and make use of it. In the case of ACP, a range of health professionals such as nurses, physicians, social workers, and other community health workers have been identified as suitable to provide ACP interventions (Litzelman et al., 2017; Malcomson & Bisbee, 2009; Splendore & Grant, 2017; Stein, Cagle & Christ, 2017). Sites for interventions include primary care practices, hospital settings, nursing homes and community settings including church-based facilities (Hendricks Sloan et al., 2016).

Lawyers and accountants also play a part in promoting the legal and financial aspects of planning for EOLC and may be the first to initiate an ACP discussion (Malcomson & Bisbee, 2009). There is evidence for this within the New Zealand context, as a Google search

for ‘Power of Attorney’ on the MOH website returned one directly relevant result giving a link to the government’s SuperSeniors website, while the same search on the New Zealand Law Society’s (NZLS) website returned 2,046 results. It appears then, that the law sector rather than the health sector takes ownership of the EPA as a legal document within their purview and active promotion of EPAs by NZLS members is encouraged by the government’s Office for Senior Citizens (NZLS, 2015).

In terms of what works during an intervention, Bravo, Dubois and Wagneur (2008) conducted a systematic review of ACP interventions, finding that “the provision of oral information over multiple sessions” (p. 1131), had the most success in encouraging uptake. This is in preference to the provision of written information without a face-to-face interaction, for instance, brochures and forms sent through the mail. Tamayo-Vela’zquez et al. (2010) also found that the best strategy was repetitive conversations within a clinical setting along with the provision of written information. On the other hand, Crowe et al. (2015) were successful in increasing ACP knowledge and approval when they conducted a series of single workshops targeting the provision of ACP information to community-based healthy adults. However, it is not known if this education initiative translated into completed ACP plans. One study where lay ACP facilitators were co-located in primary care practices also substantially increased ACP uptake (Mann et al., 2017), while Landa and García (2017) report on the success of community-based groups to promote the use of advance directives.

It appears that ACP promotion, is seen, for the most part, as coming within the purview of healthcare professionals as part of their business-as-usual tasks. This is despite its time-intensive and repetitive nature. It is not a subject that can be effectively promoted by just giving someone a pamphlet, and the seriousness of the decisions to be made also demand that the information given is comprehensive and of excellent quality. In addition, Llewellyn et al. (2017) make the point that those initiating EOLC conversations, including ACP interventions, need to consider other aspects, such as the timing of the engagement, as well as

the age, ethnicity, and health status of the information recipients. Despite all these considerations, Bravo et al. (2016) make the point that, even with the best efforts, not everyone is going to be able to face the reality of their death or sign forms that will eventually hasten their demise.

Motivators and Barriers

The broadest frame of reference for hypotheses about why individuals are motivated or hindered in their completion of a plan, is the understanding that human beings are not only self-conscious but aware of their own awareness, with the result of this awareness having a profound impact on human motivations, emotions, and behaviours (Hardie-Bick, 2015). These behaviours include health choices, such as those made during the ACP process (Pyszczynski, Solomon & Greenberg, 2015). Understanding the specific motivators and barriers influencing these choices is important to the uptake and successful completion of ACP plans. Psychology as the science of mind and behaviour, may offer explanations for why people choose to engage in ACP. This has already been recognised through the introduction of nudging, as the primary public health strategy for ACP, in that nudging is based on the psychological understandings that underpin the behavioural sciences.

Motivators.

Any level of planning based on inner-directed motivation shows a wish for continued self-determination at the end of life, even if the decision is to hand over power for decision-making to others. In that case the self-determined element is that the power goes to ‘others’ of your choice. Motivation to undertake EOLC planning therefore rests on a wish to exert control over the future (Ernecoff, Keane & Albert, 2016). Motivating factors are often experiential and relational in nature. They include getting older, becoming unwell, witnessing another’s illness, and the quality of personal relationships. In addition, individuals are motivated to organise EOLC in advance so that they do not become a burden on their loved ones (Kelly, Rid & Wendler, 2012).

Older individuals are more motivated to plan for the end-of-life (Lovell and Yates, 2014). This is also a trend that continues within the older adult cohort itself, in that the older you get the more likely you are to complete a plan (Kahana, Dan, Kahana & Kercher, 2004). The transition to acknowledging the need for, and then completing an advance care plan, is explained in part by psychological theories of change. For instance, ACP has been mapped onto the transtheoretical behavioural change model by Sudore et al. (2008), who propose a generic ACP model with several stages reflecting the process of behavioural change. The stages are pre-contemplation, contemplation, preparation and values clarification, actions and maintenance or reflection. These stages are represented in the model as cyclic in nature but Sudore et al. also acknowledge that some stages may be skipped or revisited and repeated during a single cycle.

Fried, Bullock, Iannone & O'Leary (2009) also found that individuals are at varying levels of readiness to engage in specific stages of ACP, including readiness to communicate with family and health professionals or openness to discussing treatment options. They point out that undertaking ACP is only one of several change processes that individuals engage in when considering the deterioration of their future health.

In addition, the Theory of Reasoned Action/Planned Behaviour is useful for understanding the underlying reasons for engaging in ACP. This theory talks of intention as a predictor of behaviour, with intention being influenced by subjective norms, attitudes about outcome expectancies, and perceived behavioural control (Ajzen, 2002). Viewed through this lens, ACP is a socially normative instrument which allows individuals to feel some control over the future. It gives individuals a sense of self-efficacy over their healthcare and supports a positive attitude with respect to outcome expectations.

Deteriorating health also motivates discussion about end-of-life matters. Influencing factors related to personal health status include, how well an individual understands their prognosis, level of impairment, and disease type (Lovell & Yates, 2014). For those who

already have a terminal illness, McLeod-Sordjan (2014) refers to the growing awareness of the need for ACP as 'death preparedness'. This transition is from the 'sick' role to the 'dying' role (Noyes & Clancy, 2016; Parker-Oliver, 1999). Parker-Oliver refers to terminally ill patients becoming stuck in the 'sick' role through the expectation of recovery and the need to move them to the 'dying' role where the expectation shifts to non-recovery. This is a crucial point at the end of life and ACP has the potential to facilitate change through the individual's engagement in a process that allows them to explore an alternative perception of themselves. In addition, moving through this transition may facilitate important dialogue with medical, spiritual, and significant others. Of course, this example of transitioning to ACP refers to the personal experience of a life-threatening illness. Yet, human beings have the ability to learn vicariously from the experience of others as well.

Psychological theories on Social Learning and Social Cognition (Bandura, 1991; Grusec, 1994) refer to shared constructs and a sense of agency, whereby people learn from the experience of others and gain a sense of self-efficacy from vicariously observing successful behaviours in someone else. Amjad, Towle & Fried (2014) found through interviewing 304 older adults, that witnessing another person's demise, particularly if there was inadequate medical care, is a motivating factor for engaging in ACP behaviours. This type of vicarious experience also includes hearing about a bad death through the media as well as working in a palliative care setting (Amjad, Towle & Fried, 2014; Kahana et al., 2004). The result of witnessing the end of another person's life under these varied circumstances, heightens the perception of vulnerability (Fried et al., 2009). Then again, witnessing the successful implementation of ACP in such circumstances may also support the perceived control and outcome beliefs of Reasoned Action/Planned Behaviour Theory, thus motivating people to complete their own planning.

Other types of shared experiences also affect the ACP process. Boerner, Carr and Moorman (2013) found that higher functioning family relationships encourage ACP

discussions with spouses, and to a lesser extent, completion of advance directives. Boerner et al. speculate that the mechanisms involved are social control and social support. They explain social control as referring to the regulation of an individual's health behaviours by significant others while social support covers both tangible and intangible assistance received from others, including emotional support, information, and more practical forms of help and Boerner et al. posit that the positive social connections inferred by this support, can encourage individuals to make good health decisions out of consideration for those to whom they are close. Ko, Lee and Hong (2016) agree that a positive attitude plus good social support encourages the uptake of ACP. The positive attitude part of this equation resonates with the self-efficacy factor of the Theory of Reasoned Action/Planned Behaviour.

In summary then, both social control and social support can influence the uptake of ACP as a positive health behaviour. The difference lies in the locus of motivation being either intrinsic or extrinsic. Being aware of these motivators is useful for the promotion of ACP. However, it is just as important to understand the many barriers to engaging in planning for EOLC.

Barriers.

There is a plethora of barriers to the uptake of ACP. For example, Kermel-Schiffman and Werner (2017), in a systemic review of 37 studies, found that lack of knowledge about ACP is a major barrier to uptake. While Fried, Zenoni, and Iannone (2017) found that barriers include subject avoidance, value-based differences, and the influence of proxy decision-makers. On the other hand, McLennan, Boddy, Daly and Chenoweth's (2015) findings included the complexity of ACP documentations and misperceptions of the relevance of ACP based on an individual's health and age as being barriers to ACP. Schidedanz et al. (2009) added relationship issues, and time constraints during the professional-patient encounter, while Radhankrishan, Saxena, Jilapalli, Jang, & Kim (2017) discussed the hesitation by health professionals to engage in cross-cultural ACP discussions as well as the lack of

access to culturally-appropriate health education materials on the subject. West and Hollis's (2012) cross-cultural study found three common barriers. These were denial and fear, education about ACP, and issues with proxy decision-making. The cost of legal documents can also be a barrier (NZLS, n.d.). Almost all these barriers can be grouped into the domains of culture, psychology, and public health, and it is from these vantage points that the challenges intrinsic to the ACP landscape becomes clearer.

As ACP spreads globally, it is challenged to reflect the values and meet the needs of multiple cultures, often concurrently in one country. This is no easy task, as health resources and practices often reflect the values and norms of the dominant culture. Sudore, Schillenger, Knight and Fried's (2010) give an example of this when they talk about Pacific Island and Asian patients in the United States being more uncertain about treatment decisions than members of the dominant culture. They suggest that this may be a language and acculturation issue.

Even when language is not a barrier, ACP, as a western form of death discourse, does not necessarily overlay harmoniously onto alternative ontologies, for instance those influenced by the Asian philosophies of Confucianism and Taoism. Within the Chinese Taoist tradition, life is to be prolonged if possible to stave off the unluckiness of death, and in addition, the topic of death is not to be discussed directly with the patient as this may destroy hope (Hsu, O'Connor & Lee, 2009). These cultural strictures can make it difficult to have an open, autonomy-focussed ACP discussion with the patient (Hsu, O'Connor & Lee, 2009; Hsiung & Ferrans, 2007).

From the psychological perspective, confronting death is perilous and there is sometimes a preference to concentrate on living rather than talk about dying (Fakhri et al., 2016). For example, Hardie-Bick (2015) applies this idea to mortality awareness when saying that, rather than think on their own mortality, "people have become competent in the arts of distraction. People lie, cover up and deceive themselves by immersing themselves

into their everyday projects and concerns “. However, Edmondson, Park, Chaudoir and Wortmann (2008) state that when faced with thoughts of impending death, a religious struggle within the individual breaks down psychological defences. They suggest that this leaves a person vulnerable to existentialist dread which results in increased anxiety, depression, and functional disability, factors that are likely to influence both healthcare and personal decisions made towards the end of life. Thus, the process of ACP has the potential to tap into deeply embedded fears with the unintended consequence of causing psychological harm. It is therefore a process that needs to be undertaken with care.

In evolutionary psychology, this drive to push away death is explained as a survival instinct, and within the public health domain, this instinct is explained through Terror Management Theory (Pyszczynski, Solomon & Greenberg, 2015). This theory suggests that thoughts, behaviours, motivations and emotions are all affected by the suggestion that death is imminent. The resulting existentialist terror is responded to by either, strengthening adherence to cultural belief systems or choosing health behaviours that distance oneself from death (Arndt & Goldenberg, 2017; Bevan, Maxfield & Bultmann, 2014; Pyszczynski, Solomon, & Greenberg, 2015). Kirkpatrick & Navarrete (2006) question the evolutionary concept of a ‘survival instinct’ and its function as a motivating factor in Terror Management Theory. However, they do acknowledge that existentialist terror may be the result of the evolutionary development of human cognition and the fear engendered through being able to reflect on personal mortality.

Currently, Terror Management Theory supports health promotion initiatives such as death-priming, which uses the display of shocking images in advertising to increase death anxiety and drive beneficial health-related choices (Hansen, Winzeler & Topolinski, 2010). Thus far, Terror Management Theory and ACP have had little connection with each other in scholarly debate. However, there seems to be an overlap between Terror Management Theory and ACP, in that Terror Management Theory as a death-cognition theory, purports to

explain choice-making behaviours that are also intrinsic to ACP. Thus, although it is currently used to explain how to ‘stop’ negative health behaviours, it may also provide insight into how to ‘start’ positive health behaviours such as ACP.

Other psychosocial factors impacting on ACP uptake include communication and relational issues. These barriers are multiple and complex and include how family members relate to each other, including the influence of the surrogate decision-maker, and even an inability to find a suitable surrogate, which becomes a barrier to ACP (Liantonio, Liqouri, Lakhtman & Parks, 2017).

Death-related conversations within the family bring into one space, differing emotional and value-based perspectives, as well as responses to practical stressors such as financial concerns over care options. It is not surprising then, that family dynamics can influence the ACP process (Carr, Moorman & Boerner, 2013; Mockus Parks et al., 2011). Several communications and relational theories explain family dynamics. Of particular relevance to ACP are Van Scoy et al.’s (2017) use of Multiple Goals Theory to highlight the multitude of sometimes conflicting goals that inform ACP conversations. On the other hand, Communication Privacy Management Theory refers to how choices are made to conceal or reveal personal information. Trees and Ohs (2016) use this theory to explain the tension caused by privacy versus disclosure during end-of-life conversations with families. For those tasked with ACP interventions, these theories can explain behaviours that may become apparent during the process, such as a wish not to talk about death or the influence of family on the process.

There are other barriers to uptake that are situated at the systemic-level, that is, within the public health domain itself. Again, many of these are communication-based issues. They include, a lack of communication about ACP as well as inaccessible forms, language difficulties, misunderstandings, and constraints on the time available to communicate with potential ACP consumers. Some of these barriers may be straightforward to address, for

instance, inaccessible ACP forms such as advance directives (McLennan, Boddy, Daly & Chenoweth, 2015). However, other barriers need clearer communication at all levels of the public health system.

An important challenge for the public health domain is that many health consumers do not know about ACP. Hagen et al. (2015) found a dearth of public engagement with the subject as a systemic barrier to uptake. Prince-Paul and DiFranco (2017) attribute this hesitation to engage from the public health perspective as a lack of cultural transparency about death and from the health consumer's perspective, a wish to ignore the subject until a health crisis occurs. Unfortunately, leaving the discussion until there is a health crisis, narrows the window of opportunity for engaging individuals in ACP decision-making, to a time of stress and ever-decreasing choices (McLennan, Boddy, Daly & Chenoweth, 2015).

Health consumers who are aware of ACP, do not necessarily understand its relevance and benefits. They are fearful and mistrusting of the process which leads them to avoid it. McLennan et al. (2015) ascribe this, in great part, to misinformation and they suggest the need for further public education on the topic.

There is also a hesitancy on the part of health professionals to engage their patients in face-to-face discussions about end-of-life planning. In a systematic review of the literature regarding physicians discussing ACP with their patients, De Vleminck et al. (2013) found evidence that a lack of skills in dealing with the topic, waiting for the patient to bring the subject up, fear of taking away hope, and finding the 'right' moment were barriers to such conversations taking place. On the other hand, there is also a barrier on the part of patients to discuss ACP with their physicians. Kahana, Dan, Kahana and Kercher (2004) interviewed 231 older adults, their GPs and family members, finding that family members were much more likely to report knowing about plans than were the GPs.

Health consumers also struggle with understanding medical jargon and have critical misconceptions of medical information (Porensky & Carpenter, 2008). Cross-cultural

language barriers add an extra layer of difficulty to this situation and the time constraints attached to health-related conversations compound the problem even further (Sudore et al., 2010; Liantonio, Liqouri, Lakhtman & Parks, 2017; Schickedanz et al., 2009). However, clear communication about medical matters is important as the quality of medical information given may affect health choices as well as patient-family communication. Research shows that patients with a poor understanding of their prognosis are less likely to discuss their preferences with family (Wagner, Riopelle, Steckart, Lorenz & Rosenfeld, 2010).

Finally, the coordination involved in promoting and implementing a cohesive ACP process across a complex health system form added systemic barriers. These can affect whether individuals are made aware of and can access quality services. Within this context, provider-related barriers include the lack of centralised access to ACP plans for seriously ill individuals receiving health services from multiple providers, as well as competing priorities among health providers and educators, and a lack of in-depth understanding of ACP by health professionals (Ahluwalia et al., 2015; Hagen et al., 2015).

In summary, the multiple challenges to the success implementation of a public health initiative such as ACP is daunting. There are communication and relational barriers both within the family and between health providers and the individual. There are also systemic barriers within the public health system, including a lack of effective communication to the public about ACP, its goals, and processes. Cultural factors compound these problems through differing value systems and language difficulties which can lead to discriminatory outcomes. These barriers lead to fear, avoidance, and a low uptake of ACP activities.

Barriers to ACP seem to outweigh motivators for engaging in the process. Yet, it appears that a window of opportunity for engagement widens as individuals age and their health deteriorates. Thus, it appears that the closer an individual comes to death, the more motivated they are to engage with ACP, especially if the person has a previous experience of someone else's demise. Willingness to engage in ACP behaviours as death becomes more

salient to the individual could be seen in Terror Management Theory terms as engaging in good health behaviours which reduce anxiety through regaining control over death. The motivation to complete a plan for EOLC is also bolstered by support from significant others or, in some cases, by the insistence of a significant other. However, even with the growing clarity around what motivates and hinders the use of ACP, acknowledging and responding to all these elements is an interesting challenge for the promotion of this type of healthcare process. How then, has ACP fared in New Zealand?

Introduction of Advance Care Planning into New Zealand

Advance Care Planning was formally introduced into New Zealand in 2010 following an Australian conference on the subject. The National Advance Care Planning Cooperative (NACPC, 2017a) was formed by a “national collective of passionate like-minded people tasked with driving a collaborative approach to the design and implementation of Advance Care Planning in New Zealand” (para. 1) with a vision that “All people in New Zealand will have access to comprehensive, structured and effective Advance Care Planning” (para.2).

In the same year that ACP was introduced and formally recognised in New Zealand (Harré, 2015), two other important public health documents were released. One was the New Zealand government’s *Statement of Intent for Health* which included a subsidiary goal to “implement a palliative care work plan to improve national consistency of palliative and end-of-life care” (MOH, 2010, p. 25). The other document was the *Whanau Ora: Report of the Taskforce on Whanau-Centred Initiatives* (Taskforce for Whānau-Centred Initiatives, 2010). This report pertained to Māori health and wellbeing.

The Whanau Ora report emphasised the collective nature of Māori culture and thus the importance of whanau or extended family health. It also acknowledged an ageing and mobile Māori population, the latter requiring an adaptive approach by service providers to meeting extended family needs. The report stated that Māori participation in New Zealand society is inhibited by “historic patterns of exclusion, gatekeepers who are selective, whanau

alienation from societal goals and values, and economic barriers that act as deterrents” (p.45). On the other hand, the report also said that positive participation is supported by affordability, services that include extended family in decision-making, and whanau leaders who actively engage with institutions and community. He Korowai Oranga, the current Māori Health Strategy, continues to affirm that the pathway to individual and family wellbeing is through Māori participation and the sharing of aspirations at all levels of society (MOH, 2014). These reports speak to the differing needs and limited access to healthcare resources by Māori.

Durie’s (2011) Māori model of health, Te Whare Tapa Whā, with its four cornerstones of health, that is, emotional (hinengaro), spiritual (wairua), physical (tinana) and family or social (whanau), supports the incorporation of Māori values into the mainstream public health domain by providing an accessible means for non-Māori to gain a basic understanding of holistic Māori health values (Warbrick, Dickson, Prince & Heke, 2016). Te Whare Tapa Whā is now embedded in the MOH’s principles and values. This is helping to counter the disproportionate way in which the individualistic New Zealand health system attends to some health markers while devaluing others (Warbrick et al., 2016). Interestingly, within a contemporary western context, Hamilton (2016) also talks about the four aspects of care as being psychological, spiritual, physical, and social, perhaps indicating the basis for a trans-cultural understanding of the elements of holistic health. Certainly, the fact that Storey and Sherwen (2013) propose that ACP should incorporate matters of social, psychological, and spiritual importance to the individual, as well as health, also attests to a movement away from the atomistic thinking characteristic of individualistic understandings.

The MOH, in its guide for the New Zealand Health Care Workforce (2011) acknowledged the importance of healthcare access by Māori through incorporating Te Whare Tapa Whā as its blueprint for understanding Māori health needs. This commitment has also seen a Māori model of ACP, He Waka Kakarauri, introduced in 2016 (Northland District

Health Board, n.d.). This model overlays the principles and aims of ACP onto the Māori worldview. It privileges the individual as the ‘kaihatau’ or leader of the ACP journey, supported by ‘kaihoe’ or rowers, which are the family and healthcare workers. It also acknowledges the importance of whanaungatanga, or relationships to the process.

Given the bi-cultural underpinnings and the polycultural realities of New Zealand society, the need to encourage ACP in culturally appropriate ways is an extra challenge for public health promotion. The Health Quality and Safety Commission New Zealand (HQSC), a government entity, has recently been tasked with embedding ACP more firmly into the healthcare landscape. This is a task not without its challenges.

Challenges for promoting ACP within New Zealand

Having a values-based approach is a necessary quality for ACP within the New Zealand context where an historic resource-sharing agreement, Te Tiriti O Waitangi (the Treaty) exists between the dominant, individualistic New Zealand European culture and the collectivist Māori sub-culture (Ministry for Culture and Heritage, 2017). The government’s commitment to the Treaty prescribes equality of rights and resources for Māori, including in the health domain. Thus, ACP as a healthcare process is required to reflect and respect both the dominant and Māori cultures equally. This means that, in practical terms, the government is tasked with ensuring the provision of health resources appropriate to each culture’s values-based needs. However, the fact that the dominant culture of New Zealand has a western value system which is prone to the issues of cultural subordination mentioned by Baydala et al. (2006) does not make equitable resource sharing a straightforward or transparent task.

This situation is made more complex by the wider-ranging polycultural nature of New Zealand. More recent immigrant cultures, of which there are many (Statistics NZ, 2015), are understood to be party to the Treaty through their acknowledgement of the indigenous rights of the Māori people. Each of these cultures also has their own ontology and concepts of appropriate health practices.

However, the degree to which cultural differences are really an issue remains uncertain. This is demonstrated in a New Zealand study by Podsiadlowski and Fox (2011) who tested the collectivist value orientations of New Zealand Europeans, Māori, Pacific-Islanders and Chinese. They found that New Zealand European and Māori are not at opposite ends of the individual-collective continuum, rather it appears that an extended period of living within the same sociocultural context may have lent itself to a mutual acculturation process, putting them closer together on the continuum than expected. In other words, the two ethnicities have been subject to the social constructionist forces of polyculturalism. Podsiadlowski and Fox also found that Pacific Islanders had the strongest sense of collectivism and Chinese and Māori were more closely aligned than expected.

There are then, kindred-cultures in New Zealand sharing similar worldviews, but this does not mean that they will have the same response to available health resources. For instance, although hospitalisation is often a function of the medicalisation of palliative care in New Zealand, it does not necessarily suit Māori who have different views of what constitutes a good death, preferring to be cared for by family at home (Gott et al., 2013; Johnston Taylor, Simmonds, Earp & Tibble, 2014). Yet, Chinese immigrants, as a substantial and growing subculture of New Zealand (SNZ, 2016), prefer hospital-based treatment at the end of life for a variety of reasons, including the fact that their country of origin does not have a well-developed primary care system and Chinese immigrants are therefore used to being treated in a hospital setting (Gott et al., 2013).

For ACP to be considered a universal tool, which is not a force for unwanted cultural assimilation, this myriad of ethnicities needs recognition of how a good death is understood within their diverse world views. This level of complexity challenges the promoters of ACP in New Zealand to explore its flexibility as a planning process, especially as ACP tries to find a purposeful home within a relatively homogenous national healthcare system. What then, have these challenges meant for the uptake of ACP within New Zealand?

Uptake of ACP in New Zealand

Recently, the Health Quality and Safety Commission New Zealand (HQSC) has taken the lead role in ACP oversight for the health sector with a five-year strategy to increase uptake (HQSC, n.d.). Their first report states that 1,500 health providers have already been trained in ACP interventions so far, but it also recommends a comprehensive agenda to strengthen the ACP process and improve uptake (Duckworth & Thompson, 2017). One of the suggestions is for more research to “create an evidence base” for ACP in New Zealand (Duckworth & Thompson, 2017, p. 5).

The limited research that has been carried out on uptake of ACP in New Zealand has had mixed results. Gott et al. (2013) in their survey of 99 acute care patients, found little evidence of discussions around end of life care and evidence of only one advance care plan. While Keon-Cohen, Myles and Story (2017) found that 37% of 290 New Zealand and Australian anaesthetists reported rarely or never treating patients who had completed an advance directive. However, Rainsford and Glasgow’s (2016) study into ACP uptake by 329 healthcare professionals in Australia and New Zealand found that 91% had undertaken an ACP activity, mostly in the form of a conversation with family or significant others. It is clear then, as highlighted also by the HQSC report, that there is a knowledge gap about uptake within the New Zealand context. It is hoped that this thesis will help fill that gap.

Research Focus

The literature review revealed limited research into the uptake of ACP in New Zealand as well as mixed results from the research that has been conducted. This study therefore aims to contribute to the understanding of ACP uptake in New Zealand by older adults. To date, within the New Zealand context, there has not been any targeted research on this topic with this age cohort.

There are three goals to this research leading to six research questions. The first goal is to report on the uptake of EOLC planning as demonstrated through documentation or

discussion with others. To this end, the research questions are: 1) What percentage of older adults in New Zealand report the use of a Living will? 2) What percentage of older adults in New Zealand report the use of an Enduring-Power-of-Attorney? 3) What percentage of older adults in New Zealand report the use of an Advance Care plan? 4) What percentage of older adults in New Zealand are talking with a specialist doctor, general practitioner, nurse practitioner, practice nurse, social worker, friend, spiritual advisor, family member or someone else about ACP matters?

The second goal of this study is to report on factors which the literature review indicated may influence uptake. The research question is: 5) What effect do gender, age, ethnicity, socioeconomic status, education, and general physical health have on the uptake of ACP?

The third goal is to provide context to the uptake of ACP in New Zealand by exploring the reasons for choices made with respect to planning for EOLC. The research question is: 6) What reasons do people give for their planning choices?

Chapter Two: Methodology and Method

This chapter provides an overview of the methodology and methods that were chosen for this study. It also includes the rationale for choosing a mixed-methods approach. In addition, reasons will be provided for using Thematic Analysis and a range of descriptive and correlational statistical analysis tools to explore the data collected. Finally, details of the research participants, methods used for data collection, and ethical considerations will be described.

The aim of this study is to make comment on the percentage of older New Zealanders planning for end of life care. This includes descriptive analysis and demographic correlations as well as discussion on the types of choices made and possible reasons for these choices. The research questions require an explanatory mixed-methods design as both numerical and text-based methods of data collection and analysis are included.

Methodology

Quantitative research.

For this study, the first five research questions have been proposed with a view to creating numerically-based knowledge and testing for correlational relationships. In other words, how many people have taken up ACP nationally and what demographic correlates exist. To create this type of knowledge a quantitative methodology has been chosen for its strengths in collecting and analysing numerical data with a view to using the results to describe, predict and explain the phenomenon of interest.

Qualitative research.

Qualitative research methods have been used to answer the final research question in this study which enquires into the context and cognitive reasoning for the choices made, relating the themes back to sociocultural and psychological influencing factors. This approach reflects the experiential nature of the data being collected, whereby awareness of the historical and sociocultural context is required to more fully understand the choices made and what meanings have been assigned to them by the participants (Crowe, Inder, & Porter, 2015). This emphasis on the contextualised validity of individual truths, is characteristic of qualitative research. Quantitative research methods, due to their two-dimensional nature, are unable to provide this type of rich, multi-factorial insight (Yates & Leggett, 2016).

Mixed methods.

The value in using a mixed-methodological approach is to add multiple layers of understanding, thereby enriching knowledge creation (Arcidiacono & De Gregorio, 2008). McGrath and Johnson (2003) reflect on this enhancement when they comment that the two approaches are problematic when used in isolation but complementary when used in conjunction. In other words, the use of a mixed-methods approach provides both a lens on the associations between experiences, as well as insight into the contextually situated meaning-making that is a product of these associations.

Method

This research project incorporates two separate but interlinked studies. The first study is quantitative in nature, with data collected through a survey sent to a representative sample of New Zealand residents. The results were analysed using statistical methods. The survey was then followed up by a qualitative study which collected data through semi-structured interviews with a small non-representative sub-sample of survey participants. Thematic Analysis was used to analyse the interview data.

Quantitative study.

The quantitative data was collected through the Health, Work and Retirement (HWR) longitudinal survey. It is administered by the Massey Health and Ageing and Retirement Team (HART) and was sent out for the first time in 2006 to a representative sample identified from the New Zealand electoral roll. Further surveys were conducted biennially. To ensure that the sample size remained representative, refresh cohort samples were obtained from the electoral roll with each iteration. The 2006 and 2016 iterations sampled heavily for Māori to ensure adequate representation within the data. This is due to older individuals from ethnic minorities having historically poor participation rates (Gorman, Scobie & Towers, 2012).

For all survey iterations, equal probability random sampling was used to identify potential participants from the New Zealand electoral roll. Approximately 98% of all eligible voters over 50 years of age appear on this roll. Refresh cohorts were added to existing participants using the same sampling method, and to obtain a representative sample, Dillman, Smythe and Christian's (2014) sample size calculation for population surveys was employed. Using the 2013 New Zealand census data and Dillman et al.'s formula it was calculated that, for the general population, a sample size of, $n = 1066$, and for Māori, a sample size of, $n = 1044$, were required to adequately represent the populations of interest. The current sample size exceeds that criterion.

For the 2016 iteration, survey forms were mailed to 7822 prospective participants with a 51.5% return rate of 4035 forms. Of that number, 6 responses were excluded due to a mismatch of already recorded demographic information with what the respondent had provided, for instance, substantially different dates of birth. In addition, one other respondent asked to withdraw, leading to a final sample size of $N = 4028$ for the quantitative part of this research project.

Participants.

Respondent ages ranged from 50 years to 89 years, with an average age of 65.5 years ($SD = 6.585$). Of those that completed the gender question, women numbered 2203 (54.7%), and men numbered 1745 (43.3%). Only two participants indicated they were gender diverse. As this number does not allow for useful analytical comment on this subgroup, the gender responses from these participants have been disregarded for the purposes of this study. Seventy-eight respondents (1.9%) did not answer the gender question. Participants were also asked which ethnicity they most identified with and 2981 (74%), identified as New Zealand European, 764 (19%) as Māori and 176 (4.4%) as other ethnicities including Pacific Islander, Indian and Chinese (107 cases, or 2.7% were missing).

In terms of work status, 1030 (25.6%) participants reported being in full-time work for an employer, 444 (11%) worked part-time for an employer, 456 (11.3%) were full-time or part-time self-employed, 779 (19.3%) were fully retired, 161 (4%) reported being unable to work for health reasons. Another 325 (8.1%) participants were unemployed, home-makers, engaged in project or flexible work, students, or did not specify their work status (833 cases or 20.7% were missing). Two thousand, five hundred and fifty-seven participants (63.5%) were married, 443 (11%) were divorced, 346 (8.5%) were widowed, 337 (8.4%) reported being in a civil union, 289 (7.2%) were single (56 cases or 1.4% were missing). Finally, education was reported on by the participants as 936 (23.2%) had no qualifications, 929

(23.1%) had secondary school qualifications, 1297 (32.2%) had a post-secondary certificate or diploma and 804 (20%) had a university degree (62 cases or 1.5% were missing).

Procedure.

An introductory letter, information sheet, 26-page survey booklet and reply-paid envelope were sent out to all, although the content was tailored differently for extant and refresh recipients, reflecting their level of existing knowledge about the survey. A postcard was sent 2 weeks later, thanking those who had responded and reminding those who had not. A further reminder was sent at the nine-week mark to those who had not responded and had not been noted as 'lost to contact'. Included in this reminder were a final reminder letter, information sheet, survey booklet and a reply-paid envelope. The survey booklet for new recipients included a tear-out page on which they could advise their contact details.

Ethics and funding.

The content and processes used for the original survey study were reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 15/72 and Southern A, Application – 15/73. Funding for the survey was provided by the Ministry of Business, Innovation and Employment (MAUX1403).

Materials and measures.

The questionnaire survey aims to inform public policy through the exploration of health, wealth and other psychosocial factors affecting the lives of older adults. Thus, the 113 survey questions covered health, wellbeing, and quality of life (44 questions); whanau, family, and friends (24); habitation (8); work and retirement (7); financial situation (10); and personal wellbeing (20). The data used for this current study came from two questions included in the survey pertaining directly to the uptake of ACP, as well as self-report measures of health and social economic status (SES). Other demographic questions included age, gender, education, and ethnicity. These questions allowed for the exploration of which

groups were more likely to take up ACP. The following describes the full range of variables used in this project, their origins, and psychometric properties where applicable.

Variables.

Questions about the completion of ACP documents were included on behalf of the Impact Team, a joint hospice and academic team with an interest in the national uptake of ACP in New Zealand. The survey participants were asked to indicate if they had completed the following, a living will, EPA or advance care plan. Alternative choices were also provided in the form of ‘none of these’ and ‘don’t know’. More than one option could be chosen.

A question about ACP discussions was also included on behalf of the Impact Team. The participants were asked to indicate if they had spoken to others about ACP matters in the 6 months prior to the survey. Eleven options were available: a specialist doctor, general practitioner, nurse practitioner, practice nurse, social worker, family member, enduring power of attorney or lawyer, friend, spiritual advisor, or someone else (unspecified). The options also included ‘I have not had a discussion about these matters during the last 6 months’. Again, these options represented categorical data with the possibility for the participant to choose more than one answer.

The physical health variable was operationalised using a general self-report health measure (GSRH) which required participants to say how they rated their general physical health on a five-point Likert Scale ranging from excellent to poor. This GSRH measure has strong validity and reliability that includes proving reproducible in test-retest trials (DeSalvo, Fisher, Tran, Bloser, Merrill & Peabody, 2006). It has also proven comparable with longer health measure instruments such as the 36-item Medical Outcomes Study Short Form (SF-36) in predicting mortality, hospitalization, and high outpatient use (DeSalvo, Fan, McDonnell & Fihn, 2005).

SES was measured by the Economic Living Standards Index - Short Form (ELSI-SF) which assesses the participants' economic standard of living as measured by material consumption and personal possessions. The six questions that make up the measure ask the participants to indicate whether they have access to items such as a personal computer and what activities they engage in, for instance, giving presents (four response options indicating yes/no and reason); what measures have been taken to keep costs down over last 12 months (three-point rating scale from Not at All to A Lot); self-reported assessments of standard of living (five-point Likert Scale from High to Low); satisfaction with the standard of living (five-point Likert Scale from Very Satisfied to Very Dissatisfied); and the participant's view of how well their income meets their needs (four-point Likert Scale from Not Enough to More than Enough). The ELSI-SF is an additive measure where a higher score means a higher standard of living. It was developed specifically for the New Zealand context, has a high level of reliability (coefficient alpha = .88) and correlates highly with the full ELSI measure (Jensen, Spittal & Krishnan, 2005).

The gender variable was presented to survey respondents as a choice between female, male, or gender diverse with a request to specify if the latter. The three participants who responded as being gender diverse were recorded as missing for this variable. For coding and analysis purposes, males = 1, and females = 2.

With respect to age, the survey requests the participant's date of birth, which was translated into age in years for analysis purposes.

The participants' level of education was ascertained by asking for their highest level of education. The four options ranged from No Qualifications to University Degree.

For the ethnicity questions, participants were given eight options: NZ European, Māori, a range of Pacific Island ethnicities, Chinese and Indian. An 'other' option was also available with a request to specify. Given the minimal response to non-Māori choices other

than New Zealand European, these data were collapsed to represent two sub-categories, non-Māori = 1 and Māori = 2.

Analysis.

The survey data was analysed using SPSS statistical software. The analytical tests used were frequency, in the form of percentages and bivariate correlations using a two-tailed Pearson product-moment correlation test. For the purposes of this study, .10 to .20 is considered a weak correlation .30 to .50 is a moderate correlation and over .50 is strong.

Binary logistic regression analysis was also carried out with respect to the completion of an advance care plan which is the main variable of interest for this study. A logistic regression model was chosen because the dependent variable is dichotomous and therefore does not easily meet the stricter statistical assumptions, such as linearity and normality, required by other forms of regression such as linear regression (Peng, Lee & Ingersoll, 2010). For this analysis, the independent variables include the demographic characteristics and self-reported behaviours of the sample population, while the dependent variable is operationalised as Yes or No to the uptake of an advance care plan. This analytical method is both descriptive and inferential, in that it describes the data and explains relationships between variables. Logistic regression was also chosen for its prediction function, the outcome of which it is hoped will be useful as an aid to informing future public health choices. It was also chosen for its suitability for use with categorical or numerically-based independent variables in conjunction with a dichotomous dependent variable (Agresti & Kateri, 2011).

Qualitative study.

Qualitative methodologies use descriptive and interpretative tools to explore non-numerical data. For this research project, Thematic Analysis was used to explore the data collected through individual interviews. This type of analysis identifies, analyses, describes, and reports on patterns (themes) in data (Braun & Clarke, 2006). A semi-structured interview format was adopted to allow for deeper exploration of themes as they arose in conversation.

Historically, Thematic Analysis has been questioned with respect to its loose theoretical underpinnings. Braun & Clarke (2013) acknowledge this criticism but make the point that this same characteristic also allows Thematic Analysis to be used in a flexible fashion across theories and epistemologies, to organise and explore data in a meaningful fashion.

Participants.

Nine people (aged 58 years and over) took part in the qualitative interviews. Six of the interviewees were female and three were male. Eight were living with their spouse and a ninth lived alone. Table 1 shows the participants, gender, age, and ethnicity. Pseudonyms are used for confidentiality reasons.

Table 1

Characteristics of Interview Participants

Participants	Gender	Age (years)	Ethnicity
Alice	Female	67	NZ European
Barbara	Female	85	NZ European
Connie	Female	66	Cook Island Māori
Dave	Male	82	NZ European
Evalyn	Female	76	NZ European
Felicity	Female	65	NZ European
Gerry	Male	66	NZ European
Harold	Male	67	NZ European
Ina	Female	58	NZ European

Procedure.

The 2016 Health, Work and Retirement participant database was filtered for those who had indicated in an earlier survey iteration their willingness to be involved in further interview research. The resulting list was filtered again for geographic location close to where

the researcher lives. A covering letter and information sheet (See Appendix A) was mailed to prospective participants by the HART team advising of the project parameters and inviting interested persons to complete a contact request form and return it in the reply-paid envelope provided. Email addresses for the researcher and thesis supervisors were also provided as was an 0800 number if the recipients had any questions prior to or during involvement. A total of 16 letters were sent with 10 requests-for-contact returned.

All respondents, except one, were then contacted by phone to discuss any questions they may have had about the project. In one case a respondent remained uncontactable and was therefore excluded from the potential sample. All those contacted agreed to take part and the researcher arranged a suitable date and time to visit. As it is important for interviewees to feel comfortable with the surroundings when being interviewed (Braun & Clark, 2013), the information sheet offered the recipient a choice of interview venues, home, or an alternative community setting. This was discussed again during the phone call. All participants opted to be interviewed in their own home. For safety reasons, the researcher told her spouse of the interview timetable and checked in following each interview. At interview, the researcher gave each participant a box of chocolates to thank them for their participation and hospitality.

The interviews lasted between 40 and 65 minutes. At the beginning of each interview the researcher reiterated the purpose, scope and voluntary nature of the project and discussed data collection, dissemination, and confidentiality. The researcher responded to questions as they arose. Following this discussion, a consent form (See Appendix B) was signed by the participants. The subsequent semi-structured interviews were recorded with a series of pre-identified questions (See Appendix C) used as prompts where necessary. The semi-structured interview format is particularly useful for Thematic Analysis due to its flexibility in allowing inductive probing (Guest, MacQueen & Namey, 2012).

After the interview, the researcher asked the participants whether they felt any distress about discussing end-of-life care as it pertained to themselves or significant others. The

researcher offered the opportunity to debrief about the subject, as well as giving extra information about ACP. None of the participants showed feelings of distress or needed further information about any concerns they may have regarding personal health issues.

The recorded interviews were transcribed by the researcher with reference to Braun and Clarke's (2013) guidelines for transcription. Names were replaced with pseudonyms and other identifying details were assigned anonymous alternatives. The written transcript was returned to each participant with a covering letter (See Appendix D) requesting their review and any further comments they would like to make. Included also, was a permission form (See Appendix E) for participants to return agreeing to the use of their transcripts for the purposes of this research project. A follow up phone call was made to each participant to ask if they had any further questions or concerns about the interview or transcript. No concerns were raised. The recordings were erased following transcription. Following the completion of the thesis, a summary of findings was sent to each participant for their information.

Ethics and Funding.

Funding for this study was received from Massey University's Postgraduate Research Fund.

The four Principles stated in the New Zealand Psychologists Board Code of Ethics (New Zealand Psychologists Board, 2008) guided the researcher's design choices and prior to beginning the research process, an ethics application outlining the study design was lodged with the Massey University Ethics Committee. Given New Zealand's bicultural commitment and polycultural population, respect for cultural diversity was of particular concern. To this end, two Māori advisors were asked to review the details of the project including the content of the interview questions. They also gave advice on how to approach the interview and data collection in a culturally appropriate way and remained available to the researcher for questions during the remaining phases of the project. However, no participants self-identified as Māori and only one participant self-identified as coming from the Pacific Islands. This

person chose not to have a support person present, as offered in the Information Sheet. They also expressed their ease in discussing the subject with the interviewer and did not identify any concerns after the interview.

In addition to cultural considerations, the project topic was considered to have the potential to cause discomfort or psychological harm to the participants. To address possible harm issues, an explanation of the topic was included in the information sheet sent out to all potential participants. The information sheet left further contact to the recipients to initiate. This gave them the opportunity to opt into the project if they felt comfortable with the subject and the process. Participants were also invited to have a support person present. The voluntary nature of participating was reiterated prior to the interview and the researcher watched carefully for signs of distress during the interview itself. The researcher checked how the participant was feeling after the interview and then again in a phone call after the transcripts were sent to the participants.

A further ethical concern was identified with respect to approaching earlier survey recipients. Given the older age range of the recipients, the concern was that some may have been deceased and an approach about research participation could prove distressing to the family. This concern was managed by HART's removal of deceased participants as they came to notice, including through proactively checking the New Zealand register of deaths. In addition, an 0800 number was provided for the family of any deceased persons who may still have received the invitation to take part, to make contact and discuss any distress with the survey team leaders.

Another concern was maintaining confidentiality with the secondary use of survey information. In this case, for the quantitative study, all identifying details were removed by HART before the survey data for the total population was given to the researcher. While for the qualitative study, HART approached the potential participants identified from the survey, by sending out a covering letter with the information sheet and request-for-contact form and

only provided the researcher with the information given by the participants on the returned form. In most cases this was the name and telephone number. The researcher then asked the participants directly for other personal details, for instance, their address and if they were happy for the interview to be conducted in their home.

Following the Ethics Committee review of the parameters and processes, the project was granted full approval by the Massey University Human Ethics Committee: Southern A, Application 17/24.

Materials and methods.

A face-to-face, semi-structured interview was chosen for this study. Interviews are useful for exploring experiences, perceptions and understandings, and within the range of interview types, the semi-structured interview is the most common form in qualitative research (Braun & Clarke, 2013). Semi-structured interviews use guiding questions as prompts to keep the interview 'on topic' while also giving the interviewer an opportunity to explore aspects of the topic in more depth as needed. This type of interview also lends itself to rearranging the initial questions in acknowledgement that they may be answered as part of a participant's response to a different question. Completing the interview face-to-face also allows for the accessing of rich, detailed data and it is ideal for encouraging participants to talk about sensitive subjects (Braun & Clarke, 2013). However, one potential issue with interviews is their time-consuming nature. Thus, for this research project, the potential participants were advised in the Information Sheet of the maximum time that the interview would be expected to take. This allowed them to choose whether to accept that time commitment before they agreed to be included.

The semi-structured interview schedule for this study was made up of 14 questions covering factual items such as whether the participants had completed certain ACP documents, for instance a will. Other questions were value-based such as how the participants felt about the idea of ACP and why they made choices to take part or not in ACP

activities. Because the latter type of question required the participants to think more deeply about their values and motivations, the semi-structured interview process allowed the interviewer to use exploratory questions to aid this cognitive process.

Analysis.

Thematic Analysis was used to explore the interview data. The analytical process began at the time of interview with the interviewer informally noting similar themes expressed by the participants. Following the interviews, the transcripts were read several times for familiarisation, with the content being initially coded into 20 broad categories. These categories were refined further into the final seven over-arching themes reported on in this thesis. Judgement over whether a theme was salient enough to be included was based on three criteria: 1) the relevance to fundamental issues underpinning the topic, such as the theme of Self-Determination as being salient to the originating principles of ACP 2) the prevalence of discussion by the interviewees about a particular theme, for example, the often mentioned influence of previous experiences on the participants' future planning and 3) the importance that the interviewees themselves appeared to assign to a sub-theme also prompted inclusion of their thoughts and feelings as part of a larger theme. A powerful wish to die rather than be a burden on loved ones is illustrative of this.

Finally, as the project is made up of two distinct studies using different methodologies and methods, the results will be presented separately before discussing the connections between the two.

Chapter Three: Results

Quantitative Results

Analysis of the Health, Work and Retirement Survey data yielded the following results with respect to the quantitative research questions asked.

Questions 1-3. Completion of a Living will, an EPA or an Advance Care Plan?

Table 2 shows the percentage of participants who completed each type of document.

Table 2

Planning Documents (N = 3962)

Variable	Percentage
Living will	6.99%
Enduring Power of Attorney	29.27%
Advance Care Plan	3.98%

Note. A small number of participants (1.57%) did not know if they had completed a document. A further 66 participants (1.63%) did not choose any option and are considered missing for analysis purposes. Twenty six percent of the participants completed a single document, while 5.6% completed two documents and 0.9% had completed three documents.

Question 4. Discussion with others about ACP matters?

Survey participants were also asked to state who they had discussed end-of-life matters with in the previous six months. Table 3 shows the percentage of participants who reported speaking to each type of person.

Table 3

Discussions about ACP Matters (N = 3942)

Person spoken to	Percentage
Family Member	36.91%
Friend	12.25%
Lawyer or EPA Representative	7.28%
General Practitioner	2.36%
Specialist Doctor	1.29%
Spiritual Advisor	1.14%
Nurse Practitioner	0.66%
Practice Nurse	0.48%
Social Worker	0.43%
Someone Else	2.49%
No discussion	58.17%

Note. Eighty-six participants did not choose any option and are therefore considered missing for analysis purposes.

Some participants state that they had discussed matters with more than one person as shown in Table 4.

Table 4

Number of Discussion Options Chosen (N = 3942)

Number Chosen	Percentage
One Option	24.7%
Two Options	11.5%
Three Options	3.6%
Four Options	.9%
Five Options	.1%

Question 5. The Effect of Demographic Variables on ACP Uptake

This question refers to the effect that gender, age, ethnicity, socioeconomic status, education and general physical health have on the uptake of ACP. Bivariate Correlation analysis was carried out for all variables. See Table 5 for results.

Table 5

Bivariate Correlations between Demographic Factors and ACP completion

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22
<u>Documents completed</u>																						
1 Living will	1																					
2 EPA	.24**	1																				
3 ACP	.16**	.15**	1																			
<u>Discussions with</u>																						
4 Specialist Doctor	.048**	.03*	.06**	1																		
5 GP	.08**	.06**	.09**	.44**	1																	
6 Nurse Practitioner	.003	-.003	.03*	.35**	.34**	1																
7 Practice Nurse	.02	-.004	.04**	.35**	.30**	.31**	1															
8 Social Worker	.03	.01	.09**	.20**	.12**	.19**	.16**	1														
9 Family Member	.09**	.10**	.09**	.07**	.12**	.06**	.02	.04*	1													
10 Holder of EPA or lawyer	.19**	.34**	.15**	.09**	.11**	.06**	.02	.03	.26**	1												
11 Friend	.07**	.05**	.04*	.09**	.11**	.04*	.05**	.06**	.35**	.14**	1											
12 Spiritual Advisor	.04*	.02	.10**	.14**	.13**	.12**	.10**	.14**	.13**	.06**	.18**	1										
13 Someone else	.04*	.01	.06**	.03	.05**	.03	.01	.04*	.09**	.08**	.14**	.09**	1									
<u>Demographic Factors</u>																						
14 Age	.09**	.27**	.05**	-.004	.07**	-.02	.01	.02	.08**	.15**	-.02	.03	.03*	1								
15 SES	-.01	.004	.001	.02	.003	.01	.02	.002	.003	-.01	.002	.004	.01	-.003	1							
16 No Qualification	-.01	-.04**	.01	.03	.004	.01	.01	.02	-.01	.01	-.03	-.002	-.01	.11**	-.01	1						
17 Secondary Qualification	-.01	-.01	-.003	.01	.02	.01	-.004	.001	-.001	.02	.02	-.01	-.01	-.02	.002	-.31**	1					
18 All Tertiary	.02	.04**	-.01	-.03	-.02	-.01	-.01	-.02	.01	-.03	.01	.01	.01	-.08**	.01	-.59**	-.59**	1				
19 University Degree	.04*	.01	-.03	-.004	.01	.02	.01	.01	-.02	-.03	.01	.01	.01	-.07**	.001	-.28**	-.28**	.48**	1			
20 Ethnicity	-.003	-.13**	.06**	.05**	.05**	.01	.03	.09**	.09**	-.01	.03*	.05**	.05**	-.05**	-.01	.18**	-.01	.14**	-.07**	1		
21 Gender	-.01	-.04**	-.05**	-.04*	-.05**	-.04*	-.01	-.02	-.16**	-.06**	-.07**	-.04*	-.06**	-.04*	.01	.01	-.02	.01	.01	-.01	1	
22 Health	-.02	-.04**	.06**	.10**	.10**	.05**	.03*	.06**	.08**	.02	.03	.02	.03	.05**	.02	.14**	.04*	-.15**	-.14**	.13**	-.03	1

Note. **. Correlation is significant at the 0.01 level (2-tailed) and *. Correlation is significant at the 0.05 level (2-tailed).

Demographic factors are both positively and negatively correlated with planning activities. The results show a weak but significant positive correlation between age and completion of an EPA, ($r = .27, p < .01$) as well as a weak positive correlation between age and discussions with a holder of an EPA or lawyer, ($r = .15, p < .01$). A negative correlation exists between ethnicity and EPA completion ($r = -.13, p < .01$). There are also weak positive correlations between physical health and discussion of ACP matters with a specialist doctor ($r = .10, p < .01$) or a general practitioner ($r = .10, p < .01$). Gender correlates negatively but weakly with discussions with a family member ($r = -.156, p < .01$).

There are also correlations within the range of ACP activities. Weak to moderate correlations exist between discussions with different health professionals, for instance, GPs and specialist doctors ($r = .44, p < .01$). Weak to moderate correlations also exist between discussions with GPs and family members, ($r = .12, p < .01$), GPs and holders of an EPA or lawyers ($r = .11, p < .01$), GPs and friends, ($r = .11, p < .01$) and finally, GPs and spiritual advisors ($r = .13, p < .01$). In addition, discussion with a spiritual advisor has a weak correlation in relation to a number of other discussion variables. The strongest of these correlations was with discussion with a friend ($r = .18, p < .01$). A weak, positive correlation also exists between discussion with a family member and completion of an EPA ($r = .10, p < .01$). Discussions with either holders of an EPA or lawyer has a weak or moderate correlation with completion of all types of planning documents, although the most significant is between holders of an EPA or lawyers and completion of EPA documents ($r = .34, p = .01$). There are also weak correlations between discussions with the holder of an EPA or lawyer and discussions with a family member ($r = .26, p < .01$) or a friend ($r = .14, p < .01$). In addition, there is a moderate correlation between discussions with a friend and discussions with a family member ($r = .35, p < .01$). Finally, there are weak correlations between the three different types of planning documents, for example, an advance care plan and EPA ($r = .15, p < .01$).

As the correlation analysis identified a number of variables with statistical significance at either the $p < .05$ or $p < .01$ levels, a binary logistic regression analysis was run to explore the predictive power of these variables with respect to advance care plan completion (see Table 6); There were 3823 cases included in the logistic analysis with a further 205 cases designated as missing.

The baseline classification table, with only the constant included, showed 96.2% of cases as correct, yet, the classification table with all variables included also showed 96.2% of cases as correct, indicating that the model adds minimal explanation for variance in ACP uptake. However, a Likelihood Ratio Test indicates $p < .01$, confirming that inclusion of the covariates into the model does significantly increase predictive power over and above that of the null model. The Cox and Snell R^2 and Nagelkerke R^2 tests reveal that between 5% and 17% of variance is explained by this model.

Table 6

Logistic Regression of Variables for Completion of an Advance Care Plan

	B	S.E.	Wald	df	Sig.	Exp(B)
<u>Document Completed</u>						
Living will	1.14	.22	26.38	1	.001**	3.12
EPA	1.32	.21	39.56	1	.001**	3.75
<u>Discussion With</u>						
Specialist Doctor	-.41	.62	.43	1	.51	.67
GP	.76	.41	3.37	1	.07	2.13
Nurse Practitioner	-1.13	1.28	.78	1	.38	.32
Practice Nurse	.81	.99	.66	1	.42	2.25
Social Worker	.95	.77	1.53	1	.22	2.58
Family Member	.31	.20	2.39	1	.12	1.37
Holder of EPA or lawyer	.51	.25	4.20	1	.04*	1.67
Friend	-.33	.27	1.44	1	.23	.72
Spiritual Advisor	1.31	.50	6.94	1	.01*	3.70
Someone else	.65	.40	2.69	1	.10	1.91
<u>Demographic Factors</u>						
Health Status	.34	.10	12.33	1	.001**	1.41
Age	-.02	.01	1.16	1	.28	.99
Ethnicity	.72	.20	12.46	1	.001**	2.05
Gender	-.32	.18	3.04	1	.08	.73
Constant	-4.56	.99	21.16	1	.001**	.01

Note. **. Correlation is significant at the 0.01 level (2-tailed) and *. Correlation is significant at the 0.05 level (2-tailed).

Logistic regression shows that completing other planning documents, having discussions with specific other individuals and having particular demographic characteristics are variables that contribute to the prediction of advance care plan completion. Specifically, those completing a living will are much more likely to complete an advance care plan (OR = 3.12, $p < .01$) than those who have not completed a living will. Having an EPA makes it 3.75 times as likely that a plan is completed ($p < .01$). A discussion with the holder of an EPA or lawyer makes it almost twice as likely (OR = 1.67, $p < .05$) while talking with a spiritual advisor means plan completion is 3.70 times more likely to occur ($p < .01$). With respect to demographic factors, a one unit decrease in self-reported health status, for instance, from excellent to very good, or fair to poor, means an advance care plan is 1.41 times more likely to be completed ($p < .01$). Finally, individuals identifying as non-Māori are twice as likely to complete a plan (OR = 2.05, $p < .01$) than those identifying as Māori.

Qualitative Results

Seven major themes emerged from the analysis of the transcripts. The themes are: 1) Understandings and Attitudes 2) Planning in Practice 3) Too Healthy to Plan 4) Self Determination 5) Being a Burden 6) Who to Include and 7) Previous Experiences-Imagined Futures. This chapter describes these themes and illustrates them with examples.

Understandings and attitudes.

Most participants did not have a clear understanding of the term ‘Advance Care Planning’ although some of the components were known and considered useful. Five of the interviewees were not familiar with the term, other than it being the topic of the interview. Three interviewees had heard of the term but did not have more than a very limited understanding of the concept. Only one person could articulate the concept behind ACP, in that it was planning for a time when a person was not able to decide for themselves. *“When I’m not able anymore to make my own*

decisions and things like that I suppose. Or perhaps do you mean whether I'm going to want to go into care or something like that is it?" This was Barbara, who had started to complete her own advance care planning template.

However, when the components of ACP were explained further, the legal aspects proved familiar to the interviewees, for instance, six participants knew about the EPA concept. When asked where this knowledge of the ACP components had come from, most answers were in the vein of *"I don't know"* or *"we just knew that you needed to do that"* or *"these are the things that we went through with our parents too"*.

Barbara gave one of the clearest explanations for how she found out about the EPA stating that, *"She (daughter) had a friend who worked in law, and something came up. It wasn't talked about so much then, it must be getting on for twenty years ago or more, I have got it there, but its along time ago"*. Barbara also illustrated the variety of ways in which people gain information from their environment and apply it to their personal situation. *"It's probably everything really, the fact that I've been involved with rest homes, that the legal side of it has been pointed out, the talks I've heard, altogether, I could see the value in having, well, I have seen situations where people haven't done anything, I know that things can arise that make it quite difficult"*.

All nine participants expressed positive views about the concept of ACP and thought it would be valuable for themselves and others across a range of diagnoses such as cancer, stroke, and dementia. One person also saw ACP as useful in the aftermath of an accident. Comments about the usefulness of ACP ranged from, *"quite a good idea"*, *"a great idea"* to *"essential"*. Eight of the interviewees considered it to be helpful to families, for example, in making wishes known, minimising conflict, and supporting a family member's authority when dealing with health professionals. However, only three mentioned ACP in terms of it being helpful for their personal wellbeing, for example, through relieving themselves of responsibility by passing it on to another member of the family.

Connie talked about the usefulness of ACP as a vehicle for making wishes known and minimising conflict within the family. *"So, they will know what to do, and you know what your*

wishes are, and they don't argue, and one will say 'No, we do this' and the other one will say 'No, we do that'. So, there's that pulling in there, which you don't want that to happen to your family, but if you put something in place ... then everybody knows what to do, so there's no pulling”.

Dave spoke of personal wellbeing as being an ACP outcome, “Yes we discussed it and she (wife) said 'We're getting on in age. We're not getting any younger.' At the moment we are no problem, but she has Parkinson's and she is gradually deteriorating and eventually one day it's going to get to the stage there where we won't be able to handle it. I've only got to have a stroke or something like that and there we are, we'll have to go into care and then of course you've got all your goods and chattels. Dave went onto talk about the transfer of responsibilities to his children, “So to make it easier we said, 'right oh, that's the power of attorney for the kids and it's up to them, if anything happened to us and we had to go into care”.

Clearly, while the umbrella term ‘Advance Care Planning’ was not familiar to most participants, some of the components that make up ACP were well known. In addition, once they understood the ACP model, the participants could see its usefulness in planning for EOLC. However, having knowledge of a concept and its components does not necessarily mean that it is put into use, even if it is viewed positively.

Planning in practice.

The interviews revealed that planning was happening in some form, although not necessarily in the comprehensive manner encouraged by the ACP model. Eight of the nine interviewees had carried out both formal and informal planning to varying degrees. Informal planning was sometimes a precursor to formal action. For instance, Connie and Barbara talked of informal discussions with family that would eventually lead to more formal actions, such as completing an EOLC document. Two of the three male participants said that they had not thought about planning much, albeit one had discussed with his wife about staying in their home as long as possible. The other participant had faced several life-threatening illnesses but did not feel it was time to thinking about planning yet. Finally, only two participants had thought of using a planning template to help thinking, discussion and decision-making.

Formal planning centred on the completion of letters to family, legal documents, and financial planning. Two participants had committed their wishes to writing through letters to their children, although one had embargoed her letter, *“now don't open this until you have to”* and the other was not planning on giving it to her children immediately, *“in another four or five years' time maybe if we're still plodding along and everything's just the same, we might put them in the know then”*. Four participants had completed EPAs. None had completed a living will. Three interviewees also mentioned financial planning as an important aspect of preparing for the end-stage of life. Having enough money to cover what they considered important brought these participants some peace of mind. For Ina, financial planning would prolong her independence, while for Felicity, having the money to buy nutritious food to prolong good health and stave off death was a priority. Connie just wanted to make sure there was enough money for her funeral.

Informal planning was also common, with interviewees thinking in a values-based manner about what was important to them and developing these thoughts through discussion with others. Seven participants talked of informal discussions with family and friends where the outcome had not yet been committed to writing. These conversations included talking to the children about getting old and needing care; having ‘deep’ discussions about end-of-life matters with close friends; and conversations with their spouses about an EPA.

When the subject of a living will in the form of a do-not-resuscitate order arose, Ina said, *“Yeah, we're both very aware that neither of us would want to be resuscitated to a vegetative state, that when our number's up we're happy to go and the other one is, not necessarily happy, but prepared to let them go, to let them have their say in their life ((pause)) so we're fully aware of what each other wants in that respect, but we don't have it legally binding.”* Ina explained the reason for not formalising her wishes in writing as being, *“we haven't had the discussion with the children yet, because they're all young and they've got kids and you don't want them to think you're worrying about it, and we're not, we're just feel we're being realistic, you know.”* As in Ina's case, these types of conversations may signal the completion of more formalised planning initiatives in the future. Five other interviewees indicated also that they were partway through

their planning process, having identified actions still to be completed. These included setting up EPAs as well as informing adult children of decisions made.

Participants talked of these conversations occurring because of a range of triggers. The triggers included television programmes, previous experiences, and prompting by legal professionals such as the Public Trust. None talked of being prompted by a health professional. It appeared therefore, that many participants were engaging in planning in an ad hoc, reactive manner rather than in a proactive, systematic way.

While eight interviewees had completed both informal and formal planning only two participants talked of using a template as an aid to decision-making. Barbara, aged 85, had already completed an EPA but was also completing an advance care planning template downloaded from the internet. When asked, she could not say how she had found out about it. Felicity aged 65 years was prompted to create a template for others following “*a bit of a (health) scare*” of her own. She was not aware that advance care planning templates already existed. Given that templates are an important document for ACP, the fact that they were not used, underlined the participants’ lack of knowledge about the concept.

In conclusion, planning for EOLC was common to almost all participants, with some having already completed legal forms of planning. Ad hoc values-based conversations were also commonplace. Systematic planning with use of a template happened infrequently and discussion with a health professional tasked with ACP interventions appears not to have happened at all, even when participants had been hospitalised with the type of illnesses that are considered particularly suitable for ACP discussions. ACP therefore, was an incomplete activity for most participants. Of the nine participants, only Evalyn felt that she had completed her planning. She had combined in-depth family discussion with completion of an EPA, as well as having written a letter to her children about her wishes. In addition, she had moved into a retirement village with hospital and care facilities. When asked what was left to do, she replied, “*The only things there are sorting out photo albums. No, they've not important or anything. No, I think we've sort of covered, done a lot of that, they (children) know it all*”. In other words, unlike the other participants, Evalyn felt that

she had exercised all the future choices available to her, displaying a rare peace-of-mind that planning was complete.

Self-determination.

It was clear that, having a sense of autonomy over EOLC decisions was important to all nine interviewees. To a great degree, this wish for self-determination appeared to be intrinsically motivated. However, the level of self-determination was tempered in all cases by a wish to discuss possibilities and decisions with others, and in some cases, to seek family agreement as part of the decision-making process.

All participants expressed a wish for self-determination in some form. It was envisaged similarly by many of the participants, as expressing their wishes to family who in turn would treat their wishes with respect and carry them out if possible. On the surface, this appeared to be intrinsically motivated as none spoke of outside pressure from others. Alice put it thus, *“what you would like or what you prefer, how you would like to be treated, or if you would like to be put into care, if that's your choice”*.

All participants had already, or were intending to, speak with others about their potential choices, with three participants expecting possible conflict with family members over their wishes. Some participants reflected these potential disagreements as a fight for self-determination. Harold said, *“...and the thing is the family then has got to come to an agreement, whether they agree or not, if its ultimately your wishes then surely that's what they should adhere to”*. For others though, family discussion was a well-practiced, peaceful process for working through options and making major decisions.

Despite family discussions being a normal part of the decision-making process for some, there were still indications of a wish for self-determination without influence from others. For instance, although Evalyn welcomed her family's influence on major decisions such as where she lived, *“we'd talk to them (the children), the three of us, four of us would get together, decisions would come from there”*, she had still written down her personal wishes for EOLC, and given her

children a copy that was not to be opened until necessary. In this way, Evalyn avoided discussion and influence by her family about certain aspects of what she wanted.

On the other hand, the need for agreement also appeared to be an acknowledgement of the limitations of self-determination through the passing of power over ‘person’ and ‘property’ to someone else. Ina described it this way, “*you put someone in charge of yourself*”. As a reflection of the importance of this passing over of personal power, participants talked of valuing personal characteristics such as ‘level-headedness and ‘capability’ in those they had chosen to take on some form of responsibility.

In summary, as all participants had spoken, or intended to speak to family and friends about their wishes, the degree of intrinsically-motivated self-determination rested on the influence participants were open to when making their decisions. There was a wish by most participants, for these discussions to result in the unreserved validation of the participant’s wishes. This indicates a process that may need some level of negotiation and compromise. Only one participant voiced that respect for her wishes without validation of her values was an acceptable outcome. These results show that the incorporation of significant others in planning is a critical aspect for a successful ACP process. However, what concerned many interviewees as much as getting family agreement for their plans, was a strong preference not to be a burden.

Being a burden.

Many of the participants’ planning choices were coloured by a wish not to be a burden to others and all participants illustrated a wish for self-determination through their financial and lifestyle choices. Being a burden was expressed by participants in both psychological as well as physical terms and many talked of remaining independent with respect to their activities of daily living. Six participants, five female and one male, expressed the wish that family members not be burdened with caring for them.

The psychological burdens spoken of by the participants included the need for others to make decisions on their behalf as well as the possibility of arousing guilt, worry and distress in others. Gerry felt that it would burden others in the family to have to make decisions on his

behalf if he had not expressed his wishes in advance. Alice agreed, saying that planning in advance “*takes the worry away from the kids. No, we won't put that onto the kids, unless we have to*”.

On the other hand, Connie, an immigrant from the Pacific Islands, felt guilty about not caring physically for her dying father who lived in the Islands. She planned to ensure that her children did not feel the same about their actions should she fall ill, even though they may live in closer proximity to her. She spoke of not wishing to burden her family with the guilt of caring for her to the degree expected by her family’s cultural values, mentioning residential care as a possibility for herself. However, at the same time, she worried about the financial burden residential care might create for her children. As an immigrant, Connie appeared caught in an acculturation process, where geographic distance from her homeland meant a need to accept a change in values, but not enough time had passed to allow a comfortable shift away from the social norms of her Pacific Island background.

The burden of physical dependency raised even stronger feelings in some of the participants. Three participants talked with passion about the wish not be physically dependent on others. Ina and Felicity talked about ending their lives if this occurred, while Alice stated, “*I don't want to have someone live my life for me, and what I mean by that is I don't want to have someone come and knock on the door each morning and shower me and feed me and dress me. I would rather go into care. I know what will happen there, but I don't want that burden to fall onto (husband)*”.

However, the altruism expressed in the wish not to burden others was matched by a more ego-centric wish expressed by some participants not to burden themselves with experiencing life as a minimally-functioning human being. Barbara and Ina expressed the fear behind this wish. Barbara said, “*It'd be hard to be in the situation where I can't express what I want, and I hadn't told my family or done anything about it*” while Ina said that she “*would rather go out in a blaze of glory tomorrow than be 95 and I can't see, and I can't talk, and I say anything.*” This contrast between motivations was illustrated by Felicity and Ina who discussed ending their lives. Ina

talked about this choice as a way not to burden her family with her dependency while Felicity talked of it as a solution to the personal distress of being totally dependent on others.

To summarise, the thought of being a burden on family motivated interviewees to plan for alternative endings such as euthanasia or residential care. They also planned to absolve significant others of any guilt for these outcomes through expressing their preferences in advance. This wish not to be a burden reflected the individualistic value of taking responsibility for self so that others do not have to. There was also some sign of conflicting values caused through the process of immigration. Negotiating conflicting cultural values is a major challenge that the developers and promoters of ACP face. Of course, no matter what type of care is planned for, the fact that the end-stage of life may include a need for participants to be cared for physically by others adds, another level of importance to making decisions about who to involve in the planning and who should have decision-making power.

Who to include.

For all participants, planning for EOLC was understood as a shared experience, with family being the co-planners of choice in most cases. There were several reasons given for who was included, with the quality of the relationship and the character of the chosen recipient being considered particularly important.

All nine interviewees identified discussions with family and friends as part of previous or future planning. Of the eight participants with living spouses, six had discussed the future with the spouse; four had also involved their children; two had talked with friends; one spoke of a discussion with siblings; while another expected her siblings to be involved in caring for her should she need it although this had not been discussed. The widowed participant had talked with one of her children.

The level of discussion ranged from general conversations about what may happen in the future to more focussed conversations, such as those leading to the completion of EPAs. Discussions were inclined to be less focussed with friends and more focussed with family. Adult children tended to be brought into the conversation when concrete decisions needed to be

finalised, for example, an EPA was to be drawn up or an important lifestyle change was being considered. Professionals such as solicitors and an accountant were consulted on legal and financial planning matters and in two cases, professionals had triggered financial and legal activity with respect to EOLC planning. However, only one participant, Dave, suggested that he might talk to a health professional, in this case his GP, as part of his ongoing planning process. Dave considered his GP to be ‘knowledgeable’ and ‘approachable’, with a proven record of helping with earlier health decisions.

The interviewees expressed a range of reasons for choosing who they discussed EOLC matters with or assigned responsibilities to. The quality of the relationship was a key factor, as was the character of the person chosen. Participants talked almost exclusively about choices based on close and trusting family or friend relationships and, in some cases, it was clear that, although one family member may take the lead, the expectation was that any decisions would be discussed with other members of the family. The character of the recipient was also important, with participants needing to have confidence in the person’s ability to make and carry out decisions in a capable manner. The comfort of sharing similar values, or of family members just ‘knowing’ what they would want, was also mentioned, particularly when participants talked of the need to know that their wishes would be respected.

Alice summed up the trust aspect, “*Whoever you decide to choose it’s got to be someone you know you can really trust to do what you’ve talked about*”. She went on to explain her emphasis on the importance of trust as “*You can’t write that down and make it legal, a lot of it. You can make a certain amount of it legal but personal things you can’t*”. Felicity discussed who would care for her if she could not care for herself. She listed her husband first, then her family of origin, finishing with her step-children, saying, “*blood’s thicker than water*”. Considering the family-first choices made by the participants this was a sentiment common to all.

In conclusion, all the interviewees chose to involve family and sometimes close friends in their planning. In assigning decision-making responsibility, they chose only family members,

selecting the people that were close to them and that they considered the most empathetic and capable.

Too healthy to plan.

When considering the timing for planning, most participants talked of being influenced by their age, health status, and current engagement with life. This affected the level of planning they had already engaged in as well as the timing for future planning.

Even though four participants had completed an EPA, six participants also said they felt too healthy, too young, or were too busy to complete any further planning for EOLC. Of these, five were in their sixties and one was 82 years old. Gerry explained his lack of planning as being *“too busy living”*, while Ina said on the subject, *“We (Ina and her spouse) have been talking about it on our walks recently, about going and doing something with a power of attorney, we actually haven't done, we must actually do that, it's something we talk about and we keep thinking we've got time”*.

Two of the participants who said they felt too healthy, were caring for others with terminal illnesses. Harold, aged 67 years, felt too healthy to plan despite experiencing several life-threatening illnesses. He attributed this, in part, to caring for his mother-in-law, *“I think we've had more, not talks about us so much as about her (mother-in-law) and how it's going to happen and what we've got to do to plan for it, so we understand it and all that, so it's not going to be hard when we have that discussion. Again, because of our age, it's not really, we are worrying about it ourselves, its more the next generation up. You know, she's the last of them”*. Dave was already in his eighties but was caring for his sick wife. He had completed an EPA but felt that further planning could wait for a while as he remained healthy and was engaged with coping with his wife's illness.

Reflecting a similar sense of being too young and healthy, some of the participants also talked about timing, or when it would be appropriate to start planning for the end-stage of life. The right time was often linked to increasing age or declining health. Despite having a recent health scare, Felicity said *“I'm sixty-five and feel like it (ACP) doesn't apply to me at the moment.*

The way I feel now it'll be another thirty years, that kind of thing". Harold also felt that age eighty years would be the right time for him to start planning.

Among the participants who felt that there was still some planning to complete, there was a sense that there would be enough time. Ina recognised that, *"we keep thinking we've got time and all of a sudden something could happen"*. Dave also talked of putting off planning at present but being aware that something like a stroke could change the situation in an instant.

In summary, for many participants, the right time to plan was connected to ageing and deteriorating health. This is unsurprising, given, that the participants were all older adults, and their concerns often centred around medical conditions such as dementia and stroke, conditions which are more common for the older age group. Only one participant linked ACP with having an accident of the type that occurs regularly throughout the life-stages. Of course, what may happen to an individual is always an exercise in speculation, which is a state-of-affairs not easily planned for.

Previous experiences-imagined futures.

It is difficult to plan for an unknown future. Interviewees talked about this and used previous experiences to fill the gap and provide a platform from which to think about their future. Indeed, what the interviewees described during their reflections on the past, were often mirrored in how they imagined the possibilities for their own futures.

Several interviewees mentioned the inherent barrier implicit in planning for an imagined future, *"you just don't know"*. Harold spoke of this uncertainty in colourful terms, *"We make the assumption that we'll die lying in bed or through an illness or something like that, you can get wiped out with a car accident tomorrow, Trump could drop a nuclear bomb on you. It's all of these unknown things that could happen"*. Gerry's concerns were of a more specific and practical nature, *"none of us know for sure, that there would be (residential) facilities available for example, and yeah that would be an important consideration"*. However, he also thought that, *"It would be worthwhile running through a few possible case scenarios and as to what was the best thing to happen for yourself in those events and pick something you think you'd like"*.

The range of scenarios to decide on though, can be overwhelming and many participants narrowed their thinking down by basing future possibilities on what they had previously experienced or alternatively, what held the most fear for them. Those who had completed some planning already, or had plans to do so, talked about being influenced by their earlier experiences with serious illness and dying, drawing on learnings from these situations to inform their own planning. All interviewees had observed the end-stage of life with family members and three participants had personally experienced potentially life-threatening medical conditions. In addition, two interviewees had volunteered in a rest home or hospice and one drew on their spouse's experience as a palliative care nurse. It was clear that these experiences were often reflected in their imagined futures, and it was these imagined futures that frequently influenced both planning content and the planning action taken.

In some cases, previous experiences had been positive, such as Alice's involvement with her mother's 'easy' dying, and at other times they were negative, as with Connie's experience of family conflict during her brother's death as well as her own guilt about not caring for her father while he died. In either case, these experiences had informed the participants' imaginings of their own future and in some cases, it had motivated how they had planned, or intended to plan, for the end of their own life.

Previous experiences also included family conflict over end-of-life wishes and in one case, the financing of these wishes. Conflict caused by opposing views of what should be done during the death of a loved one, had a negative impact on family relationships and it was clear from the two participants who talked of experiencing family conflict that there remained residual feelings of anger towards family members. The depth of emotion triggered by these experiences influenced the interviewees' plans for the end of their own lives. The two interviewees who talked of family conflict, expressed strongly that being clear about one's wishes was important in stopping potential family arguments and both had decided to address this in their own planning.

The conflict and stress caused by not being able to meet the cost of a family member's wishes also informed one participant's planning. Connie talked about the family difficulties with

the death of her brother, “...somebody said 'Oh, he didn't want to go back to (Pacific Island), he didn't want to be cremated, all this carry-on. And I said to the ex-girlfriend that said that 'Well, he's not here to make any decision, and he didn't have any money, so he has no say ... we make the decision because he hasn't got any money. Not coincidentally, the only plan that Connie had already completed at the time of the interview was a financial one.

Four participants spoke about previous experience of family members with dementia and another four also mentioned the disease or described similar medical conditions where there was a serious loss of cognitive function. Alice, for instance, talked about going “doollaly”. This type of disease appeared to symbolise one of the more frightening health outcomes that the interviewees could imagine for themselves. Ina talked of her Aunt’s experience with the medications associated with dementia as “quite horrific” and said that the idea of having dementia “freaked” her out and she would “*be happier to die rather than have dementia*”. Even when participants did not have personal experience of dementia, their understanding of the condition made them fearful. For example, Felicity, who had not experienced dementia in her family, described the thought of it as “scary”

Six participants felt that ACP would be useful in preparing for such illnesses and two had formulated plans based directly on their experience of dementia with others. In addition, one participant, who had not formulated a plan, was currently caring for his mother-in-law who had dementia and said that the experience had given him the knowledge of what planning was needed, albeit he did not feel that his family, including himself, was susceptible to dementia. The other participant who had experienced her brother’s death from dementia, spoke of his lack of planning as an issue. Although she did not draw a direct parallel with her own planning, this participant was using an advance care planning template to ensure she had considered all her choices thoroughly. After experiencing her father-in-law’s dementia, Alice and her husband organised EPAs for themselves, “*We talked about it. It's one of those things you say 'Oh, we must go and do this' and we'd been saying that for about three or four years and I think possibly with Dad, it triggered us off and we thought 'Right, we do need to do this' because once you're diagnosed with*

dementia it's too late". On the other hand, Ina's experience with her Aunt's dementia reinforced her fears and she planned to choose to die if that choice was available to her, *'When I think of growing old that's the thing that scares me the most, the dementia'*".

However, not everyone was motivated by their previous experiences to undertake planning. Harold had experienced three life threatening illnesses of his own as well as being the main caregiver for his mother-in-law who was in an advanced stage of dementia at the time of the interview. These experiences had contributed to a denial of the need for planning. *"Personally, for me, even though I've had all these life-threatening illnesses, I've never had the worry that I'm going to die. I've always believed when I have cancer and also the heart problems, I always believed no, this wasn't my time, I'd get through it. I suppose because I've had three really serious illnesses that it hasn't got me, and I've never felt that I was going to die, it's never really worried me too much in that sense, and because I'm not that old, I'm just starting to receive the pension. I don't think that God, after what a 'good boy' I am over here (caring for mother-in-law), would give me some credit, not take me away straight away"*.

Previous experiences, both positive and negative, contributed to the interviewees understandings of future possibilities, influencing when they planned, how they planned, and what they planned for. There were also indications that observing dementia in another was a powerful motivator when considering what action to take. Only one interviewee had not undertaken any planning activities, and this was a direct result of his previous experiences.

Summary.

The participants knew of components of ACP but were generally uninformed about the concept. Many had started planning but much of it was reactive and not systematic or formalised. It remained as discussion and shared confidences with family and friends. Health professionals had not initiated planning, and with one exception were not spoken about by the interviewees as being possible collaborators in ACP activities. However, legal and financial professionals had initiated planning action for some interviewees.

The interviewees explained a lack of planning as being the result of feeling too young and too healthy, or in other words the time was not right to think about their mortality. All interviewees expressed a wish for self-determination during the end-stage of life, but they also understood that this was a limited form of autonomy, in that, they needed agreement or acceptance from others for their wishes to be carried out. Spouses and then children were the top choices as collaborators in planning activities. The wish for self-determination was matched by the participants' dread of being a burden to their loved ones and themselves by becoming a minimally functioning human being. Finally, earlier experiences with dying family members gave the interviewees a tangible platform of knowledge from which to survey and plan for their own future. However, there were indications that this could lead to limited-focus planning, especially if these experiences are unsettling or frightening.

Chapter Four: Discussion

This thesis explores the uptake of ACP, in both documented and discussion form, among older adults in New Zealand. Analytical emphasis is put on the completion of advance care plans as they are the ACP instrument that consolidates and records all planning activities. In addition, advance care plans are the focus of current public health promotion in New Zealand.

The current study found that the uptake of ACP documentation varies but is generally low. The discussion of ACP matters happens regularly but much more with family members and friends than health professionals. Several weak to moderate correlations were found between demographic factors and ACP activities and between activities themselves, the picture of what motivates someone to plan for EOC remains for the most part speculative. The first four research questions relate to ACP uptake and each of these will now be discussed in more detail. Questions five and six refer to demographic factors supplied by the survey and other contextual influences garnered from interviews with a sample sample of the survey participants. These interviews revealed several themes around getting older and facing the need to plan for EOLC. The findings from these questions are discussed in more detail within the parameters of the first four questions.

Uptake of Living Wills

A living will is important within the healthcare context as it conveys an individual's wishes directly, and in written form, to the health professionals making end-of-life medical decisions for that person. In this sense, a living will could be considered the most powerful instrument for autonomy in the ACP toolbox (Cogo & Lunardi, 2015). Yet, the current study finds that only 6.99% of participants have a living will. This low uptake rate is also reflected in the research interviews, with none of the interviewees having completed a living will.

Although globally, ACP uptake is limited, the completion of living wills in New Zealand is still appreciably lower than the 15% completion rate found in Schröder, Hommel and Sahm's (2016) large German study and particularly low in comparison to the 29.3% found by Yadav et al's. (2016) systematic review of uptake by United States citizens. One explanation for these differences is the variations between countries in regulatory, financial, and other forms of public health support for living wills. For instance, in Germany it is compulsory for medical professionals to adhere to the instructions in living wills (Schröder, Hommel & Sahm, 2016). This gives extra weight to an individual's autonomy in the face of professional paternalism. Certainly, this could make living wills more attractive to health consumers for whom self-determination is important. On the other hand, in the United States it is compulsory for health professionals to discuss ACP with patients (Prendergast, 2001), a task which attracts specific health funding (Dresser, 2016). Regulation and targeted funding clarifies who is responsible for initiating ACP discussions and helps ensure that the ACP message is promoted to health consumers. New Zealand does not use these regulatory, funding, and role clarification methods to encourage the use of living wills and this may contribute to its lower uptake in comparison.

To the contrary, the use of living wills is actively discouraged in New Zealand by the medical profession. The NZMA warns of the risks of using living wills as more than 'conversation-starters' (NZMA, 2007). The government also appears content to leave this form of planning as a voluntary activity which can be tested in a court of law but is not necessarily privileged over medical opinion.

The low level of uptake, globally and in New Zealand, may also be explained in Terror Management Theory terms as subject avoidance (Pyszczynski, Solomon & Greenberg, 2015). A living will is the document that brings an individual closest to their own mortality, in that it requires the person to graphically imagine their own death and record in writing a decision to end their life prematurely. In addition, the possibility of making the wrong decision can add further anxiety to this fear, engendering an even stronger wish for subject avoidance (Schröder et al., 2016). Subject avoidance was not evident in most of the current research interviews, perhaps due to the filtering process whereby the interviewees self-selected into a study about the end-stage of life.

For those cases where living wills have been completed, weak positive correlations found in the current study show that completing or discussing other forms of ACP documentation increases the chance that a living will is also completed. This is true for all the ACP documents. The relationship is unsurprising given that ACP documents reflect alternative or overlapping pathways to the same goal and are therefore likely to be discussed as such by health or legal professionals. In addition, as correlation does not show causation, it is unclear which document triggers completion of the others. However, given that planning templates often include a checklist for other ACP activities, it could be expected that completion of a plan triggers completion of other documents as well.

Despite previous research findings that demographic factors, such as gender and education, influenced the uptake of ACP activities (Inoue, 2016; Lovell & Yates, 2014), the current study found no significant demographic correlations with the completion of living wills. This may reflect the findings of Hart et al. (2018) where demographic differences were not observed when equal access to the opportunity for completion was made available, implying that within New Zealand there is equal access to the opportunity to complete a living will. However, the low uptake rate it may also reflect that, across the sociocultural spectrum, a living will is not seen as a useful method for organising EOLC.

A lack of popularity may explain why living wills are not completed, but for those cases where a living will has been written, what is surprising is the lack of a significant correlation with health status. This is despite earlier research finding a relationship between poor health and ACP planning (Ko, Lee & Hong, 2016; Lovell & Yates, 2014). There is also no significant correlation between discussions with health professionals or family members and completion of a living will. Considering the specificity and seriousness of the medical instructions usually contained in a living will, it could be expected that this document is more likely to be completed when health has deteriorated, and that discussion would include health professionals and family members.

Certainly, almost all the interviewees had discussed future health possibilities with family members and could reasonably be expected to discuss the completion of a living will. Some of the interviewees had also talked specifically of ending their lives prematurely should they contract a debilitating terminal illness, but they were waiting for their health to deteriorate before they took more detailed planning action. It is interesting to note however, that these interviewees discussed the hope of accessing euthanasia at an earlier point in an illness' trajectory rather than documenting a wish for treatment refusal at the point their health had deteriorated to a vegetative state. Ending their lives while still *compos mentis* was linked by the interviewees to a fear of being a burden to others. This may indicate a change in social values to ending life earlier with a view to extending relief to others from the burden of care, but the wish for an early death was also expressed by the interviewees as an existential fear of death through the loss of personhood.

The lack of significant correlation with health status or discussion with others may also point to confusion on the part of some of the survey participants about the meaning of the term 'living will', indicating that this option may have been chosen in error by some. Certainly, the term 'living will' was not mentioned by any of the interviewees and one of the major themes revealed by the qualitative study was a lack of understanding of aspects of the ACP concept. Then again, this result may also indicate what it implies, that is, there is a sector of the population who have written their treatment instructions down, perhaps in the form of a letter, but have not yet shared them with their doctor or family.

Finally, the low uptake of living wills appears to reflect a shift in the form of ACP instruments to fit the New Zealand context. In other words, the low uptake is the outcome of ACP's journey from a legal transactional model, where the original document was a living will, to the communication-relational model that fits more comfortably in the current sociocultural climate, where individualist and collectivist values are merging (Podsiadlowski & Fox, 2011). New Zealand is therefore taking a different path from countries such as Germany and the United States which are strengthening their commitment to the Principles of Autonomy and Self Determination.

Yet, the wish for self-determination has not disappeared in New Zealand. All the interviewees expressed a wish for self-determination and, it could be argued, that every 'yes' response on the survey also shows a wish for self-determination. However, it appears that along with the change to a communications and relational model of ACP, the concept of self-determination is shifting toward a shared form of autonomy. For instance, the interviewees who talked of planning also talked of getting family approval and support for their plans. It appears that self-determination is now often expressed through delegating the responsibility for meeting an individual's wishes to another person.

Uptake of EPAs

Supported by regulation, an EPA gives control for an individual's person and property to another person, making it a critically important instrument in the ACP toolkit. For interviewees, many of whom had completed an EPA, the responsibility was always given to a close and trusted family member. An EPA also stands for a compromise between self-determination and dealing with the realities of changing medical conditions. This makes the EPA the most favoured document for EOLC planning in New Zealand. However, the current study finds that only 29.27% of older adults have an EPA. Given that WHO (2011) states that 87% of those over 60 years will die of the type of chronic illness for which an EPA may be useful, this level of uptake is low.

Uptake in New Zealand is well below Jeong et al.'s (2015) Australian-based survey where total completion rate was 46.3%. It is however, more comparable, although still markedly lower, than Park and Astell's (2017) New Zealand study where 38% of participants had completed an EPA. Nevertheless, 38% uptake is still low, a result that Park and Astell's study found to be due to a lack of information about the subject. The differences in the results of these studies may be explained in part, by the fact that unlike the current nationwide survey, the other two survey samples were within localised geographical areas and therefore could have been influenced by variables specific to those areas, such as differing ethnic profiles or varied availability of knowledge-based resources.

There is a weak to moderate positive correlation between age and EPA completion. This reflects previous research findings that getting older is a factor in ACP uptake (Kahana, Dan, Kahana & Kercher, 2004; Lovell & Yates, 2014). The interviewees confirmed this, with many of them saying that they felt too young and healthy to formally plan for EOLC. The weak nature of the relationship with age may also be explained by the fact that the survey was limited to an older cohort, meaning that a survey covering a broader lifespan may result in the observation of a stronger correlation between these two variables.

There is also a weak relationship between ethnicity and EPA completion, in that it is more common for non-Māori to complete an EPA than for Māori. As the non-Māori subpopulation identified in the current research is made up almost entirely of New Zealand European participants, this confirms Park and Astell's (2017) finding that those of New Zealand European descent use EPAs more often than other ethnic groups. It also confirms both Jeong et al.'s (2015) finding that minority cultures completed EPAs less often than those who were part of the dominant culture, as well as Zager and Yancy's (2011) finding that advance directives do not find a comfortable fit within collectivist cultures. On the other hand, the weakness of the correlation also reflects Podsiadlowski and Fox's (2011) finding that within the New Zealand context there is less differentiation of values between the dominant and indigenous cultures than would normally be expected.

There is also a weak correlation between discussion with a family member and completion of an EPA. The reason for the weakness of the relationship is unclear especially as all the interviewees with an EPA had signed it in favour of a family member. One explanation may be found in the different timeframes indicated in the survey questions. Participants were not set a timeframe when asked to identify which ACP documents they had completed. However, a six-month timeframe was set when participants were asked to identify discussions about ACP matters. The six-month limit keeps the reporting of discussions within a reasonable timeframe for remembering events and it also recognises the ongoing nature of developing and maintaining an advance care plan. However, in terms of the results, it is conceivable that, while an EPA had been completed at some point prior to the survey, it had not been discussed within the 6 months preceding the survey, leading to a 'yes' for one answer and a 'no' for the other. The same may be true for the weak correlation between completion of an EPA and discussion with the holder of the EPA or lawyer.

In contrast to the living will, the higher EPA uptake may be the consequence of vicarious learning, as explained by Social Learning Theory (Bandura, 1991). The results of the research interviews provide evidence for this, as learning from others' experiences of death and dying was identified as a major theme that emerged during all the interviews.

An EPA also reduces a major risk associated with living wills, that is, the fear of making the wrong decision. Instead, medical decisions can be made in real time through consultation with a substitute decision-maker rather than referencing what may be an historic document. This offers some explanation for the fact that EPAs are more popular than living wills, and that, of the 26% of survey participants who indicated completion of only one ACP document type, most completed an EPA. This was reflected in the interview findings where an EPA was almost always the only type of ACP document completed.

The difference in uptake between living wills and EPAs also reflects promotional efforts. Unlike living wills, the New Zealand government actively encourages completion of EPAs

through its SuperSeniors website and publications (Ministry of Social Development, n.d.). Active promotion of EPAs by the legal profession also helps explain the higher uptake.

Previous research has found that legal and financial professionals can be at the forefront of EOLC conversations (Malcomson and Bisbee, 2009). This is reflected in the New Zealand context where the members of the NZLS are encouraged by the government to systematically promote EPA completion (NZLS, 2015), and some interviewees confirmed that they had been prompted to undertake planning activities by legal and financial professionals. However, the cost is substantial and considered a barrier by NZLS for those on a low income (NZLS, n.d.), This may also explain why uptake is not higher.

Uptake of advance care plans

Completing a comprehensive plan for EOLC is key to triggering the level of value-based thinking which helps ensure an individual will experience a good death according to their own measure. This document goes to the heart of the ACP concept. Yet despite its importance, only 3.98% of participants say that they have completed a plan. Confusing terminology and differing forms of ACP instruments made it difficult to compare rates of uptake with other studies in any meaningful way. However, even without comparison, 3.98% is extremely low, given that 1,500 health and allied workers have been trained to initiate ACP interventions (Duckworth & Thompson, 2017).

Although it is not clear from the survey data why uptake is so low, previous research shows that it is likely that health consumers lack knowledge about ACP (Hagen, 2015; Kermel-Schiffman & Werner, 2017). A lack of knowledge was also reflected in the current research interviews when only one of the interviewees had sourced a planning template for themselves and could therefore explain the ACP concept with some clarity. This points to a need for increased public education on the topic of ACP.

The logistic regression analysis of plan completion highlighted the influence of several factors. The most influential factors found were: completing other forms of ACP documentation, speaking with health and allied professionals or a spiritual advisor, or being non-Māori.

Completion of other forms of ACP documentation, makes it three times more likely that an advance care plan will be completed. Again, this suggests that either the professional initiating the ACP conversation discussed the range of document options, or the advance care plan triggered the completion of other documents due to its 'checklist' nature, or perhaps, the individual researched the range of options for themselves. It could also reflect the ongoing nature of planning, in that different elements are completed as and when needed. It was clear from the research interviews that planning was not a proactive, comprehensive, or one-off activity, rather it was ad hoc and reactive in nature. Therefore, document completion and other forms of planning may occur when needed and as new knowledge is gained about the options available.

Discussions with GPs, practice nurses and social workers doubles the chance of plan completion in comparison to not having a discussion. This result could suggest that promotional efforts by these professionals encourages plan completion. However, the analysis does not indicate who initiates the conversations. Previous research shows that health professionals can be hesitant to do so (De Vleminck et al., 2013). In either case, whether it is the professional or the patient who raises the topic, the professional-patient relationship shows positive signs of encouraging uptake.

Although few survey participants indicated speaking with a spiritual advisor about ACP matters, it appears that doing so means that an individual is almost four times as likely to complete a plan. This could be an interesting area for future investigation as previous research indicates that church settings are suitable for ACP conversations (Hendricks et al., 2016). This finding could also suggest that spiritual advisors, such as church pastors or hospital chaplains, have a more prominent relationship with those whose health has deteriorated and therefore become part of the discussion about EOLC.

While being non-Māori doubles the odds of plan completion compared to being Māori, the reverse is also true, in that being Māori decreases the odds of plan completion by half. Indeed, this result, and the negative correlation with EPA completion, are the only statistical relationships of any consequence between Māori and any form of written or verbal ACP activity. This suggests

that Māori are disenfranchised with respect to ACP completion. One explanation for this is the lack of health literacy suggested by the MOH (2017) as limiting Māori access to EOLC. It could also reflect the fact that at the time of the survey, ACP remained a western model of EOLC, with the Māori model only being introduced afterwards (Northland District Health Board, n.d.). The introduction of the Māori model is too recent for its effect on health behaviours to be measured.

Uptake through discussion

This research question concerns the percentage of older adults in New Zealand talking with a specialist doctor, GP, nurse practitioner, practice nurse, social worker, friend, spiritual advisor, family member or someone else about ACP matters. Almost half of the participants indicated that a discussion about ACP matters had occurred within the six months prior to the survey. This is substantial, given the brief time period. In addition, 16% of the participants had spoken with more than one person, meaning that the results therefore show only a minimum number of conversations. For instance, multiple discussions may have been held with the same person and other conversations could also have occurred prior to the six-month time period. Given the considerable number of conversations that were reported as occurring and the likelihood of further discussions outside of the parameters of this study, it appears that the end-stage of life is very much on the minds of older adults, with concerns and options being discussed regularly, particularly with those closest to them.

The interviewees also reflected on this ongoing dialogue about ACP matters, referring to repetitive conversations with, sometimes, multiple others, on the subject. However, some of the interviewees also spoke of their reluctance to burden younger family members with the topic of EOLC planning, and instead talked of ‘heart-to-heart’ conversations with spouses or close friends. These conversations were sometimes prompted by earlier experiences, where discussion with family and friends helped extract the learnings for the future.

Survey participants too, spoke most often with family and friends but discussions with health professionals were minimal. This confirms Kahana, Dan, Kahana and Kercher’s (2004) findings that individuals talk to their family rather than their physicians about EOLC matters. It

also reflects the need for a close and trusting relationship as the necessary foundation for sharing in a meaningful way. Interviewees spoke of a trusting relationship as being especially important for ACP discussions. This included the sole interviewee who mentioned the possibility of speaking with a health professional on the basis that a certain level of trust already existed in the relationship. However, Malpas and Mitchell (2017) consider that it is becoming more unlikely that GPs can build such relationships due to the nature of GP practices changing to shared-care arrangements among several physicians, and time constraints limiting physician-patient discussion to 15-minute intervals (Malpas, 2011).

Weak correlations exist between, age and discussions with a holder of an EPA or lawyer; physical health and discussions with a specialist doctor or GP; and gender with discussions with a family member. The first two correlations are not surprising, given that age is correlated to the completion of an EPA and therefore it is understandable that age would also be correlated with talking to the holder of the EPA or lawyer. The second correlation is also not surprising, in that if an individual's health deteriorates then it is more likely that discussions with a physician will occur. However, the third correlation indicates that men discuss ACP matters with family more than women. This is dissimilar to previous research. For instance, Lovell and Yates (2014) did not find a gender correlation with ACP in their systematic literature review of contextual factors associated with uptake. However, Inoue (2016) found that being female correlated with ACP uptake. It is not clear why this should be, especially as gender does not correlate, even weakly, with any other ACP activity in the current study, mirroring Lovell and Yates' findings. However, from a public health perspective, it would be useful to know if men are agents for change within the family with respect to EOLC planning, so that they can be targeted appropriately in ACP promotional activities.

The results of this study show that discussion is a more popular ACP activity than documentation. This reflects the paradigm shift from a legal transactional model to a communication-relational approach to ACP. Discussion is also likely to be an instrument in the model of behavior change suggested by Sudore et al. (2008). For instance, the interviewees

referred to ‘chatting’ informally with those closest to them to explore and make decisions on planning possibilities, prior to taking action. This reflects the contemplation and preparation/values-clarification stages of the model.

Limitations and Future Directions

This study finds that Māori appear disenfranchised with respect to ACP and MOH have identified also that Māori have unequal access to EOLC (MOH, 2017). With this in mind, one of the limitations of this study is the homogenous nature of the qualitative sample with none identifying as Māori. Given that the ethnicity variable used for analysis consisted of Māori and non-Māori subgroups, the opportunity to explore the topic of ACP with Māori interviewees would have added useful information on context to the discussion on ACP uptake.

The model produced by the logistic regression analysis is another limitation of this study, in that the variables identified through previous research as being associated with the completion of an advance care plan, only explained a limited percentage of the variance in uptake and thus did not provide a useful ‘real world’ model for the New Zealand context. However, the regression analysis found several variables related to uptake within the New Zealand context. The limited variance explained by these factors provides a starting point for further research into a stronger prediction model. Such a model would be of benefit to health promoters encouraging the uptake of ACP.

In addition, a future iteration of this study would be useful to report on the progress made by the HQSC as it completes its five-year strategy for increasing ACP uptake. A future survey would also measure any change in Māori uptake following the introduction of a Māori model of ACP.

Finally, it appears that both the health and legal sectors are currently involved in promoting aspects of ACP, meaning that both are involved in discussions with clients about EOLC. Further research into the two sectors promotional activities and methods for

engaging consumers in these difficult conversations may reveal opportunities for cooperation in promoting ACP in a cohesive and comprehensive form.

Chapter Five: Conclusion

The current study achieved its goals in reporting on the use of different forms of ACP in New Zealand with exploration of factors and contexts that may influence uptake. Factors that are correlated with different aspects of ACP uptake include age, gender, ethnicity, and physical health. However, overall there is a low uptake of ACP in documented form with EPAs being the most often completed document. Living wills are seen as problematic within the medical community and uptake is low. Advance care plans, the subject of current health promotion initiatives have a very low uptake. Reasons for the low uptake are speculative but may include, a need for further public education on the topic; a lack of opportunity or hesitancy by health professionals to initiate ACP conversations; and a hesitancy on the part of the health consumer to face their own mortality while they are still well. However, several factors have been shown to have a positive impact on uptake. These include: completing other forms of ACP documentation, speaking with health and allied professionals or a spiritual advisor, and being non-Māori. There is work still to be done to produce a useful ‘real world’ model of the factors associated with completion of advanced care plans, though part of the variance in uptake has been explained by this study.

Discussion of ACP matters was common however, particularly among family members. This indicates that the subject is on older adults’ minds, although very few of them are speaking with health or allied professionals about ACP matters. Finally, the current study has added valuable and timely information to the picture of ACP uptake within the New Zealand context by giving a baseline to measure future ACP promotional initiatives such as those planned by the Health Quality and Safety Commission as part of their five-year strategy.

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Appendix A

Information Sheet

Hello. Kia ora. My name is Wendy Brown and I am completing my Master of Arts (Psychology) through Massey University. My research project is on Advance Care Planning, or in other words, planning for medical and care choices towards the end of life.

Massey University's Health and Ageing Research Team have already provided me with national information from their latest Health, Work and Retirement Study survey about whether people talk to others about what may happen towards the end of their life, including writing down any choices they make.

I have been given your name and contact details as I understand you were part of that survey and said that you would be happy to help with other research studies. I have also chosen to contact you as you live close enough for me to visit you personally if you agree to help me with my research.

What I am hoping to do is talk to 10 people who took part in the survey so that I can start to gain a deeper understanding of why people may have answered as they did. The starting point for this discussion is that there are no right or wrong answers.

I am an older adult myself and I know that thinking about the end of life can be an uncomfortable subject to talk about. If you agree to participate, I would like to interview you in your own home where you will hopefully feel most comfortable to share your views. I will, of course, 'bring a plate' when I visit. If you would prefer to talk away from your home, then I will arrange somewhere else for us to meet.

During the interview, if the subject becomes distressing, then we will stop the discussion, or find a less upsetting way to talk about your views. Please feel free to tell me how you are feeling during the interview, and at the end when there will be time to reflect on our discussion. The interview will be recorded and then typed out in written form by a third person who will not know who you are personally. The original recording will then be erased to maintain your privacy.

Although there can never be a 100% guarantee that the steps taken to keep information confidential will be entirely success, I will try to make sure that any personal information about you will be kept secure

using a security password on the computer. The written interviews and consent forms will be kept in a locked cabinet and then sent by courier to Massey University to be held securely until they are disposed of after they are no longer needed.

If you agree to be interviewed for this project, you will need to set aside two hours of your time in total to:

- reply to my invitation
- be interviewed
- check the written interview notes
- have a final talk on the phone about how you found the process

I will use the information you provide to write my Master's research project and then write an article which will likely be published in a health or age-related magazine. You will not be referred to by name in either of these projects. A summary of the findings will also be sent to you after the Master's project is completed.

Finally, please see below the statement of participant's rights. If should you decide to accept the invitation to be interviewed, please complete and sign the consent form attached and return it in the reply-paid envelope provided.

Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- *decline to answer any particular question*
- *withdraw from the study (specify timeframe)*
- *ask any questions about the study at any time during participation*
- *provide information on the understanding that your name will not be used unless you give permission to the researcher*
- *be given access to a summary of the project findings when it is concluded*
- *ask for the recorder to be turned off at any time during the interview*
- *contact the researcher, Wendy Brown, at ... or project supervisors, Don Baken at ... , or Chris Stephens at....if you have any questions prior to, or during involvement*

Thank you for taking the time to consider this invitation. I look forward to hearing from you if you decide you would like to participate.

Wendy Brown

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application ___/___ (*insert application number*). If you have any concerns about the conduct of this research, please contact Dr Rochelle Stewart-Withers, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x 83657, email humanethicsouthb@massey.ac.nz

Participant Consent Form - Individual

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being sound recorded.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature:

D

ate:

.....

Full Name -

printed

.....

Indicative Schedule of Interview Questions

1. Have you heard of Advance Care Planning?
2. How did you hear about it?
3. What do you think of the idea in general – good and bad?
4. In what sort of situations do you think it might come in useful?
5. How do you think it would work in those situations?
6. Have you talked with anyone about what you would like to occur should something serious happen to you and you cannot speak for yourself at that future time?
7. If you have spoken to some, why is this?
8. Who did you decide to talk to?
9. Why did you choose that person/s and not someone else?
10. If you have not spoken to someone, why is this?
11. Have you written down your wishes?
12. In what form did you write them down?
13. Why did you decide to write down your wishes?
14. Why did you choose this particular form?
15. If you have not put your wishes in writing, why is this?

Transcript Covering Letter

Dear Participant

Thank you once again for agreeing to take part in this research study. Sharing your experiences and viewpoint has been very valuable to this project. As promised, attached is the transcription of your interview for your review. If you are happy that the transcript reflects your views, please complete, sign and return the Transcription Release Authority form in the reply-paid envelope provided. You are also free to add to or change information within the transcript if you feel it would better reflect your views on the subject. In that case, please return the edited transcript with the authority form.

I would also like to bring the following to your attention as you read –

- The transcription only covers the parts of the interview directly relevant to the topic.
- To ensure anonymity, identifying information such as names have been removed or changed.
- Transcriptions of verbal conversations do not flow in the same way as written communication, such as a letter, so do not be too concerned about repetition or sentences that run into each other and so on. These are normal speech patterns and sound fluent to the person listening.

Finally, if you have not received a follow up call from me by the time you receive this, I will be contacting you very shortly thereafter to check if you have any questions or concerns about our discussion.

Kind regards

Wendy Brown

Authority for the Release of Transcripts

I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature:

D

ate:

.....

Full Name -

printed

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